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Markku Leskinen (ed.)

Family in Focus

New Perspectives on Early Childhood Special Education

UNIVERSITY OF JYVÄSKYLÄ

JYVÄSKYLÄ 1994

Dedicated to

Paula Määttä

on the anniversary of her fiftieth birthday

August 4, 1994

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ABSTRACT

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Tiivistelmä

This volume consists of articles which summarize both theoretical perspectives and research themes from the project "Multidisability, Family, and Childhood" which was carried out at the Department of Special Education in the University of Jyväskylä from 1990 to 1993. All writers have participated in the project as consultants or researchers. The chapters cover a variety of topics on the theme of early childhood special education.

Thomas Weisner and Ronald Gallimore (University of California, Los Angeles) introduce (Chapter 1) the central principles of ecocultural theory and discuss its applicability to practice. Dianne and Philip Ferguson (University of Oregon, Eugene) examine (Chapter 2) the features of family-professional collaboration. In Chapter 3, Marika Veisson, Aino Saar, and Ene Mägi (Tallinn Pedagogical University, Tallinn) present preliminary results from their study on parents' needs in Estonia and support-organizations founded in the 1990's.

Markku Leskinen and Jaana Juvonen present (Chapter 4) an attributional model in which parents' responsibility perceptions predict their child-focused emotions which then predict the level of adjustment. Iiris Mäki examines (Chapter 5) the problems in the assessment of children with severe disabilities and discusses the ecological approach's applicability to early intervention practices. Marjo-Riitta Mattus examines (Chapter 6) different strategies for empowering families by concentrating especially on the of question how an interview could be an intervention.

The last set of articles concern families of small premature infants and their development. Maija Virpiranta-Salo discusses (Chapter 7) the development of parenthood in parents whose family-life starts with special circumstances. Annikki Riitesuo provides (Chapter 8) a literature review about speech and language problems in prematurely-born children. Finally, Tuula Laukkanen discusses (Chapter 9) parent-professional communication in a health care context.

Keywords: early-childhood-special-education, ecocultural theory, parent-professional collaboration, attribution, assessment, empowerment, parenthood, speech and language development, communication, parents, disability, prematurity.

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INTRODUCTION

Family-focused research has been active in the 1990's at the Department of Special Education in the University of Jyväskylä. The credit for this can be given to Associate Professor Paula Määttä to whom this book is dedicated on the anniversary of her fiftieth birthday. She has been the principal leader in the project "Multidisability, Family, and Childhood" (Monivammaisuus, perhe, lapsuus) that was funded by the Academy of Finland covering the years 1990 to 1993. The project continues its work under the new name "Early Childhood and Special Education" (Varhaisvuodet ja erityiskasvatus, VARHE). All writers in this volume have participated in the projects either as consultants or researchers. Through these articles we want to express our congratulations to Paula Määttä and wish her all the best for her coming academic endeavors in the field of early childhood special education.

A shared theme of the articles is early childhood special education but the chapters cover a variety of topics. Writers discuss theoretical principles and also research findings received in the project Multidisability, Family, and Childhood are presented. The first two chapters are written by the authors, two of whom have had a great impact on the project: Dr. Weisner and Dr. Dianne Ferguson have visited the project as educators several times and their contribution can be found from the rest of the articles. The ecocultural theory (Chapter 1) was introduced by Dr. Weisner to the project. It stresses the meaning of everyday life and routines in adapting to the demands set by a child's disability rather than the parents' pathological or psychological problems. This has been one of the most central principles in the project's working.

The Fergusons discuss in Chapter 2 their experiences with professionals and present suggestions how the family-professional collaboration could be more constructive. Dianne Ferguson's impact in this project has been twofold. First, it can be said that one of her and

Philip Ferguson's article[1] has even had a national level influence in Finland. In the article the Fergusons describe different theoretical orientations (i.e., psychodynamic, psychosocial, functionalist, and internationalist) towards the parents of children with disabilities. The project-members have presented the classification many times in their lectures to professionals and it has always received much attention. In any case, a discussion about parent-professional collaboration has started in Finland. Second, Dianne Ferguson has guided the project members into qualitative research methods and therefore an interpretivistic methodology and thinking can be found from most articles in this volume.

The research project has had cooperation with the Pedagogical University of Tallinn in Estonia. It has, for instance, organized training courses for Estonian professionals and parents. In Chapter 3, Veisson, Saar, and Mägi describe some preliminary results from the study that will finally compare families' situations in Estonia and Finland. They also present what organizations have been founded in the 1990's to improve the situation of the families of children with disabilities in Estonia.

Leskinen and Juvonen present in Chapter 4 an attributional theoretical model, in which they separate parents' onset and offset responsibility perceptions regarding the child's disability. By onset responsibility they refer to the parents' causal perceptions of the causes for disability and by offset responsibility to the parents' estimations of their own role in the child's rehabilitation. They hypothesize that these self-directed responsibility perceptions predict parents' guilt and hope emotions towards the child which then predict parents' adjustment.

In Chapter 5, Mäki examines the question of assessment in early intervention. She notes that a developmental approach should be taken with caution when assessing children with severe disabilities. In those cases, it is important to supplement the assessment by observational methods. These methods belong to an ecological approach which takes into account the context in which a child is living. In addition to this, Mäki presents selected results from her studies that were guided by the principles of the ecological approach. She brings an important and seldom studied perspective to the discussion; a child's point of view.

Mattus's chapter (Chapter 6) concerns family-professional collaboration from the point of view of family empowerment. She reviews literature on alternative models in early intervention and points out that the family-orientation in early intervention or in early childhood special education can mean, in fact, very different kinds of working paradigms. In addition, Mattus proposes that an interview about family needs,

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[1] Ferguson, P.M., & Ferguson, D.L. (1987). Parents and professionals. In P. Knoblock (Ed.), Understanding exceptional children and youth. Boston: Little, Brown and Company, 346-391.

empower families.

The last chapters deal with the families of small preterm children. It is known that premature infants are at risk of developmental problems. The first months are a difficult time for parents as well, because in the beginning there is no certainty whether the child will survive and will he or she have any developmental problems. Virpiranta-Salo examines in Chapter 7 the development of parenthood in a special situation when the child is born several months earlier than expected. She identifies a number of issues for which the parents need support.

Riitesuo reviews the literature in Chapter 8 that concerns factors in speech and language development of small preterm infants. She discusses the assessment procedures and proposes that the ecological assessment techniques should be applied in addition to traditional standardized tests. She also describes preliminary results from her own study.

Finally, in Chapter 9, Laukkanen discusses communication between parents and professionals in a health care setting. In addition to a literature review, she describes results of her own study which both indicates that the information exchange is influenced by numerous individual and situational factors. Laukkanen comes to the conclusion that in health care communication, more attention should be put to interactional skills and parents should be taken more as partners.

We hope that the chapters in this book will prove useful for a reader who shares our interest in the families of children with disabilities. The book was planned to summarize the ideology and research themes of the project Multidisability, Family, and Childhood. We are grateful to the University of Jyväskylä for publishing this volume and to the Family Research Unit of the University of Jyväskylä for its financial support. Lastly, we hope that our work and this book will ultimately benefit the children with developmental problems and their families.

Jyväskylä, July 1994 Markku Leskinen

Chapter 1

ECOCULTURAL STUDIES OF FAMILIES ADAPTING TO CHILDHOOD DEVELOPMENTAL DELAYS: UNIQUE FEATURES, DEFINING, DIFFERENCES, AND APPLIED IMPLICATIONS

Thomas S. Weisner and Ronald Gallimore

1 INTRODUCTION

Our edited volume congratulates Associate Professor Määttä for her work as a teacher and researcher at Jyväskylä University. It honors her long standing concern for special education, children with delays and handicaps of varying kinds, and for their families. We first met Associate Professor Määttä when she visited UCLA many years ago. She came because she was interested in the social and cultural circumstances which influenced successful family responses to children with handicaps, and because she was interested in qualitative and ethnographic methods for studying this topic. We are happy to say that our association has continued for many years, and that the perspective Associate Professor Määttä came to talk with us about, the Ecocultural Model of family adaptation to children with delays, has also proven of some value in understanding families with children with delays.

Our analysis of the eco-logical/cultural (eco-cultural) circumstances of families to family adaptation to children with delays is based on over eight years of longitudinal studies of 102 families and children in Los Angeles, California, who are participating in Project Child (Gallimore, Weisner, Kaufman, & Bernheimer 1989; Gallimore, Weisner, Guthrie, Bernheimer, & Nihira, 1993; Nihira, Weisner, & Bernheimer, 1994;

Weisner, 1984). In our chapter, we will outline the ecocultural model, and discuss some of its implications for parents, researchers, clinicians and those interested in interventions.

The discussion is organized around three questions.

1. What is there about an ecological/cultural approach that should interest researchers that is not already featured in existing models?

An eco-logical/cultural (eco-cultural) theory is complementary to others models but distinguished by its attention to a universal adaptive challenge all families face: *the organization of an everyday routine of family life*. This family project takes precedence because children's constant participation in daily routines is the single most powerful influence on their development.

2. Don't we need to attend to the issues of stress and coping that challenge families with children with handicaps and delays? Aren't such families likely to be at risk for greater pathology and problems?

It's the answer to this question as much as any other that warrants ecocultural theory the attention of researchers and practitioners alike: Ecocultural theory predicts unequivocally that families of children with delays *are not likely* to have greater pathology than other families. It is an unfortunate and, in our view, a wrong implication of models focused on psychological stress that families adapting to childhood developmental delays are at greater risk for psychopathology. Families of children with delays face serious adaptive problems, which they indeed struggle to solve often at great cost. But there is no greater likelihood they are more troubled than other families in similar communities (Gallimore et al, 1989; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992).

3. Are there any immediate intervention implications of an ecocultural approach?

An ecocultural approach to intervention starts with this question: what actions are families already taking that have adaptive value to the family and the child with delays or disabilities? In what portions of their everyday routines have they been able to achieve these actions? Once practitioners know answers to these questions, they can extend and expand on these practices to fulfill the ideal of building on family strengths. If new actions, or cultural *practices*, need to be implemented, however, the same prior questions must be asked: Where in the family's adapted everyday routine can we find "slots" - the times, personnel, resources - into which to fit new practices suggested by professionals?

2 WHY USE THE ECOCULTURAL MODEL AND ITS METHOD IN ADDITION TO OTHER METHODS?

Ecocultural theory features *dynamic family adaptation,* rather than static dimensions of an ecocultural environment. It proposes that a major adaptive task for each family is the construction and maintenance of a *daily routine* through which families organize and shape their children's activity and development. Ecocultural theory does not focus on a unit of analysis based on geography or social institutions. The focus of the theory is on the *process of sustained construction* of this daily routine, rather than a fixed ecology uninfluenced by cultural goals, perceptions and negotiations. We call this social construction process family *accommodation,* or the proactive changes families make to alter their everyday routines. From the perspective of ecocultural theory, a child's participation in routine everyday family activities is the preeminent experience shaping the child's development. Through construction of the daily routine, families creates activities for children that have significant developmental influences.

The focus on adaptation and the daily routine is adapted from anthropological and cross-cultural human development research. This tradition keeps in sharp focus the power of families to shape interactions. The goal is to build a theory that specifies empirically-testable linkages among the many influences on child development: cultural context, parental goals and family adaptation, the everyday routine and behavior settings, and individuals' teaching/learning interactions (B. Whiting, 1976; 1980; B. Whiting & Edwards, 1988; Munroe, Munroe, & Whiting, 1981; LeVine, 1977; Nerlove & Snipper, 1981; Super & Harkness, 1980; 1986; Weisner, Gallimore, Jordan, 1988; Whiting & Whiting, 1975).

The ecocultural model also draws on sociocultural and activity theory and research which emphasizes the socially constructed nature of cognition and mind. Activities and practices are the constitutive elements of the daily routine that produce developmentally-sensitive interactions. Within these activity-created interactions arise zones of proximal development in which more capable individuals assist communicative and cognitive apprentices to perform at levels which they will eventually achieve (e.g., Ochs, 1988; Vygotsky, 1978; Cole, 1985; Rogoff, in press; 1990; 1982; Tharp & Gallimore, 1988; Wertsch, 1985). The construction of the daily routine is the creation of what Vygotsky (1978) called the social plane of communicative and cognitive functions, from which the child eventually appropriates the internal, psychological plane.

Because ecocultural theory emphasizes family construction of the daily routine, and the negotiations and decision-making which goes into the accommodation process, families are construed as proactive agents, not hapless victims of implacable social and economic forces. Families not only "have" an ecology and a daily routine around them, they also proactively construct their family ecology and routine (Weisner, 1986). The notion of "constructing" a routine reminds us that families shape as well as are shaped by, the social world around them. In this respect, their children's developmental future is influenced by families as well as the surrounding environment. This distinguishes the ecocultural approach from some other family ecology models, since the partially constructed nature of our ecocultural world is built into the theory and the methods of inquiry.

Ecocultural theory depends on qualitative methods of interviewing and observation. To develop empirical data on the daily routine, we have developed an interview and home visit procedure, the Ecocultural Scale Interview. There is also an accompanying Ecocultural Questionnaire. Parents talk with the interviewer in an informal conversational style regarding the family daily routine and the child's impact on that routine, participation in it, changes made, new practices families have undertaken, or practices retained due to the child which might otherwise have been changed. The interviewer has an explicit agenda which covers all the ecocultural domains of interest, and a set of topics are always covered with every family. Following the interview, the interviewer codes the family along the ecocultural domains. We have established average reliabilities for this procedure of 81 percent agreement with families in our study (Weisner, Coots, & Bernheimer, ms).

Ecocultural theory also identifies features to look for in understanding the "quality" of a family daily routine. It is sensitive to cultural differences and variation in family adaptation, but it is not relativistic or neutral with regard to patterns of family adaptations. Most judgments of better or worse quality in family circumstances confound material wealth and income, with the quality of the family daily routine. Other judgments may hold up as a universal standard, parental practices better viewed as particular to one cultural group at one point in time.

Ecocultural theory looks for quality in the daily routine of the family. For example, "sustaining" a daily routine means adapting to a local ecology of material and social resources. Material and social ecology refers to two different kinds of things: (1) The material resources and constraints available (income, housing), including the physical and geographic ecology; and (2) Social constraints and resources, such as class, gender, and power - the other kind of ecology that surrounds the family. Each has its own influence in family choices regarding the most sustainable and meaningful daily routine. For example, to give their children the developmental experiences they deem most appropriate, families do not have total freedom of choice because of their material and social constraints. To attempt a daily routine that denied the reality of either would lead to instability. Sustainability is a development-sensitive measure because it represents a family's optimized, or satisfied option, not necessarily its ideal option. It is based on the family's calculation of what is possible and realistic. This implies that the "meaning" of the routine to the family - what it can provide their children and what they desire - is a factor in their calculations.

A "meaningful" daily routine is one that has moral and cultural significance and value for family members. Daily routines achieve meaning within some shared cultural model of implicit and explicit cultural beliefs and goals regarding normal child development, family life, religious convictions, and community moral standards. Cultural belief and goal models provide families a clearer, more coherent sense of what their routine should be, and what it is. Families who guided by cultural meanings should have more resilience.

The definition of what is better or worse, or what are resilient responses regarding family adaptation for child outcomes depends on the family's ecocultural definition of child competence. These ecocultural definitions are in addition to universal biomedical and maturational developmental competencies children require. In contrast, ecoculturally defined judgments of competence vary across communities, and include activities such as task competence in family subsistence (use of literacy, weaving, fishing) and social network competencies (appropriate behavior toward kin). Competencies within a developmental period such as infancy and early childhood, are defined jointly by a maturational, biological period in the life course, and as a "stage" defined within a particular cultural tradition (Harkness, Super, & Keefer, 1992, 177).

The general perspective of ecocultural theory - that culture, social ecology and family adaptation matter for child outcomes - is well appreciated in the field of developmental disabilities (Bailey & Simeonsson, 1988; Bristol, 1984; Crnic, Friedrich, & Greenberg, 1983; Farber, 1986; Fewell, 1986; Turnbull, Summers, & Brotherson, 1986; Vincent, Salisbury, Strain, McCormick, & Tessier, 1990), and more generally in family and human developmental research (Bronfenbrenner, 1979). Ecocultural theory is not simply reinventing this more general approach, nor should the ecological features described in other theories be neglected, for example, the emergence of late capitalism, or patterns of wealth distribution in a region, or changes in climate, fauna, flora, or energy supplies, or broad demographic changes. Nor does family ecology generally necessarily have a claim to the exclusive, or the only important influences on child development and family adaptation. Ecocultural theory requires a multi-determined approach to the course of developmental delay, within a multi-variate set of causes.

3 FAMILY ADAPTATION DIFFERS FROM STRESS AND COPING IN THE STUDY OF FAMILIES WITH CHILDREN WITH DELAYS

Families with children with delays must come to terms with the meaning of the event, and its emotional consequences (Miller, 1993). Individual stress and anxiety can and do result. Yet, there is now evidence that individual stress, anxiety, and psychopathology may not be as distinguishing features of adaptation to childhood disability as once believed (Shonkoff et al., 1992).

Other challenges must also be attended to as well, many involving the family as a unit. One of these is the alteration of the family's daily routine to include and accommodate a child with delays and disabilities. Altering the daily routine so that it accommodates a child with or without disabilities is not a one- or short-time coping burden. It is an ongoing *cultural project* that challenges all families (Weisner, in press).

The questions posed in ecocultural theory regarding this cultural project include: "What is the pattern of family adaptation over time, and how does that pattern relate to the child's delay? What are the more or less meaningful and satisfying parts of the family routine of life, and what assists and sustains, or hinders them? How does the child with delays fit into overall family adaptations and life goals?" These questions differ from those focused on stress or coping. They are not individual-psychologically based. They do not assume the driving force for family adaptation is distress or dis-ease. They depend on knowing the cultural goals of the family within its community - that is, what is significant in the life of the family including what they seek to make salient in the daily life of their children.

Although we can conceptually distinguish "coping" with stress and "constructing" a daily routine, families' accounts of daily life often intermingle the two topics. This reflects the parents' experience of diverse and variable psychological states, emotions and moods as they work to organize and sustain their daily routines. Careful analysis of their accounts indicates they define family adaptation in terms of a cultural project of the daily routine (Gallimore et al., 1989; 1993), the spiritual and religious beliefs which guide their efforts (Weisner, Beizer, & Seidner, 1991), their goals regarding siblings of the child with delays (Weisner, 1993), and their concerns about development of the child with disabilities (Weisner, Matheson, & Bernheimer, in press).

We believe "coping" with stress and "constructing" a daily routine are complementary but quite different dimensions of adaptation. Routine organization is more often described by parents in terms of the ecocultural goals of meaningfulness, coherence, and the ability to sustain the family routine over time given a family's resources, than it is described as stressful. Stress and anxiety sometimes are present, but embedded within this larger ecocultural project.

The cultural practices families attempt or modify due to their child with delays, by and large are not particularly culturally unusual. If families have to change their subsistence and work adaptations, for instance, they do so in ways similar to all families in California: they work different hours, keep a job for its insurance benefits, refuse a relocation, one parent quits to stay home, another starts a home business, and so forth. If parents have conflicts regarding the child, they struggle with these using the same tools as all families do: seeking therapy, talking with friends, separating or divorcing, specializing in their activities, compromising, going to religious sources for counseling, and so forth. Seldom do the accommodations made by families with children with delays seem unusual or deviant.

The families in our Southern California studies share similar cultural models of development. For instance, parents of children with delays share with most U.S.A. parents the belief that early experience is unique, and the more stimulation and attention given at this stage of life, the better. These parents share the U.S.A. cultural belief that they, more than siblings, other kin or the larger community, are responsible for rearing their child. They share the contemporary American view that a child's development is a complex interaction between environment and genetic inheritance. Hence our hypothesis: families with children with delays will be much more similar to all families in their culture than they will be different from them in their family daily routine and patterns of accommodation.

Some families do show signs of serious problems however. In our study, for instance, there is a group of families with chronic and persistent change and troubles (about 10%). Another group of families are vulnerable and struggling, yet hanging on as best they can in their cultural project of organizing their daily routine (about 15%) (Weisner, Bernheimer, Matheson, & Gallimore, ms). These per cent who are troubled or hanging on are not substantially different than what one might find, using similar measures, in the general population. Here again, our data suggest that stress and struggle confronts and can overwhelm some families, but those adapting to childhood delays are not more susceptible or more at risk.

4 INTERVENTION IMPLICATIONS OF AN ECOCULTURAL APPROACH

Many of the families in our sample reported they had received a wide range of advice from medical, educational, and social service agencies and personnel. Often, this advice led to interventions that had to be fitted into the daily routine of existing activity settings. In general, interventions by outside agencies were unlikely to be sustained if the families had to make changes in the activity settings of their daily routines which were too discrepant from those that had evolved through the families' proactivity (Gallimore, Goldenberg, & Weisner, 1993).

We can illustrate this point by describing a case of parents with a delayed child who had a strong sense of familism, and who were unable to sustain an intervention plan for integrating the delayed child into family mealtimes (Bernheimer, Gallimore, & Weisner, 1990). Different values came into conflict in this case. The family was strongly committed to optimize development of the child with delays, but not at the expense of another cultural project: familism:

> Todd was one of four children. His parents ran a mom and pop [small neighborhood] grocery store, and placed a high premium on quality family time, although it was difficult getting everyone together. One daily period of togetherness was the dinner hour. Because Todd was very withdrawn socially, the intervener felt the dinner hour would be an excellent opportunity for intensive family input for Todd. The parents were initially enthusiastic, because the intended outcome - a more socially appropriate Todd - would enhance the quality of "family time." The unintended outcome was quite different, however. In addition to being socially withdrawn, Todd was very disruptive; throwing his food on the floor, leaving his seat and running around the table in circles. Thus "family time" became chaotic and stressful. The parents designed a new intervention: Todd was fed early, and during dinner, he was seated in front of the television to watch tapes of "Sesame Street," an activity he would stay with for a good half hour. The family dinner was salvaged as "quality time" for the other members of the family, while Todd was engaged in an age-appropriate activity (REACH, Case 401; Bernheimer et al., 1990).

Neither the families in this case nor any of the other families in the study ignored the needs of their developmentally delayed children. However, activity settings introduced by interventions had to be sustainable and meaningful within the full range of what the family was trying to accomplish. This conclusion is consistent with earlier research which indicated that it is more efficient and effective to design interventions that capitalize on existing cultural features than attempt to create new repertoires and contexts (Tharp & Gallimore, 1988; Tharp & Wetzel, 1969).

In a fundamental sense, this is a break from the traditions of family intervention. At least since the 1960's a principal target of interventions has been parent-child interaction. But parent-child interactions do not occur in a vacuum. They are a concomitant of the everyday routine, and the activity contexts in which children spend time.

The family whose circumstances allow them to create and sustain a daily routine that includes a "reading and homework activity setting", for example, creates an essential prior condition for parent-child interaction to occur. The creation of the activity is prior to and encompasses the interaction, for the latter is almost sure to follow the cultural design of the former as our examples have suggested. That is, an activity not only creates a "slot" for interaction to occur, it is likely to define a purpose for the activity and thereby "script" the interaction. Some families may create the "slot" but leave it to the individual child to do the work alone. In other cultures, assistance is provided by older siblings or other caregivers. Other families may believe that certain kinds of parental assistance are essential for a reading child or homework assignee because it elicits greater motivation.

Over the past three decades, family intervention programs have compiled a record of some success and maintained a cadre of enthusiasts. Despite their successes (e.g., Landesman & Ramey, 1989; Powell, 1988; Sigel & Laosa, 1983) and "overwhelmingly positive" parent response (Florin & Dokecki, 1983, p. 47), interventions have also been controversial. Sigel (1983), for example, has expressed concern about the ethics of family interventions, which inherently have an "authoritative conception of the good, the desirable, and the healthy" (p. 8). Who, moreover, is to be the model for "optimal" parenting? Farran (1982) has decried interventions that try to remediate deficiencies in family functioning "by attempting to make [all] parent[s] behave like middle-class parents" (p. 271). Recall our comments earlier regarding the assessment of child competence in terms of the ecocultural project, not only in terms of universal developmental or biomedical milestones.

Just as we are long past the notion that individuals are blank slates or empty vessels, so too must we disavow the idea that families are passive recipients (or, alternatively, reactive rejecters) of our interventionist largesse. Family daily routines are the point of contact between individuals and the surrounding cultural and ecological environment. For families, these settings are hard-won solutions to the adaptive problem we all share - sustaining a workable daily routine that is meaningful, and reasonably congruent with deeply felt convictions. Effective, sustainable interventions depend on understanding these proactive adaptations and their subjective meaning to the people who construct and live them.

5 CONCLUSION

There is a final comment regarding the Ecocultural theory that is self-evident when we consider the theoretical and empirical tradition it comes from: the ecocultural approach is well suited to cross-national and cross-cultural comparisons. Ecocultural theory takes culture seriously as a powerful influence on family adaptation and human development - not just the particular cultural place (Southern California) in which it has been developed in work with families of children with delays. Ecocultural theory and methods are applicable in a wide range of cultures, nations, and communities around the world. The domains of the model come from studies of human development in many cultures around the world. The ecocultural methods have been used in a number of different communities already, including Japanese-Americans, Chinese-Americans, American Indian (Navajo), and Mexican immigrants in Los Angeles. Other applications of the method are underway - Finland hopefully one of these places. The current and future work at Jyväskylä we are sure will be an important addition to this tradition of comparative work leading to significant variations of the ecocultural model and methods. We wish the students, staff, faculty - and especially Associate Professor Määttä - well in their future work.

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Chapter 2

CONSTRUCTIVE ENGAGEMENT: IMPROVING FAMILY-PROFESSIONAL COLLABORATION

Dianne L. Ferguson and Philip M. Ferguson

1 INTRODUCTION

In the United States family-professional collaboration within the special education system has been official policy for nearly 20 years. The Education for All Handicapped children Act (EHA, P.L. 94-142) included a firm commitment to involving parents in the process of developing individualized educational plans for children and youth with disabilities in America's public schools. When reauthorized and updated as the Individuals with Disabilities Education Act (IDEA, P.L. 101-476) in 1990, this commitment to family-professional collaboration remained a key component.

Despite official policy, however, we only incompletely fulfill the spirit of the legislation's mandate to involve families in the educational experiences of their sons and daughters. Families hear of "involvement," "partnerships" and "collaboration," only to once again arrive at planning meetings to be presented with a completed plan. All too often the "involvement" that educators seem to want from families is one of "passive ratification" rather than "active participation" in the educational plans for their children (Cutler, 1993). What makes the relationships between professionals and families so elusive? Twenty-two years of special education for our son, Ian, provided us with a variety of experiences with "collaboration between professionals and families." Let us share a couple of examples by way of introduction.

Getting across the stages. Ian officially graduated from high school in 1990 even though our public law permitted him one more year of official schooling. It was quite important to us that Ian experience the important rituals of growth and change that all young people share. High school graduation is surely one such ritual in America. Getting across the stage, however, was not an easy matter for Ian. His official disabilities of severe mental retardation, spastic quadriplegia and vision impairment, posed some very real challenges for us, for his teachers and the high school students and principal.

Getting across the stage required our joint and collaborative attention to a number of issues. Ian needed to get across the stage in a timely manner. Nearly 300 students each needed their moment before the camera, their empty diploma case, and the ritual handshake and shiny new penny from the principal of the high school. Ian should not unduly extend the event. At the same time, we wanted Ian's journey to be dignified - not any more different than dictated by the inescapable facts of his wheelchair and left-handed handshake.

He also needed to complete the experience safely. With so many students on the stage, the passage between the toes of those in the front row and the drop to the orchestra pit was barely wide enough for his motorized wheelchair. What it didn't allow for was his sometimes erratic steering. This was an especially difficult issue for us. Using the manual wheelchair required that someone push him across the stage; an affront, we felt, to Ian's dignity and the image of competence we know he can project. And who would push him? His participation should not compromise the experience of any student who might agree to push him. Would Ian have to wait until a student helper also received their handshake? Would he manage to wait well?

We each had to consider Ian's impact on the entire ceremony. Would figuring out his participation require too many accommodations from others? Although the principal was willing and supportive, he really didn't know Ian well. Would he remember to put the penny in Ian's hand after shaking so he wouldn't drop it? Would he remember to shake Ian's left hand instead of his right? How much rehearsal would we need compared to what was really possible?

Getting Ian across the stage at the city concert hall required the working together of a lot of people. Ian's teacher figured out how to get Ian in through the back entrance to the stage where he could wait for the procession. We had already decided that it was too much accommodation to ramp the stage. However, she carefully arranged the seating so that he entered from the wings just at the end of a filled row. She also arranged for the student at the end of the next row, sitting immediately behind Ian, to be a peer tutor who knew and liked him. We eventually were impressed enough with the risk of falling into the orchestra pit to agree to the wisdom of using the manual chair, which the peer tutor agreed to push. During a long morning's rehearsal, Phil and Ian's teacher decided that this student could push Ian across the stage and then simply replace herself in sequence for her own, separate, journey. In the end, Ian made it across the stage.

Let us offer one more brief story that speaks to a different dimension of collaboration between professional and families.

Mr. Phil. When Ian was about 13 we moved from upstate New York to Ohio. After much deliberation, and several long meetings, we decided that Ian would attend the local middle school where there was a class of students with physical disabilities. First days have always been difficult for us. Ian has never been very reliably communicative, especially in new situations. As he grew older we resisted pinning a label with his name and destination to the front of his shirt, but each time the school bus door closed on a first day, we always experienced that quick clutch of fear that he would be lost on the way.

It became our practice to reassure ourselves by showing up the first day of school about 30 minutes after Ian was due to arrive. This time was also our first opportunity to meet the new teacher. Phil arrived as scheduled to find Ian part of a semi-circle of classmates arranged to look at a map of the world. The teacher, who had been talking to the students about the political crisis in Iran, introduced himself to Phil as "Mr. Larry." He then proceeded to introduce Phil to each student as "Mr. Phil." Several things about this encounter gave Phil pause. He didn't, for example, remember discussing an IEP objective requiring Ian to develop a policy on Middle East politics. He also wondered how he was going to develop a collaborative relationship with a teacher that thought he was a hairdresser. In this case, first impressions prevailed. We muddled through the year, and luckily I think, moved on to Oregon.

We share these two stories because they say something about what collaboration between professionals (in these examples teachers, but really any professionals) and families is and is not. Indeed, we believe that any discussion of a phenomenon as complex as collaboration must be grounded in how people experience that phenomenon. In this brief article will try to explicate the lessons from life of these stories, as well as a few more. First, we offer a framework for thinking about collaboration with families by beginning with a family perspective rather than a professional reinterpretation of that perspective. We will illustrate the implications of such an alternative framework with some specific examples that have emerged from our work with teachers and families in Oregon and conclude with a few words about how our experiences as teachers with families might guide us toward a better understanding of what collaboration means within our own professional circles.

2 DIMENSIONS OF FAMILY COLLABORATION

Even when we just talk among ourselves, there is a good deal of confusion about exactly what collaboration is and how it works. Much discussion centers around the relationship between collaboration and another equally complex phenomenon - consultation (Cook & Friend, 1991; Evans, 1991). Collaboration, or even collaborative consultation, teacher assistance teams, pre-referral systems, triadic models, trans - multi - and interdisciplinary teaming, collaborative problem-solving models, the collaborative ethic, illustrate just some of the language of the discussion (Friend, 1988; Gallessich, 1982; Idol, Paolucci-Whitcomb, & Nevin, 1986; Phillips & McCullough, 1990). All this discussion seems to be struggling with three things whether the actors in the exchange are all professional of the same discipline, different disciplines, or professionals and family members.

What is the purpose of collaboration? Is it a way to provide more effective services to children and youth by better informing professionals? Or better informing parents? Is it a way to get parents to do what professionals think is best, or get professionals to do what parents think is best? Is it a special education strategy for "fixing" regular education? Is it a way to keep students out of special education? More generally, is collaboration about advice giving, skill giving, or empowerment?

How does collaboration happen? What is the structure and process of a collaborative relationship? That is, can it be vertical? Must it be horizontal? How reciprocal should it be? Is it about problem-solving, problem finding or conflict resolution? Is collaboration better thought of as a noun or a verb? Is collaboration something different from consultation, or is consultation just a particular kind of collaboration?

How does collaboration go wrong? When is help unhelpful? What are the potential mixed messages and unintended consequences of various ways of "doing" collaboration? Can consultation ever be really collaborative?

Given the lack of clarity, and possibly disagreement, among even just special education professionals about collaboration, it might seem premature to try to describe collaboration between families and professionals. It might be more useful, one might argue, to achieve some better self-understanding before trying to enlarge the discussion to families. At the very least, families constitute a much more heterogeneous group than school professionals, greatly expanding the people, process and procedural variables that must be considered.

While this has some intuitive appeal, we suggest a different starting point. Instead of looking to professional/professional collaboration, we might gain more insight by looking to parents' experiences of collaboration within their own families and with other families as examples that can provide a better understanding of not only family/professional collaboration, but perhaps professional/professional collaboration as well.

2.1 Within-Family Collaboration

Any family's successful functioning depends a good deal on collaboration. Members of all ages, roles, and abilities, contribute in various ways to achieving the family's preferred lifestyle at any point in time. Relatives contribute, perhaps in different ways and on different schedules, but nevertheless represent an important resource to parents and children for enhancing and extending the entire family's satisfaction with their collective life.

Within families of children and young people with disabilities, the same elements of collaboration occur. Families negotiate patterns of activity and attention in order to meet both individual and group needs so as to maximize overall family balance and enjoyment (Turnbull, Summers, & Brotherson, 1986). Sometimes, of course, the demands of disability are unique and the balances may shift more dramatically than in families of children without disabilities. For example, many families learn early on to negotiate successfully the disproportionate attention the disabled family member sometimes needs. Securing an appropriate and successful school program may well require all the parents' discretionary energy and time be devoted to that task, sometimes at the expense of time previously committed to others in the family or to other family activities and tasks.

We have shifted our collaborative arrangements substantially over the years. As Ian has gotten older, heavier, and adult, Phil has assumed more and more responsibility for his personal care. Some of the same considerations has led to Phil's management of all doctors visits. Dianne, on the other hand, takes responsibility for dealing with the people and paperwork of the bureaucracies.

When the collaboration works, neither of us feels unreasonably stretched, either individually or in comparison to the other. We can each assume the other's responsibilities when necessary, although not necessarily with the same efficiency and skill. We also resist finding fault with each other's decisions. Dianne thinks she does a better job fixing Ian's hair so it is trendy but not bizarre, but is willing to resist comment if Phil will continue to listen patiently when she vents her frustration with yet another senseless bureaucratic encounter.

One lesson of this within-family collaboration for professionals is that the result is rarely perfect when considered from each member's perspective. We agree not only to tolerate imperfection, but to resist trying to improve some results in favor of preserving a comfortable continuing relationship. Such negotiated arrangements are not unique to families of disabled children, of course. Any family group can easily think of such carefully balanced arrangements. What might bear more thought is why this tone of mutual accommodation and change is so often missing from our professional discussions of collaboration.

Another lesson might be that as professionals one important feature of our collaboration with families is that it not unsettle within-family collaboration. Indeed, we may need to actively resist making some demands or offers in order to support and protect the family's already carefully negotiated collaborative arrangements.

2.2 Collaboration Among Families

There can be also be important types of both formal and informal collaboration among families. Parent-to-parent collaboration strategies can expand the resources available to families in ways that escape the chronic scarcity of services provided within the formal system. We experienced our first such collaborative venture with other families when Ian was about three.

In 1972 in New Haven, Connecticut, there were no early intervention services available for children with significant disabilities. In fall of that year a joint effort between the state mental health system and the local Easter Seal Rehabilitation Center brought about a dozen families together in a new center-based preschool. Since the program required at least one parent to attend, we quickly got to know each other, but it was the following Spring before we began our collaboration.

We learned that the first six months of the program had not been funded by any outside sources. As much of the cost as possible had been billed to each of our insurance companies and the remainder now arrived at each of our homes as a bill. Those of us with more comprehensive insurance coverage received smaller bills, of course; but none of us felt we could afford this additional and unexpected expense. Our subsequent meetings and discussions generated a plan to raise money through a variety of grass roots fundraising activities to pay off our collective bills. Our appointed spokespersons presented our request for the total owed by all the families to the business office only to be met by professional shock and confusion. Mumbling vague things about "usual procedures," and "confidentiality," the business manager sent us off to the program's director who explained that they had never had such a request before. Our eagerness to share responsibility for the program costs seemed unimaginable to a system used to dealing with individual clients.

We did raise the money, though it took us into the Fall. The Rehabilitation Center did not long resist giving us the financial information we requested. In fact, they watched our activities with bemusement. In the end of course, they accepted the check with grace, and probably relief. For us parents, this experience of informal collaboration to respond to our collective financial problem grew into a continuing collaboration that began to advocate for other things. We gently, but successfully, persuaded the program to make some changes in scheduling and delivery of therapy services, for example; and together we prepared and helped each other leave the program for the new special education opportunities created by the new federal legislation.

One message this kind of collaboration among families can carry for professionals is that we do not need to collaborate with the world - to be active members of every collaborative arrangement. Another feature of our collaboration with families, or with each other, might be to spur others to collaborate (Ferguson & Asch, 1990).

Dianne's experiences with teachers over the years compellingly confirms the wisdom of this message. An important commitment of all our research and development activities, often supported by federal grants, is to improve the educational experiences of students with disabilities, especially those with more significant disabilities. Since we want to make sure that anything we at the university developed is easy and effective for teachers to use, we began our efforts by entering into a collaborative arrangement with five area teachers. Our work group, which still meets, created a set of materials we later named the Elementary/Secondary System. That first collaborative work group has since grown into many different partnerships with individual teachers, groups of teachers and schools. But it was the first experience of listening to teachers and helping them create the solutions that would work in their settings that has characterized and sustained all our subsequent efforts. Instead of trying to teach school professionals new ways to work, or "fix" the deficiencies in the way they were already working, our role has shifted to providing teachers with the resources to form their own collaborative working groups. Although a bit humbling, we are finding that when trusted to find their own solutions, teachers can and do. They do not always need collaboration with us. Parents do not either.

3 COLLABORATION BETWEEN FAMILIES AND SCHOOLS

Many parents feel that family-professional collaboration is more familiar as rhetoric than reality. Some professionals feel the same about their own collaboration. We believe one reason for this inadequacy arises because we try to describe and understand our relationships with families by imagining the experience from a professional rather than a family point of view (Ferguson & Ferguson, 1986). If, however, we build our understanding of family professional partnerships in combination with the other two dimensions of family collaboration just discussed, the resulting relationships might enjoy more substance. Let us suggest how this might be so by first describing what family/ professional collaboration is not.

3.1 What Family-Professional Collaboration is Not

Family-professional collaboration is not consent. We jokingly deride the practice of convening an Individual Education Plan (IEP) planning meeting by handing a parent a completed document. Of course IEP meetings are not the only way in which professional interactions with families seek ratification and consent rather than a constructive engagement. Much of what passes for parent involvement in special education is really ratification. We most often approach parents with information collected, decisions made, plans prepared. At best a parent's "involvement" might elaborate what we have already designed. The continuing existence of such examples attests to our failure to appreciate their lesson. Ratification not only is not collaboration, it kills collaboration. When parents repeatedly receive the message that nothing they do or say will make any real difference to the result, they literally become less and less able to participate in collaboration.

Family-professional collaboration is not cooption. Over the years our various professional approaches to "working with" families have tended to place parents in the role of a para-professional (Allen & Hudd, 1987; Ferguson & Ferguson, 1987). Sometimes this role is quite explicit - teaching mothers and fathers to reconstruct family life to as closely as possible approximate the school program. Many of us created mini-classrooms and therapy rooms in a corner of our living rooms for doing the programs, lessons and routines that our involvement with professionals demanded be added to our family's evening routine along with the evening news, dishes and bedtime stories. We were "trained," sometimes repeatedly, to perform all manner of things alien to us before. In the process we learned to use the word "perseverate" instead of "he does it again, and again, and again, and again," because it made us sound more "professional." We learned about "domains," "objectives," and "criterion." We learned the reasons some motors are fine while others are gross. We passed the test, survived observation and feedback, earning our para-professional merit badge (at least while you were watching). Being a mother or a father, however, does not mean being one more type of classroom assistant. Collaboration cannot mean this kind of cooption of parental roles. Good collaboration should not be determined by how well mothers and fathers behave like teachers.

Family-professional collaboration is not collusion, although collusion can sometimes lead to collaboration. Teachers, who among all school professionals probably experience a disenfranchisement and powerlessness quite similar to that experienced by many families, often approach parent involvement as collusion. As teachers we do not have the clout to challenge the system's most troubling features; but together with parents - to whom the system always listens, we believe - we might have a fighting chance.

While effective advocacy, this kind of family-professional collusion does not endure as a substitute for collaboration. Eventually parents must shift their energies and resources from what professionals have first defined as preferred, best, or exemplary to those issues that emerge from needs parents define for themselves.

3.2 What Family-Professional Collaboration Can Be?

Viewed from a family perspective, then, the crucial element seems to be whether the nature of the collaboration is perceived to be family-based or program-based (whether the "program" is a school, clinic, hospital or center of some kind). The professional arena, with all its services and supports, is only one aspect of the world of family life. The most effective and successful family-professional collaboration is characterized by a "constructive engagement" that extends into other aspects of family life while allowing families to maintain distinctions as to roles and responsibilities.

We began this section with how collaboration between families and professionals can go wrong. Let us conclude it by returning to the two other sets of questions the field has posed about collaboration.

What is the Purpose of Collaboration Between Families and Practitioners?

If the purpose of collaboration is not an extension of the professional role, then what purpose can serve both family and professional interests? For families there is continuing need to recognize collaboration as a means to an end, and not an end in itself. For families it is not so much the doing of collaboration that matters, but what that activity produces for the disabled child. In order to be constructive engagement, collaboration needs to have some effect on a student not just within the professional's arena, but also outside of school, in the family's round of community life. When we think about what schooling accomplished for Ian, for example, it is not achievement scores, specific skills, or some set of learning experiences that spring to mind. No matter where we start, we end up with just two things: social embeddedness and active participation. Whatever schools teach exactly, in the end students should be actively participating members in their communities, with the social connectedness necessary to support that participation. Certainly this embeddedness and participation will look different for different students, depending upon their abilities and the available supports. For parents, however, it is a useful standard against which to measure any particular school plan or activity. Does it make sense to me that these goals and objectives, this activity, this course of action will contribute to my child's social embeddeness and active participation in our community?

The purpose of collaboration then, from a parent's point of view, is to contribute to their child's ability to respond to the demands of community life, now and in the future. Of course parents understand about inability as well. But living in the community requires them to constantly negotiate a "fit" between their child's abilities and the community's demands. It is much less possible to temporarily suspend life while waiting for learning to occur. A focus on ability and participation seems to resonate more easily with parents because that is what and how they live (Ferguson, Ferguson, & Jones, 1988).

What is "Good" Family-Professional Collaboration Like?

We think there are three important features to the kind of constructive engagement with parents that we have suggested is a useful way to think about collaboration. The first two are best initiated by professionals: one involves access the other affirmation. The last involves parents affiliation with adults with disabilities.

Access. Because we professionals have tended to define family collaboration from our own point of view, we have also constructed the process to be more familiar to us than to families. Family-professional collaboration, for example, occurs mainly during meetings, or perhaps phone calls. Within most families, however, meetings are rare and unusual events. People in families spend time figuring things out on the way to and from places, while they are also fixing dinner, or just in brief excerpts from the daily routine.

Even families collaborations with each other are more likely to occur in the context of other things and routines. The mothers and fathers in the preschool program we mentioned earlier did most of their collaborative work during class. The meetings, over pot luck suppers or desserts, served more to confirm than create our decisions. Many astute preschool teachers have discovered that the best time for collaborating with families is when they drop off and pick up their child from class. Unfortunately not all teachers enjoy such opportunity.

We also tend to frame our interactions with parents in concepts more familiar to us than to parents. We talk, slowly and deliberately perhaps, about skills, goals and objectives, tests and achievement and learning programs, rather than about the activities of life with which families are more familiar. As a consequence, parents must always struggle to translate what they know and experience into our terms. Some succeed better than others, but in the process, much information, and opportunity for collaboration, can be lost. Better family-professional collaboration occurs when parents can participate in ways that are natural and familiar to them and the lives they lead with their child outside of school. Finding ways to improve parents' access to collaboration with professionals is an important feature of more constructive engagement.

Affirmation. There is an inevitable hierarchy between lay people, as parents surely are, and professionals. Even parents who are professionals themselves in some arenas are lay people when they interact with their child's teachers. Unfortunately two aspects of our professional experience exacerbate this inevitable inequality with parents. The first emerges from the fact that parents involvement with schools is primarily through teachers, who themselves occupy the bottom of the school hierarchy. The resulting shared experience of disenfranchisement and powerlessness which can sometimes lead to constructive engagement too often leads to the exercise of a second aspect of professional experience what Seymour Sarason (1972) termed "professional preciousness". As professionals, he explained, we have a tendency to define problems in such a way as to require our current skills for solution. Alternative ways of understanding a problem or situation, by virtue of being nonprofessional, are simply less legitimate. Thus even when parents' access to collaboration is constructed in ways natural to their experience and understanding, their resulting contributions can seem less legitimate, more naive, as considered from the distance of professional preciousness. This peculiar professional phenomenon is so commonplace to us that we operate as if our conclusions were "truth" rather than perspective; fact rather than opinion. A constructive engagement that results in increased ability and participation for a disabled child requires professionals to repeatedly affirm, in a variety of explicit and implicit ways, that parents' engagement is on an equal footing.

Affiliation. Parents of "different" families (Featherstone, 1980) face a variety of challenges not shared by families of children without disabilities. Successful collaboration with professional can assist families to manage creatively most of these challenges. There are two, however, that are best addressed through a different kind of collaborative affiliation.

It can be especially difficult for parents to assist sons and daughters with disabilities to imagine all the possibilities and opportunities of a future with disabilities. Most of us have little experience with disability when we become parents of a child with disabilities, and what experiences we have collected may have been colored by the kinds of prejudice, limited expectations, and discomfort we now seek to change for our own child. An excellent resource for parents and their children with disabilities is adults with disabilities who have emerged from the experience of childhood and youth to construct satisfying and productive lives for themselves. These role models can teach us and our children how to not only envision more possibilities for the future, but they can often provide invaluable guidance on ways to achieve such visions (Ferguson & Asch, 1990).

For parents, affiliation with adults with disabilities can be an important support as we try to imagine and then achieve adult relationships with our disabled sons and daughters. As Ian has grown into a young man, we have struggled to understand the ways in which he can participate as an adult member of our community (Ferguson & Ferguson, 1993). On the one hand, the legally mandated stability of school has disappeared and Ian requires more and more of our support and creativity in order to pursue an active and varied life of work, friends, and social life. On the other hand, the professional in this new arena of adult services encourage us to "back of," "be prepared to let go," and let Ian "make his own decisions." Yet Ian requires more of our attention and support than ever before as he and we try to construct adult life.

We are finding that the perspective of adults with disabilities helpful in striking a balance between continuing to provide guidance and direction to Ian and letting him and his friends and supporters have the flexibility to explore options that might not always be our first choice. This tension between parents and their adult children is all too familiar to parents of young adults without disabilities. Yet it is also key to the establishment of an adult relationship. Collaborative affiliation with adults with disabilities can help parents of young adults with disabilities achieve this important transition.

3.3 Implications of "Constructive Engagement": One Example

Family-professional collaboration, then, is not about consent, cooption, or collusion. Rather, when considered in light of families' experiences of collaboration outside the professional arena, it involves enhancing ability, increasing access, and affirming equality. Let us briefly illustrate one way these notions can be addressed in the educational planning process.

Our example is taken from the Elementary/Secondary Systems we mentioned earlier that was developed in collaboration with teachers in Oregon. These materials focus on developing curriculum and teaching for students very diverse groups of students, including disabled and nondisabled students, students of differing ages, from different cultural and linguistic backgrounds, and different family structures. Many of the ideas emerged first because of out interest in students with especially severe disabilities, but we have learned through our collaborations that the underlying logic applies to any student and family's participation in the design of effective schooling.

If schools begin with the commitment to affect students' lives not just within, but also outside of school; then one important aspect of assessment and curriculum development becomes trying to discover what effect our teaching has on those lives. Parents and students, we believe, are the natural sources of this information.

First we developed lists of activities typical at different ages, grouped into three year ranges in order to accommodate natural ability variation but within reasonable age appropriate parameters. Following work done earlier by Wilcox and Bellamy (1987) for high school students with disabilities, we organized the activities into three life domains: personal management, jobs and chores, and leisure. We generated these lists by actually observing and interviewing students without disabilities and their parents in Oregon. As a consequence the lists are referenced to Oregon. When traveling to other countries and states we have found that the lists need to be modified in order to more accurately reference local norms and activities.

The activity-based assessment asks parents and students to describe their current participation and competence in each activities. For some students, participation might be partial or require adaptive or alternative performance materials or strategies. Nevertheless, the focus on real activities provides both parents and teachers with a natural standard against which to evaluate the impact of teaching. Has what we taught made any impact of the student's life?

For teachers, activity-based assessment provides information they might have difficulty discovering for themselves. Knowing that your work pays off for students when they are not with you is also gratifying for teachers who work extremely hard. On the other hand, the process allows parents to provide information that is familiar and natural to their own context and experience. Activities resonate well with parents. For families, all interaction, and even instruction, occurs within the context of activities. Formal lessons are the exception, not the rule in most homes.

An activity focus offers additional advantages for curriculum development, especially for severely disabled learners who are unlikely to acquire all the abilities and competence of their nondisabled peers. Teachers can maximize the impact of whatever instruction possible to address in a six hour school day by selecting those skills, strategies, and activity contexts that relate most closely to the life the student leads outside of school. By working on skills and activities within school that the student has a natural opportunity to encounter and practice outside of school, learning is enhanced without asking parents to do any more than lead their typical lives. This careful selection of instructional content can also avoid the error of spending a good deal of effort and time to teach a student something only to have achievement and performance atrophy from lack of use.

We find that parents and teachers like this kind of assessment. Parents find the exchange comfortable and familiar. They are asked neither to provide exhaustive detail about their family's private life, nor to describe family life in the unfamiliar terms of some official special education curriculum. Teachers learn a good deal about their students' abilities and how they use those abilities to participate in community life. While such information does not substitute for other kinds of assessment information generated in more traditional professional ways, it does provide a critical complement to that information that most teachers never enjoy, while at the same time, building the kind of constructive engagement we think family-professional collaboration ought to be. Increasingly teachers are using this kind of activity-based assessment in lots of different ways to help them tailor learning to any students. For some students just knowing what they are interested in and spend time doing and thinking about outside of school can assist teachers to create learning options that are not only more successful, but more motivating and enjoyable for students.

4 LESSONS FROM LIFE: IMPROVING PROFESSIONAL COLLABORATION

Earlier we referred to how much confusion we professionals have, not just about collaboration between families and professionals, but among professionals. We have also suggested that looking at the particular example of family-professional collaboration from the vantage point of families' experiences of collaboration more generally might assist us to think more clearly about professional-professional collaborations. We will conclude with two ways in which within and among family collaboration might help professionals as they pursue better collaborations with each other.

Knowing the Point. Too often the rhetoric of collaboration encourages people to frame their activities in terms of making people change. We need to be reminded that it is not so much people that must change, as outcomes. Services, programs, collective effort need to accomplish something different for students. That's the point. School needs to have an impact on the lives students live within and outside of school. At the same time, the specific ways for achieving the point will only become clear as people work together.

There are no templates for successful collaborative activity that can adequately take into account the unique features of the group, its members, and the contexts in which their live and work. Collaboration participants need to be given the power to manage their own accomplishments and outcomes.

Understanding the Risk. It is difficult to describe just what "collaboration" is or might mean in various situations and contexts. For many families and professionals collaboration is, like other experiences of practice, easier to recognize when it is happening than to describe later. However, one thing it probably does mean is that all members of the collaborative group must enter the process of discussion and exchange prepared to change their minds. Each member needs to understand the risk that his or her own understanding, point of view, or interpretation, might alter as a result of listening to other's understandings and interpretations. Perhaps what is missing in our collaborations is that we either fail to understand this risk, or are unwilling to take it. It is, after all, not a trivial matter to change one's mind - to have a change of mind. The real work of collaboration might lie in people learning how to articulate their own reflections in order to create a new understanding that could not have been arrived at by any member individually.

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Chapter 3

SUPPORTING FAMILIES OF CHILDREN WITH DISABILITIES: CURRENT SITUATION IN ESTONIA

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In this paper we will try to give a survey (1) on the results of the study carried out in Estonia on the needs, emotions, and problems of parents of disabled children and (2) on the practical efforts taken to support the parents of disabled children. Thus, the article describes the situation in the families of children with disabilities and indicates the measures taken for the improvement of the situation. This field has not received much attention from researchers thus far in Estonia. The impetus for the study came from associate professor Paula Määttä and researcher Markku Leskinen (University of Jyväskylä) whose questionnaire was translated and applied in the study.

1 INTRODUCTION

When parents are told that they have a disabled child, it is not easy to understand it at first. Learning the truth may cause a psychic crisis in some families. When adopting a psychodynamic orientation, it is possible to separate five stages during the crisis:

1) Shock. The first reaction to the diagnosis is shock, because parents had expected a healthy child.

2) Parents try to avoid the shock by denying the diagnosis.

3) Sadness, anger, worry - this is the most common reaction accompanied or followed by denying the diagnosis.

4) Adaptation. Finally, strong emotions calm down and parents cope with the task of taking care of the child.

5) Re-adaptation. This is a period of new emotions. Positive attitudes toward the problem develop and "normal living" sets in while the feeling of guilt decrease (Blacher, 1984).

Olshansky suggests that parents can never be fully oblivious to their tragedy. According to him longtime sadness is a normal reaction to the birth of a disabled child (see Seligman, 1983, 1991).

In most cases, parents have minimal knowledge about the disabled before the birth of their own child (Seligman, 1983). Richardson (1975, 1976) found that most of the people have a negative attitude toward the physically disabled, and the same has been observed in reference to mentally retarded people. With the development of diagnosis techniques, in some cases, it is possible to make the right diagnosis of the disability already before the birth of the child. In such a case, there still remains hope for the mother to think that either the equipment or the doctor has been mistaken and the child might be healthy (Seligman, 1983).

Kulomäki (1985) is sure, that the birth of a disabled child has great impact on the life and everyday activities of the family. The emotions and spiritual life of the parents undergo great changes and for mothers, of course, it is a hard blow for their self-image. According to Seligman and Darling (1989), fathers are worried even more than mothers about their child's future, socially approved behavior and success in life. Kulomäki and Österlund have expressed the opinion that the shock felt by fathers is greater than usually thought, but fathers may simply be more reserved about their feelings.

As proof of the enormous will of the parents, the fact is that in spite of all the obstacles and difficulties, most of the parents form very close relationships with their children. The support of other people should also be taken into consideration as a favorable factor (Seligman, 1983).

Mäki and Rusanen (1991) state that taking care of and bringing up a disabled child presents very special demands. To be successful, parents need special knowledge and support in their work. Määttä and Perkka drew the conclusion that the most important thing for the parents is the support of the grandparents and close friends.

Baxter (1986) found that the main causes for stress were connected with taking care of and treating the child. Research proves that the interference with the children's psychic needs decreases with years, whereas the worry about the child's behavior in public can increase. The child's behavioral disturbance can interfere with the family's social life.

Stress can be caused by situations where the children do not behave according to the norms or while on a visit they fail to behave correctly.

It has been shown that to cope with one's life means to communicate, love, realize oneself, educate oneself, know how to work and have the desire to work (see Gallagher & Vietze, 1986). Coping means any kind of reaction which aims to decrease the stress or to change the meaning of the situation.

Research has shown that when parents do not get along well, the attitude towards each other becomes aggravated even more after the birth of the disabled child. On the other hand, among couples where the relationship is close, they can become even closer. Blacher, Nihira and Meyers (1987) considered it surprising that among families with serious mental handicaps the number of divorces was not greater than that of families of a child with a milder handicap. Mattus (1993) states, that the more serious the handicap of the child, the closer the parents are. In such families, as a rule, fathers are of great support to mothers.

According to Baxter (1986), the most important form of support is information that parents can get from specialists. Another source of help is emotional support from different support groups. They can relieve the feeling of loneliness and isolation, and can provide a lot of information and material for comparison (Seligman, 1983). To make the life of such families normal, it might be necessary for both parents to go to work, keep up a social life with their friends, enjoy free time and change their surroundings (Seligman, 1983).

2 PRELIMINARY RESULTS

Participants. Within the framework of the given research we interviewed 90 mothers and 42 fathers of disabled children. The families were Estonian. The majority of mothers (62%) were 21-30 years old at the birth of the child. Some of the mothers were either below 20 or over 40. The majority of the children were preschoolers at the time of the interview (60 %), but basically they were schoolchildren. In the majority of cases they was the only child in the family (50%). Some 30 per cent of the researched children had either one brother and sister or two or more. The parents were married (mothers: 59%, fathers: about 100%), divorced or separated. There were also single parents or widowed ones. The level of education was higher among mothers. Among the researched fathers only 25 per cent had a higher education, whereas for mothers the figure was 33.3. 45 per cent of the fathers and only 31 per cent of the mothers had a secondary school education, one third of the parents had received a technical school education. Half of the mothers of disabled children worked outside the home, 37 per cent stayed at home and 13 per cent were out of work. So just half of the mothers stayed at home. 83 per cent of fathers were employed, the rest were out of work. In one family, the mother was a student and the child was looked after by the grandmother. In 60 per cent of the cases, the disabled child was the first child of the family, in 27 per cent of cases the second one, and in the remaining cases either the third or fourth child.

Needs. We tried to find out what kind of information and personal support parents needed most. It came out that in the first place people lacked information about subsidies and services they could expect from the state. Moreover, there is a great need for about the child's upbringing and his or her development. Parents are eager to know how to educate their child and what the chances for entering schools could be (more than 70%). Much less interest was shown towards problems of how to speak to the child (35%). On lines of personal support, parents needed primarily literature on disabled children (77%), also support from psychologists and social workers (64%) and free time for themselves (62%). Only rarely was help expected from the members of the congregation (11%). As to advice and services, the greatest need was for places in kindergartens.

We were told that both mothers and fathers would need more hobby groups and diverse ways to activate their leisure time. They are of the opinion that they should discuss their problems in the family circle much more and try to find possible solutions to them. When the spouses were asked if they would need (1) more support from each other and if household activities and (2) looking after the child should be shared to a greater extent by them, the answers appeared to be different. 70 per cent of mothers would need more support from their husbands, but 70 per cent of fathers stated that they did not expect more help from their wives. At the same time 60 per cent of fathers did not think that they should share household activities equally, whereas the same number of mothers did think so.

To the question how they coped with everyday life, mothers answers were "so - so" (57%), but fathers sounded more optimistic saying that they coped fairly well. Both mothers and fathers possess enough physical energy (fathers more), and also mental energy. Bringing up a disabled child does not prevent parents from communicating with their friends. Approximately half of the mothers and fathers cope with the training and care of the child satisfactorily. Still, the role of mothers is greater in taking care of the disabled child thus giving fathers more opportunities to meet their own needs and wishes.

The source of parents' energy is derived from the disabled child, and also of great importance is the spouse, family, cohabitation, relatives and friends. For fathers first and foremost comes work, colleagues, leisure time, their future and everything connected with it. Parents do not consider the role of hobbies, advisors and helpmates, communication with other families of disabled children, religion and praying or services too important in order to get energy for bringing up a disabled child.

Parents' emotional state. One third of the mothers considered themselves as depressed, irritated, helpless, sad, nervous, and tired out. One fourth of them felt tired most of the time. About a third of mothers are often worried whether they will be able to cope with their duties in future and are sorry for their child. Half of the mothers are most often worried about their child's future. At the same time about one third of mothers are moderately satisfied and cheerful. We found out that one third of the mothers are seldom in despair, restless and self-pitying. Only rarely do mothers blame the others for their trouble or feel desperation.

Speaking of positive emotions, the mothers often felt proud and satisfied about their child and 30 per cent of them felt hopeful. Only in very few cases, were the mothers and fathers angry with others, or embittered, and they seldom felt guilt or gratefulness. As to the latter feeling, parents were unable to understand for what or to whom they should be grateful.

Among fathers, positive emotions could be traced back more often. Fathers very seldom would feel despair, depressed, exhausted and nervous. Very rarely did fathers feel desperation, helpless or feel self-pity. In some cases fathers were hopeful, satisfied, glad and happy about their child. At the same time the majority of fathers were often worried about their child's future.

3 THE PRACTICAL MEASURES TAKEN FOR SUPPORTING THE PARENTS OF DISABLED CHILDREN

It can be said that most parents needed orthopaedic help, curative gymnastics, massage, transportation help and psychotherapeutics for their children. The fathers were, however, more indifferent toward the above. Neither mothers nor fathers consider logopedical or pedagogical help of particular importance. Help is needed at home and in treatment centers. In the opinion of the fathers, packets of humanitarian aid have been the most helpful. Too little help has been received from the churches, public figures, colleagues, family counseling centers, psychologists and speech therapists.

In Estonia, the problems of disabled children are handled by the

Social Ministry, the Ministry of Culture and Education of the Estonian Republic tackles problems of education. The State allots a monthly invalid pension of 260 EEK for these children. There is also a voluntary organization - The Chamber of Disabled Persons - the President of which is General Manager of Estonian Television, Mr. Hagi Shein with Mrs. Eha Lepik from the Social Ministry acting as Secretary. Besides the mentioned organizations, there are several other non - state organizations which try to help the families of disabled children. The umbrella organization of all the existing unions is the Association of Parents of Disabled Children. The latter coordinates the activities of more than 11 associations. In this article we will try to give a short survey of the activities of the Association of Parents of Children with Auditory Disability, the Estonian Epilepsy Association, the Estonian Mentally Retarded Persons' Support Organization, the Estonian Down Syndrome Club and the Tallinn Support Union for Children with Locomotion Difficulties.

The activities of the Estonian Children's Heart Association, the Association of Parents of Children with Cancer, the Estonian Allergy Association and the Tallinn Diabetics Society are not included in the article.

The Estonian Association of Parents of Disabled Children

The Association was founded on December 1, 1990 and has become an umbrella organization. It comprises regional organizations throughout Estonia. The Government has given subsidies to the Association through the Chamber for Disabled People. The Chamber receives 49 per cent of its revenues from gambling. So far the activity has been:

- Enabling treatment for children; general treatment - specific problems have been faced by the unions of children with mental and locomotion disabilities.

- Securing education, upbringing and teaching for children with disabilities. The most important thing is here guaranteeing the coping of people with disabilities. An especially hard situation is faced by young disabled people who simply do not have their place in Estonia. A home for children with mental disabilities and a rehabilitation center for children with serious mental disabilities is under construction.

- Enabling mobility for disabled people (free transport, including journeys to the kindergarten and special schools in Haapsalu, Tartu, Porkuni).

- Establishing summer camps; costs for these have been paid by the State, families and sponsors.

- Arranging seminars for parents giving legal information to parents.

Chairperson of the Association is Tiiu Tahk.

The Estonian Association of Parents of Children with Auditory Disabilities

The Estonian Association of Parents of Children with Auditory Disabilities is an all - Estonian social organization set up by the parents of children with auditory disabilities the aim of which is to help children with auditory disabilities and their parents to integrate into society and guarantee equal rights to them for participating a meaningful life. The Association was founded on November 9, 1991. The Managing Director of the Association is Airi Suraegin, it has a total membership over 200 persons. The main tasks of the Association are the following:

- to unite parents (guardians) of children with auditory disabilities and their supporters for them to actively participate in finding out, publicizing and tackling the problems of children with auditory disabilities and their families

- to defend the interests of children with auditory disabilities and their families in the national and local governmental bodies

- to organize cooperation with other social organizations and groups both in Estonia and abroad

- to assist in providing children with auditory disabilities with necessary technical equipment for teaching and coping in life

- to improve medical and social support

- to organize courses for the parents to learn sign language and the law.

The Association in cooperation with the Finnish Association of Parents of Children with Auditory Disabilities has published a handbook which is given to all the families of children with auditory disabilities. It has been compiled by Meelike Saarna together with the Head of the Board Toomas Sepp, Dr. Katrin Kruustiik, Ave and Vahur Lavapea and Airi Suraegin.

In 1992 a summer camp was convened in Kukulinna (68 people), in 1993 in Kauksi (117 people) and this summer also in Kauksi (150 people). It is obvious that the interest for the undertaking is growing.

Several courses of sign language have been organized with a duration of 150 hours and was budgeted by the State. The demand for the courses is bigger than the present financial means. It is also due to the Association that a new kindergarten - elementary school "The Swallow's Nest" has been opened in Tallinn. So far their have been special schools only in Tartu and Porkuni. At present there are 17 pupils in Tallinn.

The Tallinn Pedagogical School has opened a new department where teachers for children with auditory disabilities are trained. At present there are 10 students in the department. On the initiative of the Association, Christmas and other holidays have been celebrated in a festive way, and exhibitions and other activities have been arranged.

The Estonian Down Club (D - Club)

The Estonian Down - Club (D-Club) was convened for the first time in Tallinn on November 28, 1992. The Chairperson of the club is psychiatrist Dr. Mallika Käel. The aim of the club is to unite people connected with children with the Down's syndrome who want to help them support their integration into society.

At the opening meeting of the club 102 children with the Down's syndrome participated together with their parents, guardians and their sisters and brothers. Since 1993 branches of the club have successfully started their activities in Pärnu, Saaremaa and Tartu. In August of 1993 and March 1994 Summer camps for Estonians and Russians took place in the Randvere Family Center. Active sports events, music therapy, consultations given by specialists and personal contacts served as a powerful source of energy for the future.

Children with the Down's syndrome were able to participate on equal terms with other disabled persons in the traditional sport events for the disabled. Permanent physical training has resulted in excellent achievements in all respects. According to the new law of education, children with the Down's syndrome have the right to go to kindergarten and school with other children. The first positive results can be witnessed already now.

Today in special schools individual study plans are being worked out for disabled children with the Down's syndrome. A couple of years ago it was prohibited for children with the Down's syndrome to go to the same school with the other children. They were considered uneducable and their place was in foster homes. In future more printed matter will be distributed for the parents and guardians. Attempts have been made to find jobs and occupations for those children and youths who not go to school.

Kindergarten "Pine Cone"

Kindergarten "Pine Cone" has been operating for 28 years. The total membership is 240 children comprising 12 groups, among them 2 for disabled children. There are children with different disabilities. The daily attendance is by 6 - 8 children from the age of 3 - 9. Disabled children from the whole of Tallinn attend the kindergarten, not only from the nearby districts.

A new project is on its way in the kindergarten, the so-called "Pine Cone Project". It started with the proposal made by the Christian Children's Fund to carry out a project in a kindergarten. The idea was supported by the Children's Defence Union in 1991. In the first place lists of disabled children were made up by the workers of the kindergarten. The former included the names of all the children from the Mustamäe district at the age of 1-2 - 13,5. The parents filled out the forms about their disabled children which were later sent to Geneva to the European Center of the Christian Children's Fund.

On April 1, 1994 the Club of Parents of Disabled Children was set up in the kindergarten which is supervised by the Estonian Children's Defence Union. The membership is about 45 - 50 people who meet once a month in the premises of the kindergarten. The agendas have been different. Lectures have been delivered by psychologists. Talks have been given on topics about Christmas, ancient languages, etc. Parents together with the kindergarten workers attend classes of English.

Disabled children have received humanitarian aid: clothes, medicines, etc. from foreign countries. The main aim of the project "Pine Cone" is to build a new school at Mustamäe where the kindergarten children could continue their education. The necessary money will be found with the help of sponsors from the USA and Europe: So far no sums of money have been sent to the kindergarten. It will take years to carry out the project, approximately 5 - 10 years.

The Epilepsy Union

The Epilepsy Union was founded in the autumn of 1992 at the joint initiative of the Association of Estonian Invalids' Unions, the Estonian Union of Parents of Disabled Children and the Finnish Epilepsy Union.

Representatives of the Finnish Epilepsy Union conducted in Estonia a five day seminar. At first 17 people registered, regularly seven people continued to attend. Officially the Estonian Epilepsy Union as a national organization was established on January 23, 1993. At the founding meeting, the Statutes were adopted and a nine - member board was elected. So far several organizations are successfully working, especially regional ones (e.g. Viljandi, Turi). The logo of the Union is a burning candle, that is also the logo of the Finnish Epilepsy Union.

Several activities have been conducted so far. There was a seminar in April, 1993 in Tallinn. Speakers were from Finland and videos were shown. Everything presented was of great interest but unfortunately the turnout was small. In the summer of 1993 six families had an opportunity to spend the vacation in Karepa. That was financed by the Union of Parents of Disabled Children.

The Epilepsy Union participated in the fair conference "Estonian Child '93". The work of the Epilepsy Union has been reflected in the program of the Estonian Radio and an article in the Health Paper. The Estonian Epilepsy Union has received a lot of help from the Finnish Epilepsy Union that has contributed towards the founding of the Union and its development. Thanks to Finnish supporting four people from Estonia could take part in a five day tour of Finland. They visited hospitals, got acquainted with the work of the Finnish Epilepsy Union. The Finnish colleagues presented Estonians with a video film where different forms of illness have been recorded. The Finnish side has helped print publications about epilepsy and sent the newsletters of the Finnish Epilepsy Union to Estonia regularly. The Estonian Epilepsy Union wishes to find premises in order to meet and arrange club activities regularly.

The Estonian Mentally Retarded Persons' Support Organization

The organization got an informal start in March, 1988 when agencies connected with the retarded were invited to the Estonian Radio. Officially the organization was founded in January, 1990 when a president was elected and the statutes were adopted. That is an umbrella organization comprising branches throughout Estonia. Work of the organization is managed by the director who has a paid job. The Union has received money from the Social Ministry and sponsors.

All the time work arrangements and organizational questions have been on the agenda. For example, how to help mentally retarded people cope with their daily life. A link between the retarded person, medical institution and social department is necessary (social worker, guardian etc.). Much time needs to be spent on questions of patronage and care, and also legal problems. The problem of teaching retarded youths and children requires a lot of attention, for example the opportunities of learning at home or receiving therapy for retarded people. The aim is to create such conditions that every mentally retarded child could go to school in an integrated or special school.

The Union has been active with discussing various problems, for instance, questions around limited abilities, custody, ownership, and treatment. There are plans to introduce changes to the civil code as well as to the codes of marriage and family. Once a year the general board convenes and the board of Tallinn convenes once a month. Presently the chairperson of the organization is Kalev Märtens.

The Tallinn Support Union for Children with Locomotion Difficulties

The organization was founded on February 17, 1993 when the statutes were adopted and a board was set up. Seven people belonged to the board and although the organization is a Tallinn Union, it also has people from other towns and regions (especially from the Harju Region). At present 79 families whose children are physically disabled and with normal intelligence, belong to the union. Nevertheless, there are mentally retarded children in the union, but not children with serious mental disabilities. Members of the union are families where the retarded child is 0 - 16 years old but sometimes even older until finishing primary school (nine grades).

The board meets usually once every two months. The most important issue is the problem of medical treatment of children. So far horse riding classes have been arranged for children once a week and two buses are available for the transportation of the children. Much help has been received from the Estonian Evangelical Lutheran Church Deacon Union and the Kaarli congregation.

At the Deacon there is a club where children can draw, play and sing once a week. Part of the children go to the Sunday School at the Kaarli congregation. An Estonian from abroad has arranged monthly consultations of the Finnish Prosthesis Foundation in Tallinn. Necessary equipments can be ordered from there. Also humanitarian aid has been received through the Deacon from Sweden. Free dental care has been arranged for the retarded children as well and the first cases of integration among children with locomotion disabilities have taken place in preschool institutions as well as in comprehensive schools. First attempts have been relatively successful and it is planned to expand this program.

The main needs and goals that the union has identified are the following:

- support facilities are the main requirements for children with locomotion disabilities

- expand integration at school and in the kindergarten

- expand learning at home according to needs

- consultations by foreign specialists of the respective field are in great demand.

Currently the chairperson of the support union is Tiiu Aalisto.

4 CONCLUSIONS

1. The reason for the child's disability is mostly connected with pregnancy and delivery. One of the main reasons is the carelessness of medical personnel.

2. Parents need more information about the disabled child, his or her growth and development. Also more information should be available on different facilities for the disabled and on the necessary services. More support from social workers and psychologists is expected. So far this kind of help has been minimal.

3. Half of the mothers of disabled children stayed at home. The reason is the lack of places in the kindergartens or possibilities to leave the child under other people's care. As a result of this, mothers who stay at home experience more negative emotions. Fathers who go to work are much more optimistic and less depressed. Mothers need more support from their husbands and also help in household activities.

4. Fathers get necessary energy for daily life from going out to work and making plans for future. For mothers the source is the relationship with people who are close to them. Fathers prefer not to discuss problems connected with the disabled child and keep their troubles to themselves.

5. Of late, associations of parents of disabled children have started working in order to give information, organize activities for communication and leisure, for families and, if necessary, give material aid.

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Chapter 4

RESPONSIBILITY PERCEPTIONS IN PARENTS' ADJUSTMENT TO THEIR CHILD'S SEVERE DISABILITY

Markku Leskinen and Jaana Juvonen

1 INTRODUCTION

The birth of an infant with a severe disability is typically an unexpected and traumatic event for parents (e.g., Adams, Wilgosh, & Sobsey, 1990). Furthermore, when the child has a complicated condition or a set of impairments, parents have to make a series of changes in their lives to accommodate these special needs (Beckman, 1991; Crnic, Friedrich, & Greenberg, 1983; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Shonkoff, Hauser-Cram, Krauss, & Upshur, 1992). Thus, parents of children with severe disabilities are often faced with a long-term adjustment process.

In this chapter we will present some results of our study of fathers' and mothers' adjustment to their young child with severe disabilities[1]. Specifically, we wanted to understand the role of parents' perceptions of their responsibility for the onset (cf., origin, causes) of the disability as well as their responsibility for the offset (c.f., improvement, rehabilitation) of the disability in their adjustment process (Brickman, Rabinowitz, Karuza, Coates, Cohn, & Kidder, 1982; Schwarzer & Weiner, 1991). The study was guided by our beliefs that (a) each type of responsibility judgment is relevant to parental adjustment (cf., Minnes, 1988), and (b) the conceptual distinction between the two helps us better understand

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[1] This chapter follows from an article (Juvonen & Leskinen, in press) to be published in a special issue on "Psychological perspectives on disability" of The Journal of Social Behavior and Personality.

parents' adjustment process, given that they tap two fundamentally different questions: "Did I impact the onset of my child's disability?" and "Will I impact the improvement of my child's condition?". Furthermore, we believed that each of the two aspects of responsibility has unique emotional consequences, which may explain the relation between responsibility perceptions or blame and adjustment that has been debated in the coping research (e.g., Abramson, Seligman, & Teasdale, 1978; Amrikhan, 1990; Bulman & Wortman, 1977; Janoff-Bulman, 1979; Lazarus & Folkman, 1984; Sholomskas, Steil, & Plummer, 1992; Taylor, Lichtman, & Wood, 1984).

Rather than investigating parents' adjustment immediately after the child's birth or following the diagnosis of the disability (cf., Affleck, Tennen, & Rowe, 1991), we examined fathers' and mothers' perceptions of responsibility, their emotions and adjustment to children between the ages of 2 and 8 with severe disabilities. This allowed us to analyze parental adjustment at a time when they had a chance to recover from their initial reactions, and after they had opportunities to find out more about their child's condition and experience dealing with her or him. Guided by a phenomenological approach, we presumed that it is parents' *current* interpretations of the onset (i.e., past) as well as the offset (i.e., future) of the disability that explain their present emotions and adjustment level.

2 PERCEPTIONS OF ONSET AND OFFSET RESPONSIBILITY

When a child is born with a disability or when a young child becomes disabled, parents try to understand the reasons why this happened. They are likely to ask themselves: "Why did this happen to me? Did I do something that caused this? Could have I prevented this from happening? Who is responsible?". These type of causal questions are frequent, and mothers of infants at risk for developmental disabilities spontaneously bring them up during interviews (Affleck et al., 1991). Furthermore, such causal search seems to serve an important function in mothers' adjustment process, as the following excerpt from one mother of an at-risk infant suggests.

> "From the very beginning, I was trying to find out why this happened. The fact that I couldn't find any answers made this whole situation even more difficult." (Affleck et al., 1991, 60)

Theorists (Heider, 1958; Kelley, 1967; Weiner, 1986; White, 1959) have proposed that causal search serves important psychological functions, namely, the need to comprehend or master one's environment and to guide one's future actions. In addition, perceived causes of undesirable events are known to impact specific affective reactions (e.g., guilt, anger, pity), which determine a range of behavioral responses (see review in Weiner, 1986). Thus, an attributional framework lends itself to the study of parental adjustment to their child's severe disability inasmuch as it provides a theoretical model that links causal interpretations with emotions and behavior.

As indicated earlier, people who encounter unexpected and traumatic life events, such as having a child with a disability, are known to have a strong need not only to find out why it happened, but more specifically to discover whether they are responsible for the event (e.g., Burger, 1981; Jones et al., 1984). Being responsible for an outcome means that the causes of the outcome are considered controllable by the person (Weiner, 1986, see also Fincham & Jaspers, 1980; Shaver, 1985). Perceptions of causal controllability and personal responsibility evoke feelings of guilt, inasmuch as guilt conveys regret over an undesirable event that one brought about by him- or herself (Davitz, 1969; Izard, 1977; Weiner, Graham, & Chandler, 1982; Wicker, Payne, & Morgan, 1983). For example, if a mother of a disabled child believes that her use of alcohol during the first trimester caused her child's disability, she is likely to feel responsible, blame herself for the child's condition, and experience guilt. Although it may be functional for the mother to know whether she is responsible in the sense that she can now better understand the event and use this information to prevent the same outcome from happening in the future (cf., Affleck et al., 1991), the feeling of guilt is unlikely to facilitate her adjustment process.

Although causal search and assignment of responsibility may indeed be crucial at the onset of the child's disability or chronic illness, these perceptions are likely to become less important to parents over time. Parents' own accounts of their adjustment process tend to center around current or future-related practical issues, such as dealing with medical problems and obtaining assistance from various service providers (e.g., Adams et al., 1990; Turnbull & Turnbull, 1978). It may be that questions, such as "What can I do to manage this?" (cf., Taylor, 1983) or "Will I impact the course of my child's development?" supplement or supplant retrospective questions of personal responsibility (cf., Tennen, Affleck, & Gersham, 1986). The role of perceived control in facilitating adjustment and coping of individuals confronted with traumatic life events has been documented in studies of cancer patients (e.g., Gotay, 1985; Taylor et al., 1984), and persons with physical disabilities (e.g., Affleck, Tennen, Pfeiffer, & Fifield, 1987; Schultz & Decker, 1985) as well as with mothers of medically fragile infants (Affleck, Allen, Tennen, McGrade, & Ratzan;

1985; Tennen et al., 1986).

Based on the research on perceived control (e.g., Brickman et al., 1982; Taylor, 1983; Thompson, 1981) and an attributional theory of emotion and motivation (Weiner, 1986), we presumed that, similarly to perceived responsibility for the onset, perceived personal responsibility for the offset (cf., improvement) of the child's condition influences parents' feelings and subsequently affect their adjustment. However, unlike retrospective responsibility judgments, perceptions of personal agency for prospective change was hypothesized to have positive emotional consequences, given that thoughts of instrumentality increase hope (cf., Averill, Catlin, & Chon, 1990; Mowrer, 1960). If, for example, a father feels that he can improve his child's condition by enrolling her in an early enrichment program or physical therapy, he should be hopeful. Thus, hope, unlike guilt, was anticipated to positively impact his psychological well being.

Taken together, we proposed that there are two independent responsibility perceptions (cf., Brickman et al., 1982) that differently impact parents' adjustment to their child's severe disability: Onset-responsibility was hypothesized to be negatively related to adjustment, given that it is associated with guilt, whereas offset responsibility was expected to positively impact parental adjustment because it is related with hope. In addition to testing the effects of these two responsibility perceptions simultaneously, our investigation differs from previous attributional analyses of parental adaptation because we (1) differentiated responsibility perceptions from their affective correlates, (2) distinguished specific emotional reactions from adjustment outcomes, and (3) hypothesized that guilt and hope mediate or bridge the relation between perceived responsibility and adjustment.

We have also examined whether the same attributional processes explain the adjustment of both mothers and fathers. While there is considerable number of studies suggesting that causal perceptions and control beliefs play an important role in mothers' adjustment (see for reviews Affleck et al., 1991; Affleck, McGrade et al., 1985), the function of such cognitions is less clear for fathers. It may be that fathers are less likely to accept personal responsibility for their child's disability and feel less guilt about their child's condition than mothers because they are not as closely involved in the pre- and perinatal stages of the offspring's live (e.g., Gumz & Gubrium, 1972). Instead, fathers may be more concerned about the child's future than are their spouses, especially if they view themselves as the primary providers of their families (cf., McLinden, 1990; Schilling, Schinke, & Kirkham, 1985).

Participants in our study were the parents of 2-8 year old children with severe disabilities. They were identified through a Finnish national social security institution (KELA). Only children with the most severe disabilities were included. The disability categories varied from severe mental retardation to different forms of cerebral palsy, muscular dystrophies and are syndromes. However, most children had multiple disabilities (e.g., mental retardation and blindness, or paraplegia and epilepsy). Each family that qualified for the study and agreed to participate was mailed two identical structured questionnaires. Seventy one percent (N=141) of the families responded. There were 140 mothers and 111 fathers in the final sample. Two responses (both mother and father) were received from 110 families.

Parents responded to questions that tapped each of the two aspects of the responsibility ("The cause of my child's disability was in part my fault" for onset, and "I believe I can influence my child's rehabilitation" for offset responsibility). In addition, parents rated their current feelings of guilt and hope. They were specifically instructed to report how often they experience these emotions when thinking about their child's disability and her or his development. Parental adjustment was defined as (a) psychological acceptance of the child's disability (e.g., how openly parents can talk about their child's disability, how realistic they are about the limitations of the disability; c.f., Sholomskas et al., 1992), and (b) involvement with the child (e.g., how frequently they take her or him shopping, visiting relatives and friends; c.f., Caldwell & Bradley, 1978). We presumed that the more accepting parents are of the disability and the more frequently they include their child in various activities in and outside of the home, the more adjusted they are. Rather than relying solely on parents' self reports, we asked mothers to estimate fathers' adjustment and *vice versa,* and used the composite of the two (self and spouse) as the index for their adjustment. The score for the parental adjustment for the disability consisted of 10 items, whereas the involvement with the child score included 18 items.

As can be seen in Figure 1, the parents considered themselves more responsible for the improvement than the origin of the child's disability. Most parents felt that they had not been responsible for their child's disability. Similarly, parents reported that they had experienced guilt rarely but, instead, felt hopeful rather frequently. In general, the parents were rather well adjusted, although only moderately involved with the child. The mothers were somewhat more adjusted than were the fathers. A more detailed analysis of the differences between mothers' and fathers' ratings as well as some descriptive information are reported elsewhere (Juvonen & Leskinen, in press).

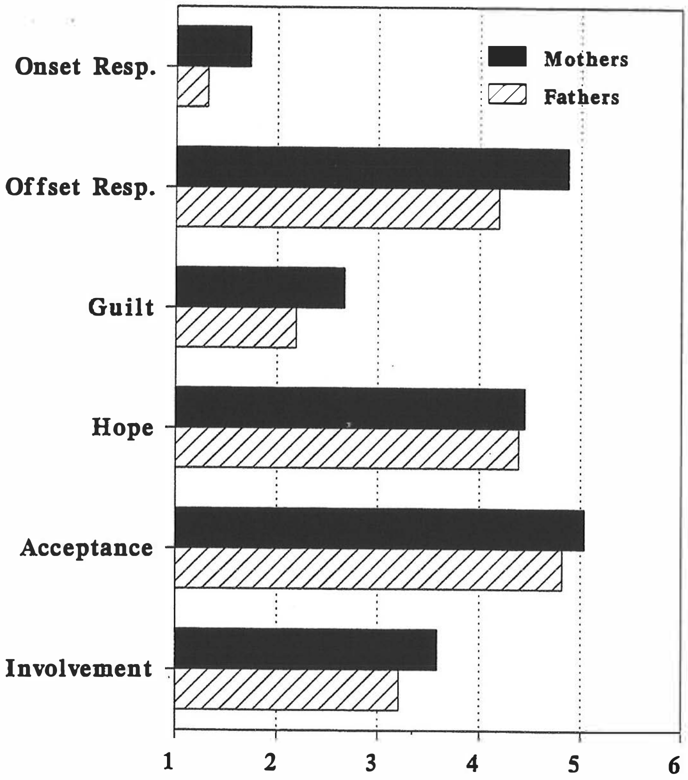

FIGURE 1 Mothers' and fathers' ratings of perceived onset and offset responsibility, emotions, and their acceptance of the child's disability and involvement with the child. All rating, except guilt and hope that were rated on a 7-point scale, were assessed using a 6-point scale. Larger values reflect higher agreement or frequency.

Before examining the hypothesized links between responsibility perceptions, emotions, and adjustment indices, the relations between the variables within each of the three constructs are described briefly. As shown in Table 1, parents' onset and offset responsibility ratings were unrelated, suggesting that the two constructs are independent. The two emotions were negatively correlated, as expected with the correlation coefficient between guilt and hope was somewhat stronger for mothers (r=-.43) than for fathers (r=-.10). The two adjustment indices, on the other hand, were moderately correlated for mothers (r=.25) and fathers (r=.31), suggesting that they can contribute independent estimates of parental adaptation.

TABLE 1 Correlation coefficients among the variables for mothers (M, n=102) and fathers (F, n=99)

		1	2	3	4	5	6
1. Onset Resp.	M	-					
	F	-					
2. Offset resp.	M	.12	-				
	F	.01	-				
3. Guilt	M	.31*	-.09	-			
	F	.16	.13	-			
4. Hope	M	.02	.51*	-.43*	-		
	F	-.11	.22*	-.10	-		
5. Accept. of Disability	M	.06	.29*	-.46*	.48*	-	
	F	-.27*	.17	-.23*	.32*	-	
6. Involvement with Child	M	-.03	.35*	-.18	.46*	.25*	-
	F	-.06	.37*	.09	.23*	.31*	-

* $p < .05$

As described in the introduction, our goal was to test a model of the parental adjustment process in which parents' perceptions of onset responsibility were expected to be related to their feelings of guilt, whereas their estimates of responsibility for the offset were presumed to be associated with hope. Furthermore, we suspected that responsibility perceptions may not be directly connected with adjustment indices, but that responsibility-related emotions would influence adjustment. Guilt was expected to negatively impact adjustment, whereas hope was hypothesized to positively affect parents' acceptance of the disability and involvement with the child. To test such a model, separate path analyses were conducted for fathers' and mothers' responses using EQS (Bentler, 1985). Maximum likelihood technique was used for parameter estimation. The goodness of fit of the models with the observed data was estimated using chi-square statistics and normed fit indices (NFI) (Bentler & Bonett, 1980).

The proposed model fit the data on mothers, $X^2=7.66$, df=8, p=.47, NFI=.94, when the residuals between the two emotions were correlated. As shown in Figure 2, the more responsible the mothers viewed themselves for the onset of their child's disability, the more guilty they felt ($\beta=.289$). Also, the more responsible the mothers viewed themselves for the improvement of the child's condition, the more hope they experienced ($\beta=.465$), as expected. Whereas guilt reduced mothers' acceptance of the child's disability ($\beta=-.311$), experiences of hope increased both their acceptance ($\beta=.347$) as well as the frequency of their interactions with the disabled child ($\beta=.459$). Except for the path between guilt and involvement with the child, all path coefficients were statistically significant. When this path was deleted, the fit of the model did not significantly improve.

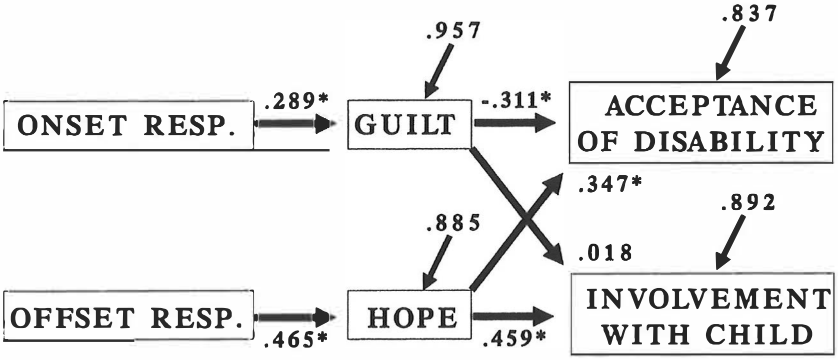

FIGURE 2 Path diagram of the relations among responsibility perceptions, emotions, and adjustment indices of mothers of children severe disabilities (* p < .05)

The identical model for fathers did not fit the data, X^2=27.20, df=8, p=.001, NFI=.52. Based on the results of a LaGrange Multiplier test, direct paths were added between onset responsibility and adjustment and between offset responsibility and involvement with the child. When the residuals between the two adjustment indices (rather than emotions) were correlated, this model fit the data. The goodness of fit of the model depicted in Figure 3 was X^2=6.59, df=6, p=.36, NFI=.89. As shown in Figure 3, the more responsible the fathers considered themselves for the child's disability, the more guilt they experienced (β=.158), and the less accepting of the disability they were (β=-.204). In contrast, the more responsible the fathers perceived themselves for the rehabilitation of the child's condition, the more hopeful they were (β=.220) and the more frequently they interacted with the child (β=.295). Thus, unlike for mothers, fathers' responsibility perceptions also directly impacted adjustment outcomes. Feeling of guilt also negatively impacted fathers' acceptance of the child's disability (β=-.166), whereas hope increased both the acceptance level (β=.289) and the frequency of interactions with the disabled child (β=.174). Similarly to the model on mothers' data, the path between guilt and involvement with the child was the weakest. However, only half of the path coefficients in the model were statistically significant.

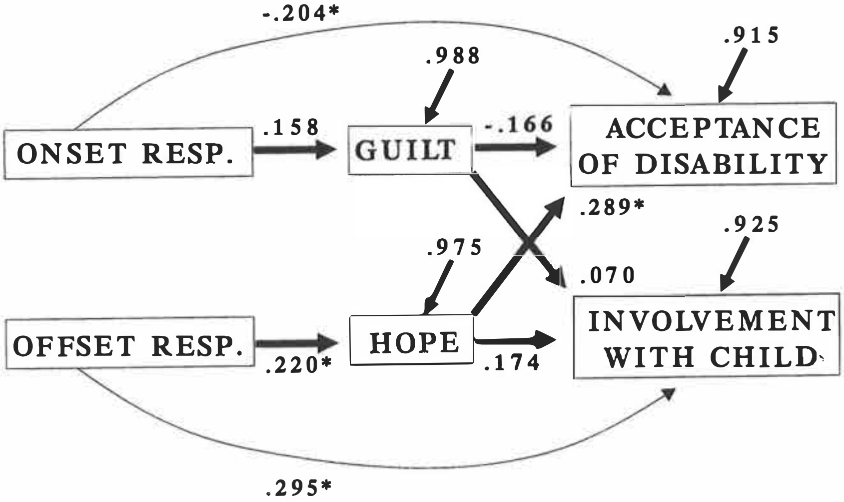

FIGURE 3 Path diagram of the relations among responsibility perceptions, emotions, and adjustment indices of fathers of children severe disabilities (* $p < .05$)

In sum, the results of the path analyses suggested that onset and offset responsibility perceptions both influenced mothers' and fathers' feelings of guilt and hope, as expected. Also, fathers' perceptions of onset responsibility directly impacted their acceptance of the child's disability and their offset responsibility perceptions of the child's condition predicted the frequency of interactions with the child. Such direct links between thoughts and adjustment were not supported in the analysis of the data on mothers.

3 DISCUSSION

Attributional studies on the parental adjustment process to their children with disabilities, chronic illness, or other medical complications have predominantly focused on mothers' perceptions of the causes of the child's condition, their self-blame and blame that they experience toward others (see e.g., Affleck et al., 1991; Tennen & Affleck, 1990). Although mothers' causal perceptions and experiences of blame have been found to relate to their self-reported or observer-rated adjustment levels or mood, the relations between maternal attributions and adjustment have been somewhat inconsistent across studies (see for review Tennen & Affleck, 1990). Our goal was to disentangle some of the conceptual issues by (a) making a distinction between onset and offset responsibility, (b) differentiating responsibility perceptions from their affective correlates, and (c) distinguishing emotions from adjustment outcomes. Furthermore, we proposed that retrospective (onset responsibility) accounts predict guilt and thus negatively affect adjustment, whereas prospective (offset responsibility) perceptions predict hope and thus positively impact parents' level of adjustment. In addition, we examined whether the psychological processes that explain the role of responsibility perceptions on mothers' adaptation are similar to those of fathers.

In this chapter, we have reported the results of our study of how parental responsibility perceptions, emotions, and adjustment indices are interrelated, but left out a detail analysis of the differences between the mothers' and fathers' ratings (see Juvonen & Leskinen, in press). However, the results showed some interesting trends. Both parents reported low personal responsibility for the onset of their child's disability but relatively high responsibility for the offset of the child's condition. In other words, at this time they felt that they had not influenced their child's impairment, but considered themselves as responsible for the improvement of her or his condition. Brickman et al. (1982) call this combination of responsibility judgments the compensatory model of coping (and helping). They propose that people characterized by this model see themselves as having to compensate for their situation with effort. Brickman et al. (1982, 372) state that: "[t]he strength of the compensatory model is that it allows people to direct their energies outward, working on trying to solve problems or transform their environment without berating themselves for their role in creating these problems, or permitting others to create them, in the first place". This statement could not be more consistent with recent movements to empower families and individuals with disabilities (e.g., Dunst, Trivette, & Lapointe, 1992; see Chapter 6 in this volume).

Although our data did not allow us to compare Brickman et al.'s compensatory model to their other models or combinations of the two dimensions of responsibility, our findings are consistent with Brickman et al.'s predictions in that this sample of parents were relatively well adjusted. These findings may in part be due to the subject selection. These parents (about 1/3 of the qualified families) volunteered to participate in the study. Thus, they may be the most active and well-adjusted parents. However, the relatively large variances in the fathers' and mothers' responsibility and emotion ratings suggest that persons in the final sample did not share the same beliefs and feelings.

The relatively minor differences between mothers and fathers suggest that there are greater similarities between the spouses than what is typically portrayed in the literature. In the popular literature, mothers of children with disabilities are often portrayed as highly emotional and guilt-ridden, whereas fathers are portrayed to be in denial or avoiding their responsibilities as caretakers (see for review Schilling et al., 1985). Our findings showed that there were no differences in parents' perceptions of responsibility or in their self-reported emotions. The slight differences in the measures of acceptance of the child's condition and especially of the frequency of involvement with the child may reflect in part societal expectations and roles. For example, mothers would be more likely to take their child shopping, visiting friends and relatives etc. than fathers.

The results of our the correlational analyses showed (a) that onset and offset responsibility perceptions are, indeed, independent of one another, and (b) that each is uniquely related to one of the two emotions included in this study. As expected, responsibility for the onset of the child's disability was associated with guilt, whereas responsibility for offset was related to hope. Prior attributional analyses of parents' adjustment have examined a guilt-related construct, namely, self-blame. However, as mentioned earlier, the relations between self-blame and adjustment have been inconsistent across studies (see e.g., Amrikhan, 1990). We suspect that self-blame is a fuzzy concept and that it does not imply an onset-offset distinction, which seems to be critical to our understanding of specific thought-emotion linkages. Thus, an onset-offset distinction may increase the accuracy of prediction of emotions more than previously proposed differentiations (e.g., behavioral vs. characterological blame).

We presumed that the relations between onset responsibility perceptions and guilt as well as offset responsibility and hope would clarify the connection between personal responsibility and adjustment. Given that guilt is a negative emotion, it was expected to decrease parents' acceptance of their child's disability and their involvement with the child. Hope, on the other hand, was hypothesized to increase parents' adjustment because it should raise positive expectations and promote parents' sense of control over future outcomes. A meaningful difference between mothers' and fathers' models was found. Whereas the model for mothers supports a mediational model in which guilt and hope link responsibility perceptions to adjustment, the model for fathers suggests that there are both indirect and direct links between perceived responsibility and adjustment.

These differences could help us not only better understand the antecedents of parents' adjustment process, but also guide service providers to better modify their intervention efforts by focusing on the most proximal antecedents of mothers' and fathers' adjustment (i.e., emotions and/or thoughts) (cf., Nixon & Singer, 1993). Whether these differences between mothers and fathers are reliable and whether they reflect some more general sex differences needs to be further investigated.

Of the two emotions, hope was a stronger predictor of parents' acceptance of their child's disability and the frequency of parental involvement with the disabled child. This finding is intriguing given that hope has received little attention in the research on coping and adjustment (Lazarus, 1991), although it has been described as "a sign of health, a fighting spirit, and faith that good will somehow triumph" (Averill et al., 1990, v). Neither has hope been included in studies that investigate parental reactions to having a child with a disability, yet it seems to be integrally related to parents' control beliefs (i.e., "Will I impact the improvement of my child's condition?"). Lazarus (1991, 282) describes hope as "a wishing or yearning for relief from a negative situation, or for the realization of a positive outcome when the odds do not greatly favor it". Thus, conceptually hope is highly relevant to parents' experiences when taking care of a child with severe disabilities.

Studies on adjustment to traumatic life events rarely examine the role of positive emotions, such as hope, but rather focus on negative moods and affect, such as anxiety, depression, hopelessness, and in some cases, guilt and shame. Although our goal was not to compare the contribution of positive versus negative emotions on parental adjustment, our findings raise the question of whether the role of positive emotions should be further investigated. In addition to hope, there may be other relevant emotions, such as happiness, joy, and even gratitude (cf., Crnic et al., 1983) that may be related to adjustment to a severe disability or illness. After all, people who have been confronted with tragic illness or accidents often compare themselves to others who are worse off and report to be grateful for being better off than their comparison others (e.g., Taylor, 1983).

Mothers and fathers in our sample represented the parents of the most severely disabled children who should not have many comparison targets who are worse off than they, yet their reactions were not unanimously negative. We presume that this variance in parental perceptions and reactions is influenced not only by their subjective interpretations of the disability but also by a range of other factors not included in this study. Families' financial status, parental employment opportunities, social support, the type of the child's disability, availability of medical and rehabilitation services as well as day care options for the child impact mothers' (and possibly also fathers') adjustment (e.g., Bristol, Gallagher, & Schopler, 1988; Wallander et al., 1989). We did not include such external variables in this study because our goal was to investigate specific *intrapsychological* processes that contribute to parents' adjustment to their child's severe disability. This relatively narrow focus obviously limits the amount of variance that can be accounted for in the outcome variables, but at the same time it allows investigators to test psychological processes that should be generalizable to conceptually similar questions. Thus, the conceptual distinctions (e.g., differentiation between onset responsibility and offset responsibility), and the links among constructs (e.g., between offset responsibility and hope) proposed in this study should be applicable to a variety of personal and social issues.

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Chapter 5

ECOLOGICAL APPROACH AND EARLY INTERVENTION

Iiris Mäki

1 ASSESSMENT IN EARLY INTERVENTION

There are two primary tasks for early intervention: to facilitate development and decrease developmental risks. So, there should be an expressed opinion on the assessment of a child's developmental status. On the one hand, a developmental assessment focusing on a child's level of skills, which are related to determined criteria can be emphasized (Thurman & Widerstrom, 1990). On the other hand, an ecological perspective has emerged in addition to the developmental approach. At a very general meaning, ecology has been defined as an organism's interaction with its environment. Currently the developmental approach and norm-referenced assessment is emphasized in early intervention in Finland. In this paper I will present some reasons why the ecological approach should be applied in early intervention and how it could be used in early education practices.

The developmental approach. Developmental assessment is based on children's normal development. Risks and problems in development are identified by standardized tests and criterion-referenced procedures and then intervention is provided to prevent disadvantages of developmental lag (Thurman & Widerstom, 1990, 11). The following tests are often applied for assessment of five or six-year-old children in Finland: Wechsler Preschool and Primary Scale of Intelligence (WPPSI), Kaufman Assessment Battery for Children (K-ABC) and Illinois Test of Psycholinguistic Abilities (ITPA).

Developmental assessment uses norm-referenced procedures and the child's developmental level is defined in those areas which are possible to evaluate with the procedure. Based on the results of the assessment, a child's diagnoses and prognoses are done about expected development and learning facilities. Recently, norm-referenced assessment has been questioned as only one perspective towards early intervention of children with severe or multiple disabilities (Downing & Perino, 1992). The developmental standard assumes that all children acquire skills in the same sequence and at the same rate (Ferguson & Meyer, 1991, 1). The use of assessment procedures as a means for diagnosis and for receiving services has been criticized, because this procedure does not help service providers to interpret and translate the test results into practices. When children have been assigned a low mental age (MA) based on norm-referenced tests, their activities are often organized to match their developmental level. This may lead to programs that rather hinder development than minimize the lag (Downing & Perino, 1992; Thurman & Widerstrom, 1990, 7). In other words, the diagnosis may be a self-realizing prognosis.

The assessment of a child with multiple disabilities is influenced by many situational features. It is important that the professional knows the child, because he or she can behave in an unfamiliar assessment situation completely differently. Thus, the results of a test may be erroneous when appraising the abilities of a child. It is not so unusual that a child refuses to do some tasks or a child with disabilities refuses to use an alternative communication mode. The result of a test depends on how familiar an adult is with the child and on the adult's ability to interpret the child's communication. This is very important, especially, if the child with multiple disabilities does not speak as the following story shows.

> The psychologist was assessing a girl with CP (about eleven years old), who communicates with bliss-symbols and signs (sign-language). Just at the beginning of the test the girl closed her bliss-symbol book and refused to communicate with bliss-symbols. The psychologist did not understand sign-language, so, she could not interpret signs the girl used. Most tasks of the test required linguistic skills. Based on the results of the test, the psychologist documented that the girl was on the same developmental level as a four-year-old child. The mother of this girl laughed when the psychologist told her the results of the test. The mother thought that it was quite surprising that the psychologist got any result without a common language with the child.

Many items of tests require the kind of practical skills that most children without disabilities have learned through daily activities. A child with multiple disabilities may have had very limited experiences and practical skills. Differences in experiences may be caused by disabilities or different environments where the children live. Moreover, a child may fail the test because of inappropriate test procedures.

The ecological approach. Ecology has many different definitions also in human sciences. One approach focuses on the way stationary features of the environment influence a subject. According to a dynamic perspective, a change in any component of an ecosystem alter all other components of the ecosystem (Carta, Sainato, & Greenwood, 1988, 218). Children do not develop separately from the context they live in being always in interaction with their environment (Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Thurman & Widerstom, 1990, 11). An ecological approach focuses on both static and dynamic features of the environment. Thus, it complements the developmental approach by the context, in which a child grows up.

Ecological or functional assessment procedures have also been developed. Ecological assessment gathers information about children's real lives: daily activities, interaction, experiences, and peer contacts in natural environments, both inside and outside of the family or day care group. In addition, the context where activities occur is assessed. Ecological assessment is based on the activities and abilities of a child instead of skills and developmental delays. The goal of assessment is to apply gathered knowledge to early intervention (Downing & Perino, 1992; Thurman & Widerstrom, 1990). The basis of the ecological approach is membership in the family, in the day care group and in other communities. Ecological assessment requires the participation of the parents in addition to professionals and sometimes participation of the child and her or his peers (Ferguson & Meyer, 1991).

Observation is the most important method in an ecological assessment of a child's developmental status. When gathering information about family and home as a living environment, interviews and other instruments are used. The ecological approach covers family functioning areas as follows: social support, coping, stress, cohesion and adaptability, family needs and strengths, parent-child interaction. Several scales for assessment of environments have been developed in the USA, for instance, The Home Observation for Measurement of Environment (HOME), Early Childhood Environment Rating Scale, The Infant/Toddler Environmental Rating Scale, The Family Day Care Rating Scale, and Early Childhood Physical Environment Scales (Thurman & Widerstrom, 1990, 191-206). The ecological approach is rather unknown in Finland and only few professionals use it in their work practices (see Chapter 6 in this volume).

2 THE ECOLOGICAL APPROACH IN RESEARCH

Interaction is a typical feature of human activity. In research, the ecological approach presumes observing activities and phenomenon in their natural context. There is no doubt that the presence of an observer in daily activity settings influences these settings, when you are studying the daily life of a child with disabilities. However, activity and behavior in regular daily routines may not change very much even though a researcher participates in these settings.

In my own study (Mäki, 1993), I observed and videorecorded the daily life of ten five-year-old children with multiple disabilities at home, in day care, and in one rehabilitation situation. Videorecordings were done during mealtimes and the child's usual afternoon activities at home. Most day care activities of a child with disabilities were videorecorded during a day. In addition, I interviewed parents, day care staff, and therapists. Later on, more play situations of three children were observed and videorecorded at home and in day care. When I collected data, I noticed that day care staff considered me a threat as a researcher whereas most families and therapists did not. Many professionals visit families of children with disabilities and many therapists are accustomed to visitors.

When I interviewed day care staff, they described that socially accepted goals guide their working and they tried to meet these goals. Based on my observations, I think, that expressed goals differed from those that guided their educational practices in real day care settings. Values, belief system, and interactional patterns govern our activity in different situations. The implicit goals may differ from socially accepted ones, which we have believed to guide our professional working. "Invisible action" includes unconscious and unorganized patterns in behavior, which guide the educational practices in day care. In school teaching this phenomenon is called the hidden curriculum. Kytölä's[1] findings showed, that children with disabilities, both boys and girls, were encouraged to play with girls more than with boys. Sometimes, boys' play situation were thought to be too wild for children with disabilities. Children with disabilities were placed into groups with younger children during structured learning, because of their developmental level and skills. However, those children without disabilities were encouraged to play with younger children, but this was supported by the argument that it develops children's sense of responsibility and their learning to help younger children.

Typically, we give excuses or assess critically our working when we

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[1] Findings about invisible action in day care are based on the data gathered by Liisa Kytölä. She focused on goals in ordinary day care centers and compared the goals set for children with disabilities with the goals of children without disabilities.

notice conflict between believed and expressed goals for our work. The more threatening day care staff felt the presence of the researcher, the easier the way of work was excused. For instance, a teacher explained that she holds responsibility for the whole group, although she included in the group other children than the child with disabilities.

Parents realized socially accepted goals, for example, by trusting professionals as authorities regarding their child with disabilities. Sometimes, parents do not dare to trust their own perceptions of their child, and do not demand any procedures based on their own observations if they differ from the professionals' impressions. The most often repeated examples of this conflict concern impressions of a child's disabilities and ability to learn. Even now, parents' impressions are interpreted as unrealistic wishes, which indicate the parents' maladaptation to disability. Professionals emphasize that goals for to a child with disabilities must be realistic. According to my own experiences, parents did not have an unrealistic opinion about their child, even when they had organized activities for their child based on their own perceptions and the professionals' impressions of the development of the child with disabilities had differed from the parents' ones. Children act differently in assessment situations than in their daily environment where parents observe them.

3 AS A DISABLED CHILD OR SIMPLY A CHILD AMONG OTHER CHILDREN?

I will describe next some findings based on the data[2] gathered for my studies about the daily life (Mäki, 1993) and play of a child with multiple disabilities. In these studies I have used two new perspectives in special education. One is the ecological approach and the other is the child's point of view in childhood research. I have observed children in the most usual daily contexts at home and in day care.

As a child who needs rehabilitation. Rehabilitation is an essential part of the life of a child with multiple disabilities. Parents thought that rehabilitation is important but there was variation in the degree of parents' involvement in early intervention. On the one hand, a home-

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[2] The qualitative data was gathered during two periods. The data dealing with daily life of a child with multiple disabilities were collected during the first period from August 1991 to October 1992. The supplementary data concerning play activities of three children were gathered between March and June 1993.

based early intervention program was accomplished at home, but on the other hand, it was thought not to be good for the mother's and child's relationship if the mother takes on the tasks of therapists. In day care, the goals set for rehabilitation were the most important goals that were carried out in the activities of a child with multiple disabilities. When a child with multiple disabilities was integrated into an ordinary group, the kindergarten teacher might feel conflict between her own principles for education and carrying out the rehabilitation of the child. For instance, a child with disabilities may not want to go to physiotherapy, because he or she is playing with other children and does not want to interrupt the play.

It was possible to separate three categories for intervention: 1) rehabilitation accomplished by therapists, 2) individual programs, and 3) common daily activities with goals that supported rehabilitation. All children were regularly in physiotherapy. Individual programs included activities to practice physical skills, such as, standing with a standing frame and rehabilitative play. They practiced children's cognitive and physical skills carried out by a personal aid or family day care taker. One family carried out a home-based early intervention program. A good example of common daily activities, that supported rehabilitation was the boy's play with a remote-controlled car. Aids and elements which supported rehabilitation made the play possible for the child. The boy stood in a frame and drove the car with sensitive pressure pads. Just playing was the most important thing for the child and his father, but many rehabilitation goals were achieved due this play. The boy trained the muscles of his limbs and tried to keep the balance of his body in the standing position. By driving the car he trained his abilities to control movements of his hand, motor skills and coordination of movements, directions and causal relationships.

Membership is not achieved - as a handicapped child. A child with multiple disabilities, who is in day care outside of home, lives daily in two different activity contexts. They describe this phenomenon with the concept dual-socialization in the BASUN-project (Childhood, society and development in Nordic countries). This means that a child learns values and beliefs from both contexts, when he or she lives at home and stays in day care and moves from one context to the other regularly (Dencik, Bäckström, & Larsson, 1988). Typically, emotional interaction brings the sense of belonging in a family, but achieving skills and such kinds of educational features are emphasized in day care.

Day care staff thought quite often that a child with multiple disabilities had few interactions with other children because of communication problems. In day care, communication problems seemed to be the most important reason, that a child did not have contacts with his or her peers without disabilities. Dianne Ferguson (1994) wonders whether communication really *is* the most important reason for interaction. She tells three stories about interaction. One participant in each situation had some kind of communication problem, but nobody was totally outside of interaction in any situation. In conclusion, experience of membership, at least a starting membership, is more important for interaction than communication skills.

Children's participation in common activities of the groups varied in day care. If a child had a personal aid, a kindergarten teacher delegated quite often the responsibility for differentiation of tasks and organizing activities of a child with multiple disabilities to the personal aid.

Achieved membership - a child among other children. Membership was achieved when a child with disabilities participated in the same group activities as other children and the group was controlled by one person. Many children needed support for starting play. According to the day care staff, the child, who needed a lot of help, played sometimes with other children without a participating adult. Getting started in a common play, the child with disabilities interacted with peers in spite of severe communication problems, and in these cases membership was achieved.

First of all a child with multiple disabilities is a child to his or her parents and siblings. He or she is as important as the other children in the family: he or she is a child among other children. How can you see this in the daily life of a family? Parents used the same upbringing principles with the child with multiple disabilities as they used with other children. They reacted flexibly to rules, when the child with disabilities did something forbidden if he practiced a skill just learned and parents did not want to forbid the pleasure of that activity for the child. Those parents, whose child had severe motor and communication disabilities, paid little attention lot how to bring up the child, because the child was quiet and calm. These parents did not have to control the behavior of the child with disabilities, and, therefore, they thought that they cannot upbring their child a lot. So, the parents connected control with upbringing.

Children, who could move without help (crawling, walking or alone with a wheelchair), interacted more with their siblings: they made more initiatives and there were more contacts in comparison with children, who moved only with the help of an other person. Children with disabilities liked be near to and touch their younger siblings, especially, they showed affection to the youngest siblings. In some cases, boys with disabilities tolerated very rough treatment from their little sisters, but sometimes brothers teased their sisters. Quarrels occurred between siblings as in any family. Children with disabilities used those means of fighting they had: yelling, screaming, biting, hitting, and slapping. Children with disabilities usually lost fights, because the siblings ran away and children with disabilities were not able to catch up with.

The view, that membership is more important to interaction than communication skills (Ferguson, 1994), supports and explains also my findings about interaction of children with severe communication problems at home. In day care centers, interaction is mainly based on verbal communication, whereas linguistic interaction at home was not based so much on speech but also on speechless children's own language. Children used different movements and gestures when they communicated with family members or with a familiar care giver. It was quite usual that siblings, or at least one of them, understood better than others what a child with disabilities said and then interpreted his or her communication to others. Probably children are more intuitive than adults and they rely on it more than adults do. The speechless child also debated with his little sister.

It is easier to interpret emotional expressions than needs of children with severe and multiple disabilities (Brodin, 1991). Children, who communicated with speech, supported their expressions of emotions with similar non-verbal gestures as speechless children did. The speechless children expressed their anger and temper, for instance, by crying and biting. At home children with disabilities showed their own will in daily activity settings. Parents asked also the opinion of the speechless child and the child was given opportunities to choose how he would like to play.

Play is an inherent way for all children to express themselves and organize their perceptions and experiences. However, there exists a belief that children with disabilities do not play; many parents and professionals still hold this belief (McConkey, 1985). Based on my observations, there are similar ideas, contents and structural elements in children's plays with disabilities as in their same-aged peers without disabilities, if you analyze the content of play itself instead of its skill-level elements. For instance, a boy and his father played with small cars so that the boy determined in which order and what way the father should park the cars. Any boy plays with cars like this. Children with disabilities seem to enjoy playing wild and violent games like their peers without disabilities. Some parents and staff in day care center protected children with disabilities and so they did not encourage them to participate in wild games with their peers. However, children with disabilities played these kind of games with siblings at home.

4 FROM EARLY REHABILITATION TO EARLY CHILDHOOD EDUCATION

In Finland, early intervention means medical rehabilitation. In getting started, rehabilitation requires that a need for rehabilitation is documented medically or psychologically. This means in most cases that a child must have some kind of diagnosis. Many developmental lags can be prevented if a risk is identified early enough. One of the principles in our health care system is that rehabilitation of a child must begin immediately when some kind of developmental problem is observed. This principle is quite difficult to attain, because it requires, that the need is justified by medical or psychological assessments. Parents' or day care staff's perceptions give only reasons for further tests, not for starting rehabilitation.

Therapists are responsible for early rehabilitation of children with disabilities. In some case, even frequent rehabilitation accomplished only by therapists is not enough to maintain a child's abilities (for example, physical ability). For effective rehabilitation, early intervention services are needed much more than our current rehabilitation system can offer. The problem with early intervention of children with multiple disabilities is that therapies and activities supporting rehabilitation are not an inherent part of the daily activities of a child with disabilities.

The purpose of rehabilitation is to facilitate development and decrease developmental barriers. Unfortunately, possibilities for early intervention in daily routines are often ignored. On the level of goals, they are aware of the importance of context where a child lives and they have paid attention to it, but when transferring goals to meaningful activities for a child, the contextual possibilities are not used as much as is possible. Children with severe disabilities cannot always generalize their knowledge outside of a learning situation (see Ferguson & Meyer, 1991). Therefore, it is important to get to know how the child behaves in other contexts in order to be able teach to play appropriately. In addition, it is important to take elements of rehabilitation into daily routines in all contexts where a child with disabilities lives.

Therapists guide parents and day care staff to carry out activities supporting rehabilitation. What is lacking? Parents need guidance from professionals to be able to interact with their child so that the child's development gets optimal support. In other words, how they play with their child with disabilities so that the child would develop, and what daily activities could be done in a standing position so that being in a standing frame does not become separate setting for the child. Day care staff need guidance how to organize daily activities in day care so that the individual goals of a child with disabilities could be accomplished the during same activities as his or her peers. For facilitating physical and social abilities of a child with multiple disabilities, rehabilitation is very important for the child. It could be done also through play that is pleasurable and motivating for a child. Children without disabilities learn many practical skills by doing without any special attention from adults. Likewise rehabilitation should become to a natural part of daily routines for a child with disabilities.

Traditionally rehabilitation means individual therapies in Finland. Individual educational programs have been adopted for special education from the USA. Individual goals for activities are required, because disabilities limit the activities of a child. Educational programs, based on individual goals, could be planned so that the program are mainly carried out during daily routines of the family or day care group without isolating children from their peers (see Määttä, 1994). It requires that professionals really are able to cooperate and want to work together. For instance, the physiotherapist or speech therapist works with the child in the day care group during common group activities to which the child participates along with his or her peers.

Professionals' working in the field of rehabilitation requires very specific education and many of them use the latest existing expertise in their work. In addition, we have a very good day care system using high level professional know-how in Finland. A great number of children with multiple disabilities are in day care before they start school. Parents of children with disabilities have up-to-date and wide observation-based knowledge of their child. Change is needed in our system so that the professional and parental expertise combine in a holistic system of early childhood education. Goals of early intervention should cover all activities of the child in any context where the child lives. This does not mean that goals of early intervention should displace other goals set for the child, as nowadays usually happens, but they should be accomplished side by side with those other goals during any activity in which the child participates. Consequently, rehabilitation should not be understood only as a medical system, but as any kind of activity which facilitates development, as in an early childhood education. I prefer the concept early childhood education instead of early childhood special education, because, I think, the child-oriented ideology of early childhood education is a suitable goal for education of children with disabilities (see Mahoney, Robinson, & Powell, 1992).

The process of change the ability to co-operate, because to change a familiar way of working and to share your own professional expertise with others presumes open interaction and courage to change your own work practices. To use existing know-how in a different way than earlier, requires also changes in the job descriptions of professionals and willingness for equal working with partners, so that partners appreciate each other's work. Therefore, the change requires relinquishing the expert power of professionals; otherwise partnership is not possible. These ideas are not new ones, because, for instance, in the USA this kind of ideology has guided working with families of children with disabilities for several years. We can find different kinds of educational systems also in Europe, for instance, a conductive education developed in Hungary is a holistic system for children with motor disabilities.

Interaction is an essential element of all developmental activities. Children with multiple disabilities have less interaction with other children and therefore one important goal for early childhood education should be an increased positive interaction between children. The findings of my studies indicate, that most children with multiple disabilities need an adult's help for interaction. An adult must actively observe interaction between children and notice initiatives of a child with disabilities and react to them immediately. Watching video-recorded situations is an effective way to observe interaction and non-verbal communication. Therefore, it is found as an effective way to affect interaction.

5 CONCLUSION

Tests used in assessment of children with severe and multiple disabilities are criticized, because they do not produce information for educational practices. Tests are related to development of children without disabilities and they are not very suitable for assessment of children with severe disabilities. We need procedures for assessing abilities and practical skills of children with disabilities in different contexts and the received knowledge should be suitable for planning activities which facilitate development of children with disabilities. In my opinion, we already have elements of effective early intervention in Finland, because we have active parents, a lot of professional expertise in early rehabilitation, and a day care system based on high level know-how. We need, however, a better coordination of highly specified services. Furthermore, in order to get good results higher parental involvement in early intervention decision making is needed in addition to cooperation with professionals and coordination of services.

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Chapter 6

INTERVIEW AS INTERVENTION: STRATEGIES TO EMPOWER FAMILIES OF CHILDREN WITH DISABILITIES

Marjo-Riitta Mattus

1 INTRODUCTION

Early intervention has mainly been child-focused. When parents have been involved, typically it has focused on benefitting the child directly. Although family impact should be addressed in evaluating intervention effectiveness, the research thus far has been limited (Ayer, 1984; Bailey & Simeonsson, 1986). In recent years, the field of early intervention has developed into a process that has led to a reconstruction of the role of families in the development of children with disabilities. These changes can be characterized by three dimensions. First, early intervention is thought to be most effective if it is directed primarily towards strengthening natural parent-child relationships, rather than encouraging parents to adopt therapeutic or educational roles which often require didactic activities similar to those of professionals.

The family-centered approach complements the second dimension, strengthening and supporting families themselves to enable them to become more competent and independent. It is the family who is responsible for maintaining everyday routines - an adaptational role common to all families (Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993). As a part of the intervention process, families can be empowered to become more confident and competent in their decision-making roles and to improve their ability to get formal and informal supports from the network of individuals, groups, and agencies. Within this framework, the traditional disability-focused early intervention programs constitute only one segment of a child's developmental and support system (Dunst, 1986).

The social systems theory suggests a broader-based conceptualization and definition for early intervention. From this perspective, Dunst (1986) defined early intervention as "*provision of support to families of young handicapped children from members of informal and formal social support networks that impact both directly and indirectly upon parental, family, and child functioning*" (Dunst, 1986, 122; emphasis in original).

Third, a new model for parent-professional relationships has evolved. It consists of a true partnership, where all parties work together in order to meet the needs of families and children. These new approaches, which involve families in early intervention programs, are grounded on help-seeking and family systems theories as well as ecological, adaptational, and social network models (Dunst & Trivette, 1987).

My purpose in this paper is to present a strategy of interview as intervention. Furthermore, if an interview used as intervention would produce some benefits, results could be increased in family involvement and family empowerment because of the specific characteristics of interview. The questions to be explored in this paper are (a) what is the relationship between assessment of family needs and resources and intervention, and (b) can the involvement of families be increased in assessment and intervention through the interview.

I begin by drawing upon the literature that describes what early intervention has been based on, how interviews have been used as a means of gathering information, and what the main goals and ways of help-giving are. Then I describe the assessment and interview as intervention. Finally, this approach is proposed as a strategy to empower families of children with disabilities and make some implications for research and practice.

2 REVIEW OF ALTERNATIVE MODELS IN EARLY INTERVENTION

This review of literature on early intervention issues is based on a consideration of five themes: a medical emphasis in early intervention services, goodness-of-fit concept, parent-professional partnerships, help-giving and social support in early intervention, and family-centered paradigms. These themes will be described through the discussion on the field of early intervention in its different forms. Intervention could be conceptualized as an aggregation of the many different types of help and assistance provided by the members of family's informal and formal support network (Dunst, Trivette, & Deal, 1988).

The interview has traditionally been a means of gathering information to make individualized service or rehabilitation plans for the child with special needs. Successful implementation of a comprehensive family involvement program requires the commitment of professionals, many of whom are educated and experienced in working with children, but who may have little or no formal training to work with families. There may be a need for re-training professionals to work with whole families.

2.1 The Medicalization Emphasis in Early Intervention Services

Traditionally, parents and all kind of professionals are wary of one another. They come together hindered by pre-conceived assumptions and ideas. Parents usually have been expected to agree with professionals' opinions and planned programs, or have been given the opportunity only to agree or disagree with decisions already taken. Many recipients of professional services have complained bitterly about the generalizations and judgements of professionals - that a disabled child means a "disabled" family, and that all parents need help in order to "accept" their child as disabled. Generalizations and stereotypes should constantly be questioned: no two parents are alike (Mittler, Mittler, & McConachie, 1986; Broderick, 1993).

It is believed that medical doctors' attitudes differ from those of parents. The difference is not so much related to their lack of understanding of what a disability means to the individuals themselves, their families, and friends, but rather because of medical attitudes which perceive work with people with chronic conditions as low in status and even unglamorous. These more general attitudes are probably the result of medical practitioners' dissatisfaction who find themselves powerless to help in traditional medical ways or unable to cure and hence feel they fail their patient. In some cases, the sense of failure may be increased by the belief that births, for example, of babies with Down's syndrome, could have been prevented (Nursey, Rohde, & Farmer, 1990).

Social workers, psychologists, and other professionals usually have a psychoanalytic orientation, which locates the source of human problems within the psyche of the client or the client's parents rather than in the structure of the social system. When seen from this perspective, parents' concerns about their children are interpreted as indicators of parental pathology. It is traced to parental guilt of giving birth to an "imperfect" child. According to this interpretation, expressions of parental love may be defined as "idealization" and treating a child as normal may be seen as "denial". Sometimes the parents describe their situation as they have heard professionals do (the quotes of family members are from my pilot study):

> "...obviously it's the situation that we go on with the process with the child; it feels as if everything's awfully open, yet, and in a way, all the time there's coming something new that is not very comfortable to hear. So, a kind of basic process seems to be going on..."

Regardless of whether parents apparently accept or reject their children, their actions are believed in both cases to be based on guilt (Ferguson & Ferguson, 1987; Seligman & Darling, 1989). Professionals can evoke strong feelings in their interactions with parents. Health-care professionals are powerful significant others. Unfortunately, the influence professionals exert is often experienced negatively (Robinson, 1993). Professionals tend to adhere to the dominant societal story that views life with a chronic condition as problem-saturated. They are oriented toward servicing one's illness or disability rather than helping in getting on with life. This is a markedly different perspective than that held by families whose story of life is dominated by normalization. Thus families who live through the story, often experience the negative judgements of professionals who see the normalizing efforts as evidence of denial.

Most of the families actively construct and define their every day routines in order to meet the "family-themes" that give meaning to parents' decisions concerning their daily life (Gallimore, Weisner, Kaufman, & Bernheimer, 1989). They can see the discussions with professionals like this family in my study: "Sometimes I feel that different professionals make the simple things so complicated."

Similarities Among Families. Families of children with disabilities are like other families. Gallagher, Scharfman, and Bristol (1984) found out the similarity in the parental division of family responsibilities in two-parent, middle-income families, regardless of the presence of a child with disabilities in the family. Ordinary families take many forms. Like other families in society, families of children with disabilities are from various socioeconomic and ethnic backgrounds; they may have one or two parents; they may include grandparents or other relatives; they may have parents who work or who are unemployed (Seligman & Darling, 1989).

Parents of children with disabilities are not pre-selected on the basis of their qualifications and knowledge. Nor is there a reverse selection in which only the worst couples are chosen. Rather, the parents of children with special needs represent a cross section of society (Ferguson & Ferguson, 1987). However, it is important to realize that children with disabilities do not function in isolation. Persons live within a context and when something happens to one member of the family, everyone is affected. A family is a unit comprised of a certain number of individuals functioning in dynamic interrelationships (Turnbull & Turnbull, 1986).

There is a compelling finding of Shonkoff, Hauser-Cram, Krauss and Upshur (1992) that for most families, the birth of a child with disabilities did not produce major changes in their lives. The stable level of family adaptation, shown by a preponderance of families, was striking to the authors. What appears to happen is that parents are committed to rearing their children and that this commitment is not negated by the birth of a child with some mild problems. On the other hand, children with severe disabilities increased parenting stress and adverse family effects.

Numerous researchers have studied the stress (Depner, Wethington, & Ingersoll-Dayton, 1984; Robinson, Rosenberg, & Beckman, 1988), stigma (Baxter, 1989), social support (Kazak & Wilcox, 1984; Shinn, Lehmann, & Wong, 1984; Shumaker & Brownell, 1984), coping (Seligman & Darling, 1989), or adaptation (Gallagher, Cross, & Scharfman, 1981) as the most important factor in the life of families of children with disabilities. On the contrary, the family accommodation describes a process and proactive efforts of a family to adapt, counterbalance, and react to all the competing and sometimes contradictory forces in their lives (Bernheimer, Gallimore, & Weisner, 1990).

The process of accommodation is not dependent on social class and thus it can avoid the often implicit assumption that a better status and education, more income, or living in a two-parent married family arrangement invariably would produce "better" developmental circumstances and consequences (Gallimore et al., 1993). According to the ecocultural theory, family-accommodation occurs within the context of a larger ecological system and has meaning for families within their cultural goals and values (Gallimore et al., 1993; Nihira, Weisner, & Bernheimer, 1994). Families can see both the difficulties and positive effects of their child with disabilities:

> "It is different. You can't put him alone to play with neighboring children. On the other hand, he connects family members because we often go out together, for example, to do sport."

2.2 Goodness-of-Fit Concept

Some approaches have taken a social systems perspective. The family-focused intervention model suggested by Bailey and colleagues (Bailey, Simeonsson, et al., 1986), proposed a "*goodness-of-fit*" concept for designing early intervention services to reflect family needs. The goodness-of-fit concept is a model to explain positive adaptation of a family.

Drawing on figural representation of the goodness-of-fit model (Simeonsson, 1988, 141), a representation was made of the actual situation in Finland in the 1990's. We can see a family of a child with disabilities in Figure 1. If the child had only one disability, there are services for the disability but not necessarily for the child or the family. If she or he has other disabilities, there are other services for them, but maybe some disabilities remain without services because the family has not enough time, money, or energy to take the child to every distant hospital. No professional or agency in the service delivery system has a responsibility for the whole child, his or her education, and upbringing and, however, the family may be left quite outside. Only the family has a holistic view of the child but usually, the parents cannot express this point of view in the jargon that professionals understand. As discussed earlier, the family of a child with disabilities is often seen as a "disabled" family and parents as neurotics with their child-related concerns. Additionally, plenty of professional contacts can diminish normal social contacts and isolate the family, too. The actual Finnish situation can be described as a professional-centered/institution-centered/disability-focused system.

A figural representation of goodness-of-fit concept in the future situation in Finland is a family-centered one (Figure 2). Then you do not need different specialized services for every disability of a child but you have to know what are the individual family needs and resources. Families often have other needs that take precedence and consume their time and energy. Family-identified child-level needs are inversely related to needs in other areas, and until the latter are adequately addressed, the family may not indicate that they have needs related to enhancing their child's development. There is a good place to live for every member of the family when family needs are adequately met.

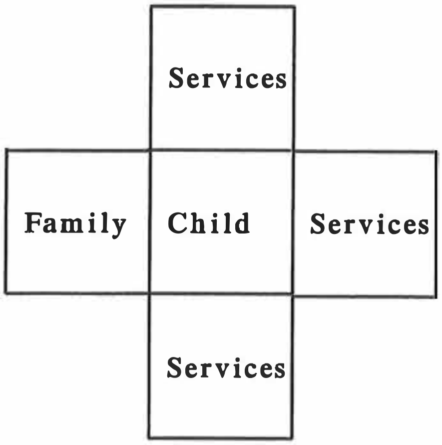

FIGURE 1 A representation of a professional-centered/disability-focused service delivery system where every single disability has separate services; early childhood special education may by well arranged but the family is an outsider.

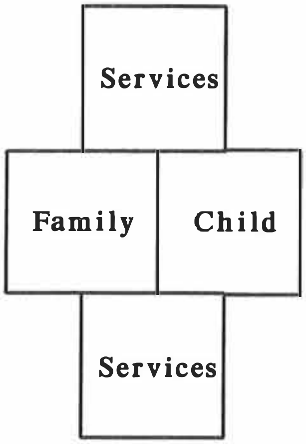

FIGURE 2 A goodness-of-fit representation of a family-centered service delivery system where family needs are the basis of the services delivered.

2.3 Parent-Professional Partnerships

Even in countries where many surveys have been done of the needs and feelings of families of children with special needs, services may still be set up in ways which reflect more the needs and priorities of professionals and organizations/institutions rather than those of families (Mittler et al., 1986). It is surprising how rarely parents' opinions have been asked - for instance, what their child should learn. Although parents do have a lot of information, they may not know the "right" terminology to report this knowledge to professionals or they are not asked in the right way.

An approach to the use of expert knowledge is based on partnership, in which professional and client together identify what the client wants and needs to know (Mittler et al., 1986; Dunst et al., 1988; Seligman & Darling, 1989; Dunst & Paget, 1991; Guralnick, 1991; Brinker, 1992; Williams, 1993). Instead of a one-way transmission of knowledge from professional to client, there is now a two-way transaction, building on the existing knowledge and experience of the client, according to the client's perceived needs, and the professionals' response to these needs. Families of children with multiple disabilities and chronic illnesses may need immediate help. Then they need to know that they will be regarded as experts when having concerns about their children:

> "When the child has many problems and she seems to be sick you never know which illness you begin to cure and to which physician you should go. For these children, there should be the one and only physician all the time, easily to be caught by phone, to whom you can go, even at once."

Borrowing ideas from business literature, Dunst and Paget (1991) defined a parent-professional partnership as an association between a family and one or more professionals who function collaboratively using agreed-upon roles in pursuit of a joint interest and common goal. Partnership means that parents can be involved with professionals in an active working relationship with frequent communication. It does not mean that parents should be put under pressure to do so (Mittler et al., 1986).

Partnership implies professional accountability to parents and equality between parents and professionals. It can take many forms but all must rest on a basic recognition that each side has areas of knowledge and skills to contribute to the joint task of working together.

Partnership enables partners to accomplish a mutually agreed goal or interest by empowering one another to act on behalf, and in the best interest of, the partnership. The term "enable" connotes making something possible by creating a means or opportunity. Empower implies providing power or authority to make decisions or offer judgments. Thus, partnerships create opportunities for partners to become empowered to make informed decisions about the best course of action to achieve a shared goal or interest (Dunst & Paget, 1991).

Brinker (1992) asked, what does a family-centered partnership that empowers chronically disadvantaged mean? The point is that partnership is a form of effective helping that enables and empowers both parents and professionals as part of collaborative efforts. Descriptions of empowerment as philosophy can be found in the writings of Dunst and his colleagues (Dunst & Trivette, 1987; Dunst et al., 1988; Dunst, Trivette, & LaPointe, 1992). The translation of this philosophy into practice has been accomplished in a number of ways. For example, Dunst and his colleagues (1988) describe a system of family-centered intervention practices for identifying family concerns and desires, strengthening family capabilities, building supportive resource networks to meet family needs, and adopting interactive roles that promote and enhance family competencies.

In a specific field-test of the implications of this philosophical stance, Dunst, Trivette, Gordon and Pletcher (1989) demonstrated, that in cases where the above principles guided nearly all aspects of program practices, unempowered families from very poor backgrounds with limited resources gained the ability to mobilize their social support networks to meet their needs.

2.4 Help-Giving and Social Support in Early Intervention

Help-givers, whether friends, relatives, or neighbors, offer aid and assistance hoping that it will have positive influences. Professionals who offer premeditated help for their clients also wish that a help will produce both immediate and long-term positive consequences. However, there is now substantial evidence that different types of help, and assistance, and the manner in which they are offered, can have either empowering or usurping consequences depending upon the intertwining of a host of intrapersonal and interpersonal factors (Shinn et al., 1984; Dunst & Trivette, 1987, 1988; Dunst & Paget, 1991; Shonkoff et al., 1992). Certain types of helping relationships have been found to produce such negative consequences as learned helplessness, dependency on the help-giver, lowered self-esteem, indebtedness, ambivalence, embarrassment, and perceived inadequacy (Dunst & Trivette, 1988). In addition, various situational conditions partly determine whether the help is likely to have positive or negative consequences, for example, non-contingent help-giving, unsolicited help, incongruent help, and unnecessary help have had clinically negative consequences under certain circumstances (Dunst & Trivette, 1988).

A family-oriented approach can rectify the counter-productive view that the child with disabilities should be the sole focus of concern. When the family is considered as a client, one must necessarily keep in mind that families differ in terms of culture, ethnicity, and lifestyle. In addition, as structural changes in family life occur over the years, professionals must be cognizant of the special needs of divorced and reconstituted families. And finally, some children with disabilities live in fragmented and highly chaotic situations that do not provide a nurturing environment. One cannot assume that professionals have a right to intervene in families simply because those families have a child with disabilities. Parents must be active participants in determining what kinds of help they need and how much help is needed. When families agree that therapeutic intervention would be beneficial, professionals trained in a family systems perspective can be tremendously helpful to them.

Therapeutic approaches include interventions that are designed to change families. But not all families need to be changed. Professionals in the helping professions have had a pathology orientation. When families neither need nor desire therapeutic intervention, such counseling may be more intrusive than helpful. On the other hand, some families *do* express a need for therapeutic help, either directly or indirectly, and professionals must be able to meet the need when it arises (Seligman & Darling, 1989).

According to Shinn et al. (1984), the social interaction and social support should be distinguished. Social support refers to beneficial interaction whereas the valence of social interaction can be either positive or negative. If social interaction is an exogenous variable whose effects are always beneficial, then we should simply increase social interaction to obtain benefits ranging from reduced incidence of low birth weight among infants to reduced mortality among the elderly. But if social support is not an exogenous variable, then we must consider the reciprocal process it is embedded in. When the effects of social interactions are negative, we must pay more attention to the factors that determine the valence of the effects.

We can see the importance of fit between social support and individual circumstances in five dimensions: amount, timing, source, structure, and function of support (Shinn et al., 1984). For example, too much support may be problematic for people in dependent roles. An environment that provides too much support and too little challenge for a well-functioning person (e.g., parents of children with disabilities) may foster dependency and deterioration, although the same environment may provide too little support and too much challenge for a frail person.

The starting point has to be that of the family. When learning themselves, family members can change their functioning style. Although the mother in the next example is convincing, afterwards she wondered: "Why is it always me?" and began to use a babysitter and respite care.

> Interviewer: At the moment, you don't use a babysitter in your family. Why? Haven't you got any?
> Mother: In fact, we haven't got any and no one can care for him as well as I do (laughs). So, we don't use any. If we'll go somewhere we'll go all together or we don't go at all.

About six months later:

> Interviewer: Did you feel you received something concrete and useful during or after the interview?
> Mother: ... personally I felt that - when I'm always at home - how I could use others, so that somebody else would care for the child for a while. I began to think why it's always me.

2.5 Family-Centered Paradigms

It has been discussed whether the target of intervention is a child, parent, family, siblings, or a different combination of these. Bailey and his colleagues (1986) came to the conclusion that the child is and will remain the primary target for services. However, the family is also a consumer of early intervention services, indirectly as those services pertain to the child, and directly as family members attempt to meet their own needs as individuals and as a living, growing system. In carrying out this important service role in early intervention, the need for a systematic, functional model of family services becomes critical (Bailey et al., 1986).

Different family characteristics greatly influence the family's capacity to nurture children. Interventions that focus on the family, parents, or social and economic context are necessary when the life-conditions make it impossible for parents to perform their child-rearing functions adequately. Under these circumstances, no direct form of intervention aimed solely at the child is likely to have substantial impact.

Instead, the needs or all family members must be taken into account (Robinson et al., 1988).

Brinker (1992) assumed that parents do not come into early intervention programs because they have marital or economical problems, problems in finding a job, or overcoming a drug or alcohol addiction. Nevertheless, all of these family problems may enter into consideration as parents and interventionists develop a family-centered Individualized Family Service Plan (IFSP) which, in turn, was the target of Dunst and his colleagues' (1988) critique. They called the IFSP as "Inevitable Failure due to Static Planning" (p. 132) because it is not possible to take into account the changing needs. Additionally, Brinker (1992) criticized Dunst and his colleagues (1991) for arguing that interventions could be assessed in terms of parameters that measure the degree to which a program is family-centered. He (1992) reviewed critically also the notion that early intervention should be family centered rather than child-centered and transactional. His opinion was that intervention always is and has to be child-centered.

As a result of their training and experience, professionals may adopt a clinical perspective that regards diagnostic nomenclature, instruments and functions as important components of their profession. A preconceived diagnostic nomenclature tends to prevent the clinician from seeing the client in a new or creative way (Seligman & Darling, 1989). It may take many years before an established medical diagnosis is found for the child's problems. However, the diagnosis is very important in curriculum planning and service delivery. Then, we can ask why the diagnosis has to be medical. Can it not be educational? Referring to International Classification of Impairments, Disabilities, and Handicaps (ICIDH, 1980), we can also ask where we need three levels. Could it be the impairment-level we do not need any more? What would that mean to the discussion of child- or family-centered intervention?

Anyway, I see the family-centered early intervention to help, not to complicate the situation in the family. As one mother stated the point: "Is it a purpose to support so that you don't search for defects but rather emphasize the points we should go on with?"

According to Dunst et al. (1991, 118), "paradigms are models that provide a way of understanding particular phenomena (e.g., family-oriented programs), a segment of the universe of the phenomena (e.g., family-centered programs), and the relationship between elements (e.g., family support principles) that uniquely define particular segments". Examples of practice indicators for the four family-oriented program paradigms are presented in Table 1. Early intervention policies and practices have changed very quickly from professional-centered during the 1980's and the 1990's (Dunst et al., 1991). In Finland, we are far from the family-centered support practice. Discussions with professionals and families who participated in my study, however, indicated that it is important to separate the paradigms.

Bailey, Palsha and Simeonsson (1991) have pointed out that the early intervention professionals did not feel competent in working with families, endorse family-oriented roles, or were concerned about changing to family-centered practices. Common questions for early interventionists at this level included: Does a family-centered approach reduce the quality of services for children? Do families benefit from this approach? Can I modify the approach to fit my own philosophy, or do I have to follow a single model? The concerns are surprisingly similar with those I heard from the professionals who participated in my study. However, professionals have been interested in using a new kind of practice as a part of their work.

TABLE 1 Examples of practice indicators for the four family-oriented program paradigms (Dunst et al., 1991, 119)

Paradigm	*Practice Indicators*
1. Family-Centered	* Broad-based family concerns and needs "drive" the assessment process. * Nothing is written on the IFSP without the family's explicit permission. * A family's needs and life-style determine the roles of case managers.
2. Family-Focused	* Assessment practices are mostly restricted to family needs as they relate to child development. * IFSP goals/outcomes are mutually selected by both families and professionals. * Case management practices primarily promote the family's use of professional services.
3. Family-Allied	* IFSP implementation focuses on services aimed at influencing child development. * Families are enlisted to carry out professionally prescribed interventions. * Case management practices expect families to play professionally determined roles.
4. Professional-Centered	* Assessment practices focus on professional assessment of family functioning. * IFSPs are primarily implemented by early intervention program staff. * Case managers mobilize/coordinate services for families.

Note. IFSP = Individualized Family Service Plan.

Based on my experience (see Mattus, 1993) and the families in my study, I have noticed that well-being of the family depends on well-being of the child with special needs. When such fine-tuned tests are not available to recognize improvement in abilities and the competencies of a child with multiple disabilities, the crucial means is to study the effects on family-level outcomes. The ecocultural theory suggests that also the following concepts are important: whether accommodations are meaningful to families in terms of their beliefs and values; whether accommodations are congruent with the child characteristics; and whether accommodations are sustainable for long periods of time, given the constraints and opportunities of the families (Gallimore et al., 1989).

3 INTERVIEW AS INTERVENTION

3.1 Interviewing in Assessment and Intervention

One of the many means of gathering information from a family is through an interview. Interviews are useful because they are often informal and provide family members and the professional conducting the interview an opportunity to build rapport with each other. Interviews can provide a good deal of information in a relatively short time. Often the interviewer will have a specified set of questions to which families may provide answers. For example, the interviewer may ask specific questions concerning the family structure, the child's developmental progress, or the nature of the family's social support system (Winton & Bailey, 1988). At the same time, the interview may give family members an opportunity to bring out and discuss issues that are important to them (Thurman & Widerstrom, 1990).

In addition to interviews, a number of paper and pencil instruments have been developed that can be used to obtain information about families. These instruments measure areas of family functioning, such as social support, coping, stress, cohesion, needs, and resources (for review, see Bailey & Simeonsson, 1988; Dunst et al., 1988; Thurman & Widerstrom, 1990).

Interview is always a form of intervention. Interview as gathering information for the plans of service delivery, different support and rehabilitation has led to the situation where the family's role is only to give the information professionals could need for basing their decision making. This has been unsatisfactory from the family point of view because the family has the responsibility to arrange the daily routines of the child. Simultaneously, there is a lack of consciousness about the fact that the interview always works as an intervention. In the next section I will describe the characteristics of interview which has interventional goals.

Family-therapeutic principles of interview as intervention are, according to Selvini Palazzoli, Boscolo, Cecchin, and Prata (1980), (a) giving conceptual definitions, descriptions, and practical examples of applications and (b) to aid the professionals in stimulating the family to produce meaningful information. I am advancing the interview as intervention, not for family therapeutic purposes but as a means of increasing family involvement and empowerment. The influence of this kind of intervention is, without doubt, also therapeutic.

The implementation of the assessment and intervention is guided by a belief that emphasizes a proactive and highly responsive approach to working with families. Enabling families means creating opportunities for family members to become more competent, independent, and self-sustaining with respect to their abilities to mobilize their social networks to get their needs met and to attain desired goals. Empowering families, refers to carrying out interventions in a manner in which family members gain a sense of control over their own developmental course as a result of their efforts to meet needs. Strengthening families means supporting and building upon the things the family already does well as a basis for promoting and encouraging the mobilization of resources among the family's network members. Enhancing the acquisition of competencies refers to providing families with the information and skills necessary for them to become more self-sustaining and thus better able to promote personal well-being as well as have positive influences in other areas of family functioning (Dunst & Trivette, 1987; 1988).

The process when the family is identifying sources of support, matching resources with needs, and assessing the ways in which different characteristics of interaction influence decisions about asking and accepting help, is itself an intervention. The process also sets the occasion for promoting the use and acquisition of skills and competencies necessary for the family to mobilize its social support network. To the extent that this is done in a proactive way, actualizing the plan should have positive influences on parent's, family's, and child's functioning (Dunst et al., 1988).

A number of considerations should be taken into account when identifying family needs in an interview format (Dunst et al., 1988, 66). The interviewer should:

1. be positive and proactive in arranging the first contact with the family

2. take time to establish rapport with the family before beginning the interview

3. begin by clearly stating the purpose of the interview

4. encourage the family to share aspirations as well as concerns

5. help the family clarify concerns, and define the precise nature of their needs.

6. listen empathetically and be responsive throughout the interview

7. establish consensus regarding the priority needs, projects, etc.

3.2 Needs and Resources

According to Turnbull & Turnbull (1986), the functional assessment of family needs means to assess the needs of families and the method by which they would prefer to have those needs met. Needs also change over time (Dunst et al., 1988; Seligman & Darling, 1989). Consequently, assessment should be an ongoing process, and the interventionist should be sensitive to any changes that occur (Seligman & Darling, 1989).

Professionals' primary goal is to understand what families want for themselves and their children and what they need from professionals in order to achieve those aspirations. In this context, a *family-need* may be viewed as a family's expressed desire for services to be obtained or outcomes to be achieved. A *family-strength* is the family's perception of resources that are at its disposal and could be used to meet family needs (Bailey, 1991).

Needs change so rapidly and so do the resources which can be found from small things, for example:

> "There's never time enough to rehabilitate and care for the child. Sometimes I feel that I can't stand one more day. Depression comes when you feel that the child doesn't develop at all. Another day a tiny sign of progress gives you energy for days. Things change."

Bailey (1991) asked, what are family strengths and needs related to the development of a child? Historically, early intervention has been seen as a way to prevent or ameliorate developmental disabilities associated with organismic or environmental deterrents. A compliance with intervention goals is less likely to occur. Dunst and Trivette (1990) combined the system theory with a social support model to examine the relations between various dimensions of support and individual and family development.

The family-level assessment and intervention was divided into four components: identification of family needs, identification of intrafamily resources (strengths and capabilities), identification of extrafamily source of support and resources, and proactive interventionist roles in helping families mobilize both intrafamily and extrafamily resources to meet needs (Dunst et al., 1988).

There is a danger in using the word "strength" to refer to family capabilities because the term implies a continuum, with strengths at one end and weaknesses at the opposite end. For this reason, Dunst and his colleagues (1988) prefer the term "family functioning style" which implies unique ways of dealing with life events and promoting growth and development.

Identification of family strengths and capabilities works as a basis for emphasizing the things the family already does well. The purpose of identifying the family's unique functioning style can be used to secure additional resources and untapped but potential sources of aid and assistance (Dunst et al., 1988; Dunst & Trivette, 1990; Trivette, Dunst, Deal, Hamer, & Propst, 1990).

Many existing and potential sources of support may often be overlooked by early intervention practitioners because they easily fail to consider the full range of social support options available for families. Social support network mapping provides a mechanism for ensuring that we do not over-professionalize families when less formal sources of support can be used to meet needs (Dunst et al., 1988; Dunst & Trivette, 1990).

4 INTERVIEWING AS A STRATEGY TO EMPOWER AND ENABLE FAMILIES

Can the interview empower families? If it can, in which conditions can the interview as intervention increase family involvement? How strong is the effect of traditional training of professionals? Is it a barrier to use a new instrument which has the purpose of strengthening the family to function by itself without needing help-givers too often? What is empowerment, then? Can it be defined as releasing the natural creative problem-solving within the family?

To the extent that we do not recognize and explicitly consider empowerment of families as the goal of intervention, we are more likely to believe that we have done a good job. In fact we may have lost an opportunity to enable and empower the family and perhaps have even created dependencies by engaging in non-contingent helping (Dunst et al., 1988).

The family-centered intervention is not synonymous with intervention focused on the mother alone. In Bailey and his colleagues' (1986) application, fathers and mothers (or other primary caregivers) separately completed all measures. Talking with all family members about family concerns does not mean that it controls whether the mother has told the truth but to help the family to manage their life demands together, instead of the professionals' focus on the mother - child dyad by leaving the father as an outsider.

Some remarks concerning fathers could be mentioned as an example: Fathers liked the assessment method because they found it as an opportunity to express their opinion and to ensure that other family members and the professional, too, had to listen to them. Professionals found out that it was the first time they could get closer contact with fathers after working with the child a long time. Both mothers and professionals seemed to be surprised about how concerned the fathers were about the situation of the child with disabilities.

When I interviewed families about six months after the interview professionals had implemented, I recognized that the fathers had waited for my call (I had sent an announcement about the date and the time of my phone call beforehand). Also in cases when the mother answered first, the father wanted to answer my questions as well.

From these few examples we could conclude that the interview as intervention has, not only increased the involvement of parents but made visible the formerly unknown kinds of involvement of parents; especially of fathers. Additionally, parents seemed to feel comfortable that they had had an opportunity to choose the topics of discussion with the professional.

From these issues discussed above I have developed a model which should be tested with further research. In Figure 3 it can be seen that an interview is a form of intervention. An interview can work as intervention when it helps to increase family involvement and to produce family empowerment. If we then come back to the concept "goodness-of-fit" (Figure 2) we can see that interview as family-centered intervention has the same characteristics. Based on my pilot study, the use of this model and its guiding principles can improve efforts to work effectively with families. Whether it can increase professionals' ability to both enable and empower families, is to be seen in future research.

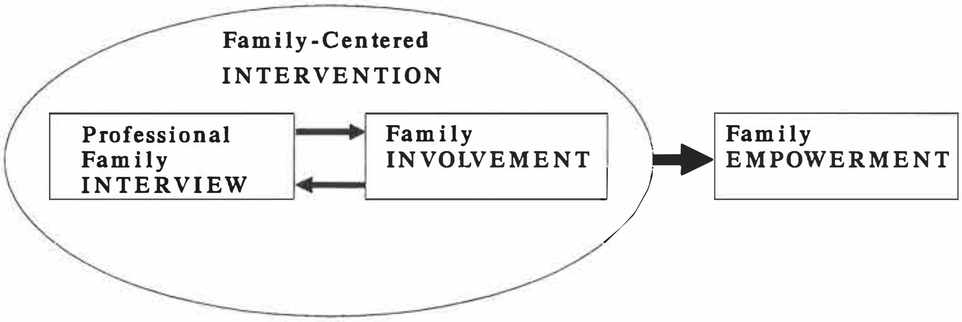

FIGURE 3 A model of the interview as intervention which is expected to increase family involvement. The purpose of the family-centered intervention is to empower families.

The previous training of health and welfare practitioners has shifted from the inculcation of knowledge to an emphasis on skills and competence. However, competence implies the ability not only to respond to what is known and familiar but also to new and unpredictable situations. In this task, the characteristic of an effective practitioner is awareness of the way in which problems are framed and what makes responses appropriate (Mittler et al., 1986; Walmsley, Reynolds, Shakespeare, & Woolfe, 1993).

The interview as intervention is quite flexible concerning the place where an assessment can be carried out. This can be viewed positively: for example, families can be interviewed at home, in a hospital or at a rehabilitation center. I agree with researchers who argue that, to ensure ecological validity, social support should be studied in field settings (see Shumaker & Brownell, 1984).

Interviewing skills should be part of the training that professionals in the early intervention field receive. Without such training, they may feel uncomfortable in asking personal questions and may not be able to elicit valid responses. I would recommend that a course in social research methods, counseling, or a similar course be included as part of the pre-professional curriculum offered to those planning to enter the early intervention field. An alternative for those already working in the field would be appropriate in-service training.

There may not be a better way to raise a child with disabilities than to reinforce the ability of the parents to do so. Enabling, empowering, and strengthening families may constitute the major goals of the assessment and intervention process.

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Chapter 7

THE DEVELOPMENT OF PARENTHOOD IN A FAMILY WITH AN EXCEPTIONAL CHILD

Maija Virpiranta-Salo

1 THE DEVELOPING NATURE OF PARENTHOOD AND PARENTING

This article deals with parenthood and parenting as a continuous, developing process and similarities between families, regardless of the different situations of the parents and children. The basic conditions for parenthood are always the same, but each child sets his or her own requirements for parenting. In order to be the best possible parents for their child, the parents must respond to these requirements and needs. The parental experiences used in this article are taken from my studies on the parenthood of preterm infants and children with single or multiple disabilities (Virpiranta-Salo, 1992; 1993)[1].

Preparation for parenthood begins when one plans to have a child or, at the latest, at the onset of pregnancy. Pregnancy and the first weeks and months after childbirth have been called a *transition to parenthood* (e.g., Goldberg & Michaels, 1988; Karila, 1991). This concept has been dealt with extensively in the literature (Cowan & Cowan, 1988; Fedele, Golding, Grossman, & Pollack, 1988; Gloger-Tippelt, 1989). After their child's birth, a couple becomes parents, a mother and a father. Parenthood as a whole, however, develops and transforms itself; it is a

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[1] The results come from three data: (1) Virpiranta-Salo (1992): The qualitative data of families of children with various disabilities (N=13) in Central Finland. Material consists of interviews and questionnaires. (2) Virpiranta-Salo (1993): The quantitative data of families with severely disabled children aged 0-6 in Finland (N=229). (3) A study in progress. Qualitative follow-up data from 24 families including mothers' and fathers' interviews (4-8 times during two years).

process which takes its course according to the child's needs and development. There is no static state of parenthood except for the fact that a woman and a man who have one or more children are called parents.

2 THE BASIC CONDITIONS FOR PARENTHOOD

The past few decades have seen the publication of several popular guides for educators (e.g., Bettelheim, Gordon, and Miller) which discuss the essence of successful parenthood. No writer has been able, or wished, for that matter, to define perfect parenthood, but researchers agree on some important points: every child needs care, love, and a sense of security, and parents should be able to provide these regardless of the family's or the child's condition. Premature birth, illness and disability do not change this. In fact, special situations just increase the demands for parenting.

All parents have an influence on their children. Quinton and Rutter (1988) state that parenthood includes not only what parents do with their children or how they do it, but parents also have a global influence on the child's social, cognitive and emotional development. Parents draw from previous experiences of children in general and the child they are raising in particular. The social context for parenthood also has an impact (Gallimore, Weisner, Kaufman, & Bernheimer, 1989).

Parents must, therefore, possess the necessary knowledge and skills to care for their child. Mothers and fathers need skills to deal with their children's fears, unruliness or social approaches as well as settling conflicts and personal problems. These skills reflect the parents' sensitivity to interpret the child and his or her messages. They also reflect the parents' responsiveness in the different stages of their child's development. Parents need skills for social problem-solving and dealing with stress. They need to know how to play with and talk to the child. In addition, they need skills to use effective disciplinary measures which enhance the child's self control (Quinton & Rutter, 1988). The parents of exceptional children also need many specific skills depending on the child's condition. They may need to know, for example, how to lift or exercise the child correctly, or they need to learn a new method of communication.

3 EXCEPTIONAL CHILDREN SET DEMANDS ON PARENTING

Family routines undergo a change whenever a child is born, and life in the family must be reorganized (Seligman & Darling, 1989). As the child grows, family members must constantly adjust to changing situations. The changes in families with premature infants or disabled children are greater than in families with healthy, full-term children. Caring for an exceptional child is more work than childcare in general, and the physical strain of caring for a disabled child may be constant. It is important, however, to keep in mind what Ferguson and Asch (1989, 108) have said: "The most important thing that happens when a child is born with disabilities is that a child is born. The most important thing that happens when a couple becomes parents of a child with disabilities is that a couple becomes parents."

One of the central findings of family research is that the birth of a preterm infant (Hanline & Deppe, 1990) the detection of a long-term illness in a child (Hänninen, 1993), the birth of a disabled child or the later disablement of a child (Seligman & Darling, 1989; Virpiranta-Salo, 1992; 1993) cause parents to face a situation of which they do not have enough information and which they cannot control. These situations are strange for both the parents and the environment, and must be learned about and adjusted to. In order to succeed in their task as educators, parents need information and support. The following chapters deal with the effect of premature birth and disabilities on parenthood and parenting.

3.1 Premature Birth Affects the Initial Stages of Parenthood

The number of successful preterm births has increased during the past few decades, since modern medicine and highly developed technologies can save very low birth-weight and early preterm infants. Both parents in a family with a small preterm infant face a new situation with new tasks (Freud, 1989). Few women are able to breast-feed, and parents are not able to fully participate in the care of the child. Small preterm infants (24-33 weeks) are born so early that neither of the parents has usually had time to prepare for the role of a parent. It must also be noted that examinations and care procedures are often unpleasant and even painful for the child. Some of the parents who participated in my study concerning families with preterm infants found it very difficult to deal with the suffering of the child. One mother had considered refusing to continue intensive care because it was clearly very painful for the child. Mothers in particular found it important to be with the child, even if the incubator and necessary care procedures limited the child's chances of normal interaction with the parents. In the beginning, the parents also felt uncomfortable and even frightened in the intensive care unit environment. (Kyllönen, 1993; Levy-Shiff & Sharir, 1989; Miles, Carter, Riddle, Hennessey, & Eberly, 1989).

The birth of a preterm infant put the parents in an unexpected situation in which they had to live and function without preparation. The preterm delivery with its dangers caused strong emotional reactions; fear, concern, and sorrow. The premature birth was a traumatic experience, especially for the mothers: she was immediately separated from the child, often without even laying eyes on it. The chances for the mother to participate in the care of her child from the beginning were minimal. Pregnancy and premature delivery sensitizes the mother, and she may be tearful weeks after the child is born (Affleck, Tennen, Rowe, & Higgins, 1990; Hägglund & Hägglund, 1987). This was true also for the mothers in my study. The sadness and pain of many were increased by the uncertainty of the child's survival. The Fathers were allowed to see the child and admitted into the intensive care unit immediately. The parents were satisfied with the relevant information concerning their child's physical condition they received daily during the intensive care phase, although they would have liked more information about premature birth in general, intensive care and their own opportunities of participating in the care of their child.

According to Hanline and Deppe (1990), the parents may have mixed feelings when the infant is discharged, losing the intensive support of the hospital personnel and having to take responsibility over their child. The parents in my study, however, did not consider the homecoming difficult but relieving, because at home they had a chance to care for the child without restrictions or imposing advice. A preterm infant develops more slowly than a full-term infant. During the first year especially, the parents had to accept the fact that their child was smaller and developmentally behind full-term infants of the same age. During the second year, most children reached the level of their age group, which relieved the parents' fears.

It follows from this that the parents of preterm infants had to learn to cope with the changes in the family's life, since many of them had to stay in the hospital for months in the beginning. The parents also had to acquire self-confidence as parents, because otherwise they might feel inept as parents during the intensive care phase, and the child might seem the hospital's more than their own. When increasingly participating in the care of the child, the parents began to feel more confident about their abilities. The parents were also forced to explain the special needs of their child to friends and relatives since the family's social life was restricted, often for months, because of the risk of infection.

3.2 Disability Affects the Routines of Parenting

Studies concerning families with disabled children have often concentrated on the emotional experiences of the parents (Ferguson & Ferguson, 1987, 357-358). The disability of a child, however, also has a concrete effect on daily routines. The parents reported experiencing most difficulties organizing the daily life of the family: arranging temporary care, ensuring enough rest for themselves, and securing the finances of the family (Virpiranta-Salo, 1993). Studies have shown that if the parents get sufficient support and information to cope with their child's disability, life in the family can continue harmoniously (e.g., Dunst & Trivette, 1990). Ferguson & Ferguson (1987, 386-388) have used the concept of a *relative balance* in the family, found through learning and sufficient support.

When the family is told about the child's disability, the parents face new, unforeseen practical arrangements and developmental functions. These functions, according to Mitchell (1985, 140-141), include the following: the parents must decide on the child's medical care and whether to keep the child, put him in an institution or give him up for adoption; they must learn to cope with the disability, understand their own reactions to it and deal with them; understand the nature of and reasons for the disability as well as their child's developmental possibilities. They must also reach mental balance and raise their self-confidence, reach a positive parental relationship with the child, and understand the reactions of family, friends, relatives and the community and cope with them. Last, but not least, the parents must strengthen their mutual relationship.

In the beginning stages, the parents usually had little knowledge about their child's disability. This was evident in my studies concerning the parents of children with single and multiple disabilities (Virpiranta-Salo, 1992; 1993). For this reason, the parents expected professional, factual information concerning, among other things, their child's chances of survival, what the disability meant and what they should do as parents. In many cases, the initial information they received was purely medical, and the parents did not expect much else since the informing professional was usually the doctor. However, the parents felt the there were several questions left: How do we cope with daily routines? What are the implications of the disability in our daily life? What kind of help is available for our family?

After the child's disability has been detected, the parents face new developmental functions. Mitchell (1985, 144-145) lists, among others, the following: getting acquainted with other families with disabled children; finding information about various forms of support and using available services; establishing contacts with various professionals; coping with the reactions of the society; learning about the rights of the disabled and their families, and finding a balance in the family and as an individual;

creating suitable conditions in order to promote the development of the disabled child, and learning daily rehabilitation and care routines.

It is important to note that after the beginning stages, the parents' hopes concerning information and support changed. Medical information about the child's condition was not considered as important as in the beginning. Information about available services, benefits (rights) and financial support became more important. Information was also needed about the child's development, upbringing and schooling. It was also important for the parents to be able to get away from daily routines and therefore two thirds of the informants considered it essential to find temporary care. (Virpiranta-Salo, 1993.)

The parents' informational needs underwent further changes as the child grew. In the beginning stages, the need for medical information concerning the child's disability was pronounced. However, there was a constant need for concrete advice on how to care for and bring up their child from the outset. Furthermore, information about social benefits and services was considered as important. Many of the parents regarded peer support - getting acquainted with other families with disabled children - as important, since sharing the experiences of other families in a similar situation gave support in many ways. As the parents' needs changed, the differences in mothers' and fathers' opinions became pronounced, particularly concerning discussing their feelings and exchanging experiences with other families: mothers considered these far more important than fathers. Another mother or father who had gone through similar experiences was considered a good confidante. In addition, seeing other parents and children with similar disabilities as their own child's helped the parents to see the child's ability to thrive despite their disability. (Virpiranta-Salo, 1992; 1993.)

Other parents can give better information concerning disabilities than official organizations or professional helpers. It is interesting to note that through the years parents become experts on their child's disability, and they possess a wealth of knowledge about their child - they often have more knowledge than any professional working with the child could ever have.

4 THE IMPORTANCE OF ESTABLISHING INTERACTION AND ATTACHMENT

It is important for the child's development that a parent-child attachment emerges early on. The child's later socialization is based on this relationship (Stern, 1985). The child possesses a biological readiness for interaction and attachment, if the parent creates a framework within which this can take place. Studies concerning neonates show three different factors affecting interaction. Firstly, newborn infants react particularly to human characteristics (Stern, 1977; 1985; Murray, 1988); the child's most active interest is geared towards the human face (Field & Fox, 1985; Field, Woodson, Greenberg, & Cohen, 1982); and the child possesses a readiness to react particularly to human voice (Eimas, 1985). Secondly, newborns have been found able to interact, since they are able to form facial expressions corresponding to those of adults (Trevarthen, 1979). Thirdly, newborns quickly become used to and develop an affection for the characteristics of the person who regularly cares for them. In other words, the newborn recognizes the mother's face soon after birth (Field & Fox, 1985) and the mother's voice within 1-2 days (De Casper & Fifer, 1980). At the age of 5-6 days the child can distinguish the smell of his or her mother's breastmilk from other breastmilk (McFarlane, 1975). According to Stern (1985), early interaction is greatly influenced by the child's observations and his or her comparative evaluations of them as well as by his ability to quickly recognize features.

These empirically verified factors can be realized when the parent is allowed to take care of the infant immediately after birth. The situation changes when premature birth, illness or disability requiring intensive care delays the emergence of an interactive relationship. The delay may be caused by the child's physical condition, conditions in the care environment, or the parent's feeling of helplessness when the need for medical attention surpasses the parent's needs.

In addition to the above, other factors influencing mother-child interaction are the mother's previous experiences of small children and her own childhood experiences (e.g., Hall, Pawlby, & Wolkind, 1980). Stress during pregnancy and factors concerning delivery have also been found to have an impact (e.g., Richards 1978). A few mothers reported having difficulties accepting that their child was alive after birth when having been told that the child would die. The mothers had already gone through a period of mourning and "buried" their child, therefore having to start over and relive the fear of losing the child.

In conclusion, both premature birth and disability delay the emergence of interaction. The child is not ready to or is hindered by a disability from responding to the parent's attempts to establish contact. Many parent of preterm infants reported little or no eye contact or other response to their attempts during the intensive care phase. The time the parents were able to spend with the child was also limited. Interaction increased after the initial crisis in the hospital and especially after the discharge of the child, when the parents were able to be with the child constantly. The Fathers reported increased interaction through play and communication as the child grew.

Based on his interaction research, Bowlby (1951, 1969, 1988) introduced the concept of 'attachment' in the early mother-infant interaction. According to Bowlby, human attachment has a biological foundation, and mothers are genetically programmed to react appropriately to the child's born key signals. Bowlby (1969, 1988) considered the emergence of attachment crucial for the child's well-being and development. Therefore, separation from the mother would create psychopathologies. However, oversimplified interpretations of the significance of mother deprivation have been justly criticized (e.g., Rutter, 1990). Furthermore, it is not only children who suffer when separated from their parents: the separation also causes pain and concern for the parents (Bretherton, Biringen, Ridgeway, Maslin, & Sherman, 1986).

In my studies I found that the parents' experiences of the premature or disabled infant and their impact on the emergence of attachment varied. The mothers found a basis for attachment in the physical experience of the child during pregnancy. Some mothers felt the existence of an "emotional umbilical cord" between the infants and themselves. They reported immediate feelings of love towards the child. Others considered the child a stranger and it took days or even weeks before they had similar feelings. Furthermore, if there was a danger of losing the child, some mothers did not let themselves feel attached to the infant. In these cases, the mothers felt the child was the hospital's more than their own.

These findings are consistent with the concept of "bonding" introduced by Klaus and Kennel (1977) and Richards (1979) to describe the crucial early interaction. One may assume that the immediate feelings of love by mothers are manifestations of bonding. Some mothers establish emotional ties to their children during pregnancy and these ties are strengthened after the child is born. In some cases the emergence of an emotional tie is delayed because of the mother's personality or the situation. The fathers often declared that "of course I felt that the baby was ours right away", but they did not mention attachment or love until later, after getting acquainted with the child. After discharge from hospital, the parents had a tremendous need to substitute lost time, and during the first days and weeks the infants were held almost constantly. Both parents described attachment as a growing feeling. (Virpiranta-Salo, 1992.)

5 PARENTHOOD NEEDS SUPPORT

Families with premature or disabled infants often need outside support in their new situation. Emotional support is important as well. All parents with premature infants and some parents of disabled children or children with long-term illnesses must spend long periods of time in the hospital with the child. If there are other children in the family, a baby-sitter is needed. If there are no grandparents or friends to share the experience with, the family may need professional help. According to recent studies, appropriate forms of social support have a great importance for the family's survival and its ability to support the child's development (Dunst & Trivette, 1990).

In our studies concerning families with premature or disabled infants (Kyllönen, 1993; Virpiranta-Salo, 1992; 1993) both mothers and fathers considered their spouses their best support both during pregnancy and after childbirth. Many mothers, but few fathers, also had friends with whom they could share the experience. Parents need someone to listen and understand when they talk about the child and their feelings. This is a way they can cope with the hospital phase, learn about premature birth or the child's disability, and find ways to organize the family's life so that everybody's needs are taken into account.

Particularly American studies (e.g., Bromwich, 1981; Jordan, Gallagher, Huntinger, & Karnes, 1988) have clearly shown the importance of early, appropriate support for both parenthood and the positive development of the child. The need for support begins in the hospital. Social support should not be offered as a generic package; it should be individualized, geared towards the particular family's needs, taking into account other forms of support the family might be getting (i.e., unofficial support). Both parents should also be considered equal partners when planning and organizing the child's care and rehabilitation (Ferguson & Ferguson, 1987, 379-380). Training parents to be sensitive towards the child has been found to be more effective for the positive development of the child than merely training them to develop the child's physical skills (Affleck, Tennen, & Rowe, 1991; Barrera, Kitching, Cunningham, Doucet, & Rosenbaum, 1990). Training is also more efficient when done at home, which is the natural environment for both the child and the parents (Beckman & Pokorni, 1988).

The parents who participated in the studies concerning the families of preterm or disabled infants pointed out the significance of parental support groups (Virpiranta-Salo, 1992). There had been no organized groups, but the parents had met in the hospital, during visits to the clinic, and during classes organized to inform the parents about the child's disability or illness. The parents considered communication with other parents who had been through a similar experience very important. In addition to sharing their experiences, the parents shared tips and advice for daily life and for using the support and services offered by society.

It was discovered that life in all families with children is largely similar. The families might have problems with upbringing, day care, illness or finances. The joys are also similar, including enjoying time together, following the child's development, and having joint hobbies. However, families with disabled children have problems other families do not have. There are continuous practical problems concerning the child's care and rehabilitation. The greatest practical problems in families with preterm infants without disabilities or illness occur during the first months or the first year.

6 THROUGH INITIAL PROBLEMS TOWARDS LIFE CONTROL

Life control is a global process in which perceptions and evaluations are joined with emotions and either motivate action or suffocate attempts (Brandstädter, 1989). According to Brandstädter (1984), challenges, crises, transitions, losses and achievements are examples of situations in life during which the individual's assessment of his situation and his actions and goal setting are crucial for his survival.

One of the most important findings in my studies (Virpiranta-Salo, 1992; 1993) was the parents' need to control their lives. For example, the parents of preterm infants felt relieved after the hospital phase and the child's discharge, because at home they were able to care for the child themselves, without professional supervision. The parents of disabled infants wanted information about the child's development, schooling and upbringing to be able to better care for the child. Spouses considered each other to be their best supporter and listener, and the exceptional condition of the child was reported to strengthen their mutual relationship. The most important sources of strength for the parents were the disabled or premature child, the family's other children, and the marital relationship. The parents wanted and used services offered by society, but professional support was not considered as important as mutual support within the family.

As reported by the parents, factors promoting life control concerned the disabled child: feeling positive about the child; the family's emotional growth through the child; the positive impact the child had on its environment; survival of the initial problems; and getting used to the disability and the consequent normalization of life (Virpiranta-Salo 1993).

There were several factors, both internal and external, that negatively affected the achievement of life control in the families of disabled children. Firstly, internal factors included things like the physically demanding care of the child; concern for the siblings of the child; negative change of life; and the fact that the disability hindered normal life. Secondly, external factors included things that could be changed by concrete actions or education by society. These included the lack of social support, support persons, and temporary care; the problems of single parenthood; the lack of emotional support, rehabilitation and equipment; denial by the community and the underestimation of the parents and the child. (Virpiranta-Salo, 1993).

Parents feel in control of their lives when they feel that they are able to handle the needs and situations they encounter as parents and that they can control events in their lives.

7 CONCLUSION

The parents who participated in my studies (Virpiranta-Salo, 1992, 1993), concluded that parenthood consisted of responsibility, care and emotions. Parenting was coping with daily life with its problems and tasks. This was influenced by the child's personality and needs. Parenthood changes and develops as to its functions, but the basic requirements stay unchanged. The disability or premature birth of a child requires the parents to have special skills.

Premature birth affects especially the initial stages of parenthood, since the parents must live with the fear of losing their child, sometimes for a long time. The long hospitalization of disabled or preterm infants affects the emergence of interaction and attachment. It is essential that the parents be allowed to participate in the care of their child.

The disability of a child, on the other hand, affects the reality of parenting throughout the childhood, because the special needs including communication and handling the child must be taken into account every day. It is crucial for parenthood that the parent-child interaction works, since it is the basis for the child's development and socialization. A common need for the parents with exceptional children is the need for support, be it informational, emotional or financial. The common goal of these families and parents is to be able to control their lives. Premature birth or the disability or illness of a child may rock the harmony of the family, but once the facts are known and the family feels in control of them, life continues with a new harmony.

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Chapter 8

CRITICAL FACTORS IN SPEECH AND LANGUAGE DEVELOPMENT OF SMALL PRETERM INFANTS

Annikki Riitesuo

1 INTRODUCTION

Sameroff and Chandler (1975) proposed the transactional model, in which environmental and social factors predict neurological outcomes of low birth weight infants rather than perinatal complications. This model is now well known also in neonatal intensive care units (NICU) and it has influenced the emergence of a new subdiscipline: environmental and developmental neonatology (Wolke, 1987). Development is conceptualized in this model as a continuous process of adaptation of internal and external systems. The internal system is the physiological and behavioral organization of the infant. The external system refers to the various aspects of the physical and caretaking environment. (Wolke, 1987.)

The development of the term infant is thought to happen by itself and, for instance, the development of speech and language does not need any extra support. The situation is different with a preterm infant and he or she needs support right from the start in a NICU. An interactive atmosphere and the teaching of feeding skills there, may both have influence on the subsequent language and speech skills of preterm infants. Early interactions provide a foundation for the development of the infant's communication patterns (Field, 1977) and in the development of feeding skills, for instance, a parallel development occurs in the movements and processes considered necessary for speech production (Morris & Klein, 1987). I will describe in this article the concepts of these internal and external systems, some special questions in assessment, the development and special problems in speech and language skills, and, finally, my own follow-up study and preliminary results of the development of speech and language skills of small preterm infants during the first two years of life.

2 THE INTERNAL AND EXTERNAL SYSTEMS OF SMALL PRETERM INFANTS

The internal system is the physiological and behavioral organization of the infant (Wolke, 1987). Als, Lester, Tronick and Brazelton (1982) proposed the synactive model of infant behavioral organization in order to explain the way in which newborn infants, specifically premature infants, interact with their extra-uterine environment. These authors propose that newborn infants interact with the environment through five behavioral subsystems: physiological (autonomic), motor, state, attentional and self-regulation, which in turn interact with each other (synactive development). Infants, who are born before term, often lack maturity and stability in part or all of the subsystems and are unable to coordinate the systems to interact appropriately with the environment. The model describes a series of typical behaviors displayed by neonates. These behaviors serve as cues to caregivers and parents who may assess the infant's responses through these cues in interactional situations.

Premature infants develop the ability to interact socially as their nervous system matures (Vergara, 1993, 63). Gorski, Davidson, and Brazelton (1979) termed this process as a neurosocial behavioral development. According to the authors, premature infants progress through three developmental stages before they gain the necessary stability in the subsystems to interact effectively. The stages that have been identified are turning in, coming out, and reciprocity. Social interaction should be avoided with infants who are still in the turning-in stage (infants under 32 weeks of post-conceptional age), because their energies are focused on achieving physiological stability. In this stage we can influence the environment and support the family. Infants in the coming-out stage (between 32 and 35 weeks of post-conceptional age) can tolerate monitored social interaction, but caregivers must respect the infant's physiological stress signals and schedule interaction interventions around the infant's best periods. At the final stage of reciprocity (older than 36 weeks of post-conceptional age) infants are ready for, and have a good tolerance for social interaction.

The external system refers to the various aspects of the physical and caretaking environment. Development is progressing well if there is a good fit between the physical and caretaking environment and the behavioral organization, at each point of time of the evolving systems. However, development may be deviant if the fit between the external and internal system is unsatisfactory. Fortunately, due to the plasticity of the central nervous system and the adaptability of the infant's internal system, the infant can deal with a number of reproductive or environmental hazards. (Wolke, 1987.)

NICU-environments have been improved by reducing pain, distress and other harmful conditions (noise pollution, light exposure, unclear day-night cycle), that may have adverse short- and long-term effects on infants. It has been thought, that the infants in special care are understimulated or overstimulated, or, that they suffer from inappropriate patterns of stimulation (Wolke, 1987). For this reason, the preterm infants are offered different therapeutic experiences in the form of water mattresses, "nesting", massage, music or other auditory stimulation (mother's heart beat or voice), tactile, smell, and taste stimulation and opportunities to suck during and between gavage feedings (Als, 1986).

Miller & Holditch-Davis (1992) studied preterm infants when the parents were incorporated in the process of evaluating the behavior of their preterm infant in order to learn to know their child and interpret his or her cues. Results showed that nurses and parents provided different stimulation: nurses were more likely to engage in procedural care and parents more likely to hold, talk to, move, and touch the infants affectionately. Infants did more sleep-wake transitions, larger body movements, and jitters when with nurses, and more active sleep and smiles with parents. It is believed that through changes in the physical and caretaking environment we could decrease preterm infants' most common subtle problems: language disorders, behavioral problems (hyperactivity and attention disorders), poor visual-motor integration, and deficits in spatial relations (Als et al., 1986; Aylward, Pfeiffer, Wright, & Verhulst, 1989; Lawhon & Melzar, 1988; Wolke, 1987).

3 SPECIAL QUESTIONS IN ASSESSMENT

The Brazelton Scale (1973, 1984) is the basis for many scales which measure the development of the behavioral organization of preterm infants (e.g., Als et al., 1982; Als, 1986). According to a literature review by Aylward et al. (1989), the Bayley Scales of Infant Development (1969) was the most frequently used assessment instrument outside hospitals. The test is, however, standardized for term, healthy infants, and it does not pay attention to preterm infants' problems. Vietze (1988, 403) writes, that traditional tests are based on estimations whether the infant passes or fails items. None of them measure mental processing or learning processing. Similarly, none of them are specialized in testing disabled infants or those at risk of developmental disabilities or otherwise having mental or physical impairments. Skill-area estimations should clearly specify the different developmental areas and focus on the research separately on the motor and language skills of low birth weight infants (Mazer, Piper, & Ramsay, 1988). Zelazo (1989, 94) points out that test developers have put too little effort in to being able to distinguish verbal and physical expressiveness from central processing ability. During the first 1½ years, the majority of items on the Bayley Scales of Mental Development require age appropriate neuromotor facility either directly as neuromotor items ("reaches for a dangling ring") or indirectly as measures of imitation ("pushes car") and language comprehension ("points to shoes"). Moreover, throughout the first 30 months, a child's success in conventional tests requires his or her cooperation with a stranger and unfamiliar examiner. Difficulties in development (e.g., neuromotor facility, expressive language, or compliance with the examiner's requests) affects performance and may cause an underestimation of mental ability. This unidirectional error with the assessment of mental development may lower parents' expectations and also the child's performance.

For the reasons mentioned above, we ought to measure underlying learning processes. In this process-oriented research, focus has been on visual attention and habituation to novel stimuli; that is, the infant's ability to encode, extract and retain information, and visual preferences (Fagan, Singer, Montie, & Shepherd, 1986; Kopp & Vaughn, 1982; Landry & Chapieski, 1988; Lewis & Brooks-Gunn, 1981; Rose, 1983; Sigman, Cohen, & Forsythe, 1981; Sigman & Parmelee, 1974) and on auditory processes (Fox & Lewis, 1983; Kurtzberg, Stapells, & Wallace, 1988; Wallace, Escalona, McCarton-Daum, & Vaughan, 1982). Early infant measurements of perceptual and sensory functions have been found to differentiate between at-risk preterms and low risk full-terms during the first year of life (Lukeman & Melvin, 1993). In the information processing system, it is possible to bypass the traditional mind-body dichotomy that vitiates many studies of prematurity. Comparative studies consistently show lower neurological maturation in preterm than in fullterm neonates. Therefore, the formers' competence must be assessed by realistic parameters and take into account this limitation. Preterms' sensorimotor deficits are related to cognitive and interactional deficits, which should be studied by using a multidimensional approach. (Manfredi & Poropat, 1987.) In contrast to traditional measures of intellectual ability, the habituation - dishabituation paradigm requires a minimum amount of movement and no communicative ability (McDonough, 1988). As mentioned earlier, research should focus on preterm infants' underlying learning processes, language, visual-motor integration and visual-spatial relations and behavioral problems (attention and hyperactivity) (Astbury, Orgill, Bajuk, & Yu, 1983; Aylward et al., 1989; Calame et al., 1986; Lukeman & Melvin, 1993). While using process-oriented testing, it is possible to start interventions earlier and to carry out more specific therapy procedures (Fagan, 1988; Manfredi & Poropat, 1987; Lukeman & Melvin, 1993; Ruff, 1988; Zelazo, 1989).

It has been shown, that the development of preterm and fullterm infant is equivalent if the appropriate age correction is made. There is not, however, complete consensus whether correction for prematurity should be used or not, and what its degree would be. Siegel (1983) states, that the use of correction may be appropriate in the early months, because then, the degree of maturity has most influence on test results. According to the latest research (Blasco, 1989; Lems, Hopkins, & Samsom, 1993), mental and motor functions should always be kept separate and use full or partial (e.g., half) correction. Full correction should be used in the assessment of mental development of relatively healthy preterm infants during the second half of the first year, but for the motor development during the same period a partial correction would seem to be more appropriate (Lems et al., 1993). Blasco (1989) states, that after six months of age, partial or no correction for language and partial correction for visual-motor skills seems to be the most appropriate strategy. Both corrected and uncorrected ages should be used when assessing first-year development, especially in very premature children (Matilainen, 1987). It has been argued, that the use of corrected scores should occur up to 2 years of age or even into middle childhood (Aylward, 1988; Aylward et al., 1989). Correction for prematurity may place children in a "healthy" group too early and may prevent an identification of children at risk from later problems and as a result intervention starts too late (Lems et al., 1993; Lukeman & Melvin, 1993). The question of age correction is rather complicated and it can hardly explain alone the development of preterm infants, because they are introduced into an environment for which they are poorly adapted (DiPietro & Allen, 1991).

4 PROBLEMS IN THE SPEECH AND LANGUAGE DEVELOPMENT OF SMALL PRETERM INFANTS

The development of language, especially expressive language of preterm infants, seems to be delayed during the first two years of life. Preterm infants vocalize less during the first year of life and their vocalizing is monotonous (Mielo, 1994; Ross, 1985; Sajaniemi, 1990), they increase their non-distress vocalization later (Beckwith, Sigman, Cohen, & Parmelee, 1977), and produce less two-syllable babbling (Eilers et al., 1993; Jensen, Boggild-Andersen, Schmidt, Ankerhus, & Hansen, 1988) or show a tendency to produce well-formed syllables less consistently (Oller, Eilers, Steffens, Lynch, & Urbano, 1994) than full term infants do.

It has been shown, that at two years of age, preterm infants use verbalizations and gestures less frequently to express themselves (Landry, Schmidt, & Richardson, 1989), have a smaller vocabulary, less verbs and a shorter mean length of utterance (Seidman, Allen, & Wasserman, 1986) than full terms do. Besides the problems of expressive language, there may also be delays in verbal comprehension and symbolic development at two years of age (Cohen, Parmelee, Sigman, & Beckwith, 1988; Hubatch, Johnson, Kistler, Burns, & Moneka, 1985; Piekkala, 1988) and further at three years of age (Craig, Evans, Meisels, & Plunkett, 1991), four years of age (Forslund & Bjerre, 1990) and at five year of age (Herrgård, 1993).

Certain conditions and illnesses seem to be related to delayed speech and language development. Birth weight is known to be related to developmental outcomes and may greatly influence the reported test scores. The birth weight may vary from 500 g to 1500 g, but in both cases the same label can be used: a very low birth weight (VLBW). (Mazer et al., 1988.) The AGA-SGA problem (AGA = birth weight appropriate for gestational age, SGA = birth weight small for gestational age) also underscores the erroneous tendency to view low birth weight groups in a homogenous fashion (Aylward, Pfeiffer, Wright, & Verhulst, 1989). Towen (1986) suggests that VLBW infants should be grouped into three categories: (1) extremely premature babies (gestational age) with AGA birth weights, (2) less premature babies with SGA birth weights, and (3) older preterm and term infants with extreme SGA birth weights.

Preterm infants' speech and language development has been studied from the viewpoint of VLBW and growth retardation. Speech and language development in preterm infants born below 1000 g birth weight has been found to be delayed while no neurological problems were identified (Menyuk, Liebergott, Schultz, & Chesnick, 1991; Portnoy, Callias, Wolke, & Gamsu, 1988). The research results (Matilainen, Heinonen, & Siren-Tiusanen, 1988; Martikainen, 1992) have indicated the connection between the SGA-condition and delayed speech and language development, but in some of the studies the relationship was not confirmed (Siegel et al., 1982; Vohr, Garcia-Coll, & Oh, 1988; 1989). In the cases, when AGA-preterms got poorer scores, the explanation was poor socio-economic status (SES) (Vohr et al., 1988; 1989) or perinatal situation (need for longer mechanical ventilation, more incidences of birth asphyxia and apnea) (Siegel et al., 1982).

Intraventricular hemorrhage was related to preterm infants' delayed speech and language development and, especially, to their expressive language delay (Bendersky & Lewis, 1990; Byers-Brown, Bendersky, & Chapman, 1986; Grunau, Kearney, & Whitfield, 1990; Janowsky & Nass, 1987; Ross, Lipper, & Auld, 1987). The outcome of a cerebral injury seems to depend on the type, the size, location of the lesion, and, to some extent, on the neuroplasticity of the developing brain. Preterm infants with small hemorrhages had a good outcome and developed as well as infants without any observed changes in ultra sound screening (Fawer, Calame, & Furrer, 1985.) Furthermore, lung diseases (Hubatch et al., 1985; Meisels, Plunkett, Pasick, Stiefel, & Roloff, 1987; Zarin-Ackerman, Lewis, & Driscoll, 1977) and chronic otitis media (Kenworthy, Bess, Stahlman, & Lindström, 1987; Pearce, Saunders, Creighton, & Sauve, 1988; Vohr et al., 1989) delay the speech and language development of preterm infants.

There are also studies that have found no differences between preterm and term infants' speech and language development. For instance, no differences were found between term and preterm infants in their phonological development and in the size of vocabulary when using either corrected or uncorrected ages or when comparing infants on the basis of risk factors (e.g., low birth weight, intraventricular hemorrhage, lung disease, chronic otitis media and socio-economic status). However, comparisons of the extremely low birth weight infants (ELBW) with term infants indicated that there was a significant difference between the two groups (Menyuk, Liebergott, & Schultz 1986; Menyuk et al., 1991.) Siegel et al., (1982) noticed that differences between term and preterm groups disappeared when using corrected scores at the age of two. It seems, that the differences, which can be seen in the beginning, will disappear along with time (Greenberg & Crnic, 1988; Mazer et al., 1988; Ungerer & Sigman, 1983).

Eilers et al. (1993) found that, at corrected ages, the preterm infants appeared to begin canonical babbling earlier than their fullterm counterparts. It is also suggested, that preterm infants may understand more language because they have been exposed to language for more weeks than full term infants (Stevenson, Roach, Leavitt, Miller, & Chapman, 1988). The good interactional milieu at home, especially the quality of mother-child relationship (Beckwith et al., 1977; Crnic, Ragozin, Greenberg, Robinson, & Basham, 1983; Dale, Greenberg, & Crnic, 1987; LeBlanc, 1989, Morisset, Barnard, Greenberg, Booth, & Spieker, 1990; Rocissano & Yatchmink, 1983; Stevenson et al., 1990), and socio-economic status (Largo, Molinari, Comenale Pinto, Weber, & Duc, 1986; Largo et al., 1989; Stevenson, Roach, Leavitt, Miller, & Chapman, 1988; Vohr et al., 1988; 1989) has been shown to be related to the advanced speech and language development of preterm infants.

5 RESEARCH PROJECT: "SPEECH AND LANGUAGE DEVELOPMENT OF SMALL PRETERM INFANTS"

As shown earlier, preterm infants' speech and language development has received much attention from researchers, but very intensive and early started follow-ups are lacking. I try partially to fulfill the gap through my own study (in progress), in which I have applied an ecological viewpoint in addition to traditional scale-based evaluations. The ecological viewpoint means here, that the children were assessed at home and the parents acted as evaluators concerning their childrens' development. My hypothesis was that through a very intensive follow-up it may be possible to indicate different and, perhaps, new risk-factors in speech and language development earlier than in previous studies. I will next describe briefly the design of the study and some preliminary findings.

Procedure. I followed the development of small preterm infants from birth up to the corrected age of two years. The study included 24 infants (13 girls and 11 boys) from different hospital districts in Finland (Helsinki, Jyväskylä, Oulu). Criteria for entering the study was the infant's gestational age 33 week or less and a very low birth weight <1500 g. The smallest child weighed 530 g, and 14 children weighed less than 1000 g at birth. Families participated in this study voluntarily.

The children in an intensive follow-up group (N=9) were visited monthly during the first year and every two months during the second year. The rest (N=15) were visited during the two year period 4-7 times at their corrected ages as follows: 0 - 2, 9, 18, and 24 months. The data were completed by telephone interviews at 12, 16 and 20 months of age.

The data consist of videotaped children's behavior and parents' interviews. Special focus was put on oral-motor development (for instance feeding was videotaped during every home visit) and infants' cross and fine motor developmental milestones were checked. In addition, verbal comprehension and infants' interactional skills were estimated. The following tests were used: The Bayley Scales of Infant Development (1969), Piagetian-Based Sensorimotor Assessment Scale (Uzgiris & Hunt, 1975), The Receptive-Expressive Emergent Language Scale (Bzoch & League, 1971), The Reynell Developmental Language Scale (1985), Infant/Child Monitoring Questionnaire (Squires, Bricker, Potter, 1990). I wrote after every home visit (N=214) a fieldnote about my observations. Also hospital documents of the children were available. Data collection was started in spring 1991 and was completed in early summer 1994.

Preliminary results. Findings indicate, that small preterm infants had problems especially in their expressive language skills. They were "silent" children whose vocal imitation was scarce (Riitesuo, 1993) and who increased their non-distress vocalization late (see Mielo, 1994). They produced well-formed syllables less consistently (see Oller et al., 1994) and seemed to compensate for vocalizational limits with gestures, or, with other behaviors - in a positive or negative way. Longer expressions were difficult and they often produced only the first or last syllable of the word during the one-word-stage in speech production. Some of the children showed difficulties in attentional skills and it was difficult to assess their real comprehension level by using the traditional tests.

In sensorimotor development at the age of four and nine months the preterm infants without major disabilities (e.g., CP) performed well according to the standards of the piagetian scale when using corrected ages (Riitesuo, 1993). Cross motor disabilities and difficulties in working with hands in midline were childrens' most common problems. Four of the children were diagnosed to have CP, and one of them also had visual damage. Many of the children had transient motor problems.

The most noteworthy result, gained so far, is that, during the first months of life, children's development is approximate to the corrected age, but when children are approaching the first year in life, their development already comes closer to the chronological age if they do not have major disabilities.

6 CONCLUSION

I agree with Lester (1988, 115) that with the increasing survival rate of high-risk infants there is a growing concern over the early detection of those infants who are most likely headed for adverse developmental outcomes; for example, learning disabilities. We know that preterm infants are at risk, and, on the basis of research, it is possible to predict language development at school age by assessments during the first two years of life (Cohen et al., 1988; Largo, Graf, Gundu, Hunziker, & Molinari, 1990; McDonald, Sigman, & Ungerer, 1989; Siegel, 1992). For this reason, we need to follow the development of preterm infants carefully and start interventions as early as possible when the infant's nervous system is more plastic and can accommodate change. Early identification is also crucial, because it provides feedback to the parents who are often aware of the child's deficit (e.g., an unusual cry) long before it can be confirmed medically.

Today we lack reliable, easy-to-use assessment tools for detecting infants at risk at the early stage. Especially, information processing tests are needed in order to be able to bypass a classic body-mind dichotomy. In the assessments of my own study, I applied the ecological viewpoint, in other words, the children were assessed in their own environment and also the parents were interviewed. For several reasons, it is advantageous to use parents as experts. Squires, Nickel and Bricker (1990) state that parents possess information often unavailable to professionals and, on the other hand, parents may increase their knowledge about child development and increase participation in their children's intervention program. It has been shown, that the parents presence during the administration of infant assessment and their participation in the child's rehabilitation as program realizers have positive developmental effects (e.g., Constantinou & Korner, 1993; Katona, 1988).

Ecological assessment techniques include informal observational methods as well as formal checklist approaches (Thurman & Widerstrom, 1990, 206), and a child is valued as an active partner rather than an object in the testing (Fewell, 1991). I have used also standardized tests (i.e., Bayley and Reynell) and so it will be possible to compare parent- and researcher-oriented approaches. I believe, on the basis of several visits of children's homes, that when assessing infants in their own environments, test results are more reliable than assessments in laboratory settings. Whether to use corrected ages or not, is a very difficult question, and perhaps it would be wise to use both uncorrected and corrected scores at least during the first year of life and keep mental and motor scores separate (see Matilainen, 1987).

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Chapter 9

COMMUNICATION IN HEALTH CARE OF PRETERM CHILDREN: PARENTS' PERSPECTIVE

Tuula Laukkanen

1 PARENTS AS COMMUNICATORS: THE HIGH DESIRE FOR INFORMATION

One of the basic problems in families with at-risk children[1] appears to be the relationship with health care professionals (e.g., Lynch & Staloch, 1988; Nursey, Rohde, & Farmer, 1991). Criticism has been focused on communication, but also at professionals' attitudes and manners. Communication of physicians seems to include more elements of power than partnership (Fisher, 1984; 1991) in their work with families.

As a social phenomenon, medical power seems to cover all those problems which are seen as curable in medical care (Tuomainen, Myllykangas, & Elo, 1994). Issues, which have not been possible in an earlier health promotion, have become a part of the new reality because of the technological progress with the increased expectations for medicine and physicians. Many of the extremely low birthweight (ELBW) infants are nowadays alive, not only due to the mercy of God, but as a gift of technology. The future of the child extends from an hour, at first, then into a day. If he or she survives, the further follow-up will be intensive.

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[1] Infants who experience any type of prenatal, perinatal, or postnatal risk or who have a family history of risk are generally labelled "at risk," whereas infants who have to be managed in Neonatal Intensive Care Unit (NICU) after birth are frequently labelled "high risk" (Vergara, 1993, 19).

Besides, the parent-child interaction presumes very intensive parent-professional interaction.

The first important factor in the preterm child's situation which enhances the need for effective parent-professional interaction is the unstable medical state of the infant. Approximately, every third seriously-ill child below 1 500 grams, will not survive despite neonatal care (Järvenpää, 1981; Similä, Vähäsarja, & Koivisto, 1988). The risk of dying and becoming disabled is the highest with ELBW infants: for instance, the mortality of infants below 750 grams is about 70%, and nearly half of the survivors will have serious complications (Raivio, 1987). The need for medical care of ELBW infants is especially obvious when comparing them with full-term children (Lewry & Wailoo, 1985; Similä et al., 1988).

Secondly, the NICU environment with all it's sounds, lights and equipment, is a strange place for parents, at first. Medical assessments and the care of the infant presumes that parents are able to adopt a lot of new information. Thirdly, even the child's development will exhibit problems more than normally, for example, the children have problems in feeding, and they have infections and injuries (Lloyd, Pursall, & Emery, 1981). Later, the development of the child will be followed in order to prevent or identify developmental problems.

2 PARENT - PROFESSIONAL INFORMATION EXCHANGE

In a doctor - patient relationship the information-exchange has been emphasized (e.g., Waitzkin, 1985; Ridderikhoff, 1993), possibly because of the adopted model of biomedical consultation. Despite that, the information has been supposed to be the ownership of the professionals, which includes a lot of power as well. Besides, medical knowledge with the skill of curing has required that a patient should listen to, sympathize and act in compliance with the doctor with those medical "gifts". However, the compliance with the doctors' orders has been indicated to be relatively low (Trostle, 1988).

When stressing the parents' perspective, the doctors have been especially criticized because they give the first news of the child's illness or disability in a manner that parents have not liked (Quine & Pahl, 1987; Cunningham, Morgan, & McGucken, 1984). Parents' hope that the doctor would be empathical and would listen to the parents' concerns, will not always come true (Sharp, Strauss, & Lorch, 1992). Besides, the parents have been dissatisfied with the doctor's talk of the child's illness, and they have had problems in understanding the information (Chenail et al., 1990).

The studies of communication in health care have analyzed a patient's role in the interaction from a rather narrow perspective; his or her principal task seems to be an evaluation of the professional's functioning, including (analyzing) communication with patients, by using patient satisfaction-scales (e.g., Waitzkin, 1984). Nevertheless, the communication context and the patients' experiences and ways of thinking as important determinants of the interaction, have not been problematized enough in the previous studies.

Summarizing the doctor - patient information studies, they seem to have three basic features. First, the flow of information has been interpreted as giving information from one person to another, but the qualities of information, such as, its meaning and usefulness, have not been analyzed properly. The doctors have been blamed because their knowledge was not forwarded to the patients properly who have not, in turn, expressed their wishes. Second, the information has easily been understood as "valuable professional knowledge", which was taken as more important than the knowledge based on personal experiences. Furthermore, the information has been only loosely tied to the interaction, although, the more fruitful perspective would be to see that the better interaction increase the information change.

3 PARENTS' VIEW OF THE INTERACTION

In my own study of parents with low (<2 500 grams) birthweight infants and their interaction with physicians (Laukkanen, ms.) the focus is on parents' experiences and point of view to their communication with doctors, as well as, the real parent-doctor interaction during the child's one-year follow-up. The health care communication context of each family and, furthermore, the context of each follow-up, was defined based on the gathered data. The purpose was to deepen the analysis by taking into account the situational elements in the interaction.

The study consisted of 23 families of preterm children in three central hospital districts. The parents were interviewed by telephone after they received an orientation paper for the interview. The observations were made during the childrens' follow-up visits to the doctors. Nearly all of them were observed by the researcher. The families were interviewed again three days after the consultations, and their experiences and the usefulness of the visit were put into question. The doctors were interviewed, if possible, immediately after the consultation.

The analysis of the study was made using qualitative content analysis and interpretative analyzing methods. The results, gained so far, deal with the health care contexts of the families. The results indicated, that the relationship between the professionals and families varied. The families put the meaning on the professionals' communication, especially according to the child's medical and developmental situation, but it was also important, how the communication worked between the spouses, and furthermore, between the family and other supporters.

Securers, Help-Seekers and the Parents Seeking for Something Else

Parents were divided in three types in their interactions between healthcare professionals. Parents in the first group were *securers*. These parents wanted to be sure, that everything with the child was OK. They trusted in their own perceptions of the child, but they also have learned, that the perceptions of professionals and their own may differ. According to the parents, it was sometimes possible, that the doctors gave too much attention, for instance, to the child's motor development, or the facts that the child welfare clinic had also checked. Usually the parents found the doctors' involvement with the child's situation as good, and their information clear. The image of the child was positive and the parents stressed their child's individuality as important when they communicate with the professionals. The parents found themselves active and eager to ask when communicating with professionals. Usually, the mother, rather than the father, consulted the doctor. It seems, that when the professionals were "satisfied with the child", the parents communicated with them more by telling positive things about the child. Communications were mostly between women, and seemed to go easily, if there was no evidence of problems expected to come out during the consultations.

The parents may have felt feel uncertainty and be disappointed after the consultation, if any problems with the child occurred. Especially, when the communication was found as negative. Moreover, in cases where the communication has went positively, the parents seemed to talk about the child's situation openly, although there could have been problems with the child. Their relationship with the professionals was found as good and easy. The parents described their relationship more in terms of the elements of good interaction, than with the elements of information exchange. Usually, the situation of the child was good. The parents concentrated on the present, but the future of the child was also a topic of conversation with the professionals.

The second group of parents was called *help-seekers*. They looked for practical help or meaningful information about the child's medical or developmental situation. Usually, both parents participated in the consultation situation, and their problem was something they had thought about before the meeting, or sometimes, the problem came out during the conversation. Usually these parents interpreted information during the consultation and asked more or "thought aloud". The searchers lived strongly in the present, whereas the help-seekers thought how the earlier periods, like the very early neonatal intensive care or the pregnancy, influenced the child's current situation.

The manner by which the parent described his or her own everyday life's functioning, was related to their descriptions of the co-operation with professionals. The parents' a goal was to make their relations with the doctors as co-operative and responsible as possible. The help-seekers seemed especially to communicate in an assertive way by asking questions and checking the given information when they consulted the professionals. These parents seemed to behave very co-operatively, too; they used a kind of "family-based" memory to remember important issues. Using that "memory-store", they found it more easy to communicate with the doctor together, rather than alone. The parents seemed to be conscious of their differences; in how they remember, experience and function with different things, which they sometimes openly announced during the conversations. These parents sat, in most cases, face to face and reacted to one anothers' nonverbal and verbal cues. Both parents expressed an active responsibility for the child in relation to the professionals and the spouse.

The presence of both parents in consultation did not always mean, that the mother and the father were as active in communicating with the professionals. The communication responsibility seemed to be shared by the way in which the family found useful; usually one of the parents took the child-care responsibility in the consulting situation. However, if the mother participated alone, then she usually looked after the child and communicated with the doctor at the same time. Sometimes, the child/children were taken care of by a (hospital's) nurse or a relative of the family during the conversation.

The third group's parents *sought for something else.* They had interpreted the information or practical support as in adequate or not suitable for their situation. The problem was not the lack of information, but rather its applicability to daily life. The families were not able to create meaningful ways to take care of the child or the parents needed practical help to manage. At the beginning first with the child at home, one of the parents, at least, had not got enough, emotional support or practical help to cope with the family life, for instance.

The situation of child, whose situation had been found as difficult, nowadays or earlier, may have a different meaning to the parents than to the professionals. In the family, the preterm child was taken as a family member, at first, and maybe as a sibling in interaction with other people outside the home, too. During the hospital visits, especially, if there is "nothing positive to say" about the child, the parents found, that the problems are central issues of the conversations.

In their relationship with professionals the parents stressed the importance of the professionals' involvement with the child's situation and the expertise of the doctors. However, the parents sought information actively and the means to function, not only from the health-care professionals but also from the other people, institutions, and libraries.

The daily workload in these families seemed to be high and they lived in the present because of the uncertainty regarding their child's future. The parents described their relationship with the professionals rather as something they have to do, not as something they like or want to do, for example, "we have to trust the doctors", "we have to go to the hospital". The parents were active in their interactions, but there seemed to be more stable elements of conflict or uncertainty in the relationships, than in the other family groups. Even the professionals named the elements of a "not so good relationship" between them and the parents.

In conclusion, it is important to note, that the type of the family's relationship with the professionals is not static. Changes with these parents even occurred when the parents encounter various professional practices and professionals, but also, when the parents became more conscious of the importance of their own active communication style.

The communication tasks varied even in the same consultation. The same family could use securing, help-seeking and seeking for something else in the consultation. Topics of conversation with some new, unclear or very important issues were repeated, if needed, as the other issues seemed to be less important. All of the families had features of securing and help seeking, but just a few of them looked for *meanings* and *something else* in consultations.

Summarizing the results, the parents experienced their first or new kind of parenthood and they created cooperation with the professionals. The parents seemed to "be forced" into behaving as active, assertive and able parents in the NICUs. Somehow, they found this "education" as good, because they "had to use" different kinds of professional practices in different hospitals and wards. The parents had also learned to function with the professionals in a way, which made it more necessary to increase the family-based cooperation in the health care of Finnish at-risk infants. After the child's hospital period the families had contact with the health-care professionals in follow-ups or care or rehabilitation periods. At best, good parent-professional interaction had improved family life. The hospital had become a place of strength giving for the parents, which prepared them to meet the challenges of daily life.

4 TOWARDS PARTNERSHIP

The positive side in the parents - professionals interactional problems could be, that parents usually have strength, ability and willingness to take responsibility and to be independent in family life. Sometimes, they do need some help from the professionals and other important people in their life. The families of preterm children are supposed to need especially empathic expertise from the health care professionals. The expertise could be reflected in a new way, not as the relation between science and practice (Eräsaari, 1993), but, in this case, as an interactional process between the parents (customs) and the professionals, seeking for resources in cooperation. Beck (1993) stresses the interaction between research and practice. He separates the traditional "institutional expertise" and "professional expertise", and also the kind of "expertise of daily living", in which scientific analysis and social reality all meet. The experts do not have a monopoly anymore, but they are qualified in their professions. In other words, expertise is seen as many-sided, complex, and reflective.

According to Eräsaari (1993), professional practice is a problem-solving process including choosing and decision-making. The conventional view of health care expertise seems to be quite one-sided from the families' perspective. In that kind of expertise, the able information-giver meets the customer, who is "limited" with his or her knowledge and skills. This kind of expertise maintains monotonous interaction, which, at the same time, continuously adds requirements in order to meet a very skilled professional.

The parents, of course, need the qualified doctors, but they seem to consult them, especially, to make sure, find meaning and safety for their lives through the information they get. Whether the professionals meet the needs of the families, or not, it is important to motivate the parents to cooperate, and to be able to evaluate the child's situation and need for care as far as they can. How profound the co-operation is depends on the seriousness of the child's situation, the parents' resources and the attitudes of both parties in cooperating.

On the basis of my study, doctors are trying to work more with the families, but they do not always know, how it could be done with the resources they have. Instead of interfering with the organizational issues in the hospitals, I will next present some communicational guidelines in how to support the parent-professional interaction during the NICU period. The first support is very important because of the families' new and unsure situation, and also later cooperation with professionals. The family-centered view could also be useful in solving problematic family - professional relationships.

Family-centeredness means, at first, the supported interaction of the parents with the child, professionals and relatives, friends and so on. The individuality of the parents and the need for honest and open interaction are considered. (Case-Smith, 1993, 241-245). The parents also need clear and useful information concerning the status of the child, the care equipments, and the medical assessments of the child. The parents could be helped to get a better knowledge of their child, which could be difficult to understand, at the beginning. All this presumes guiding and motivating the parents to take care of the infant as soon as it is possible.

Parents' acquaintance with the child presumes interaction with the professional care-givers of the child in NICU. The cooperation and involvement of the parents with the child-care could be improved by respectful, honest and clear communication, expressing understanding, making deals about the goals together, and sharing the planning, decision-making and evaluation of the progress. This also presumes the information flow from parents; at least an open and responsive attitude without blaming and labeling. (Bailey, 1991.)

The parents' involvement in their child's situation presumes a personal relationship with the child, and, the medical and developmental knowledge from the professionals. Parents differ in their ways of getting information and processing it. They are the best ones to control the amount and quality of information they need. If the parents do not ask questions, it does not always mean that everything is clear to them. At the beginning, it is difficult to ask, when you do not even know what to ask, because the things are unfamiliar. This is the time when a parent needs time, but also conversations with empathic professionals. It is possible for the parents to create the meanings, to make matters more clear and to get some concrete help.

It would also be useful for the parents to have conversations with other preterm childrens' families, who already have had experiences of the daily life with the child. However, it would also be helpful to get some kind of information about how to function with other "normal families", relatives, acquaintances and other people asking about the child. As a whole, the situation of the families with children with different needs would be much better known, if there were more literature available in, for instance, the basic health care units.

Follow-up services may not be offered for a sufficient length of time. They may also be focused on physical or general development issues or be determined by the availability of health care resources (Lukeman & Melvin, 1993). However, the parents' peace of mind is greatly dependent on the developmental and medical state of the child. If possible, the families may use health care and rehabilitation services for years. Despite all of these, they really need suitable services for the child and themselves. If the parent - professional relationship functions well it often has positive effects on the family life. The attitude towards the child should be positive, if not, the family will be continuously unsure of the child's needs and future (Redshaw, Rivers, & Rosenblatt, 1985; Cottrell & Summers, 1990). The reason is, in part, the insufficient or unclear information given to the parents.

The parents' functioning for their children has been found to have compensatory effects on the child's possible at-risk development (e.g., Landry, Chapieski, Richardson, Palmer, & Hall, 1990; Achenbach, Phares, Howell, Rauh, & Nurcombe, 1990). The parents should not be given strict criteria of the child's "proper" care (Lukeman & Melvin, 1993), because sometimes it is impossible for the parents to make them true because of, for instance, economical or family's inner problems, or because of the surroundings (Minde et al., 1989). Furthermore, the family's values and ways of functioning may differ from those of the professionals.

5 GOOD INTERACTION, NOT JUST INFORMATION EXCHANGE

The interpersonal information shift will be possible only when both the parents and the professionals aim to respect, trust and value each other. This kind of relationship presumes, that both participants are brave, open-minded and ready to cooperate. Also, the families can support the work for at-risk children by describing their experiences and expressing their opinions about professional practices. This is the way to develop cooperation, which is profoundly important, especially, when the child is at home already. At least, this is the time for parents to be responsible and enterprising with the child's developmental issues. In later meetings between the families and the professionals, the families' view should be evident even as the result of a few short consultations.

As a conclusion, it is good to note, that family life and ways of functioning differ between families and professionals. Hospital routines and family wishes are not always easy to combine. However, from the parents' point of view, the professionals' way of showing trust and sensitivity is the most important thing in early intervention (Summers et al., 1990). The family-oriented care, which stresses cooperation with parents and professionals, could create a positive relationship with the new family-member. It can also help the parents to trust themselves as caretakers of a child with different needs. In addition, the skills to interact with professionals will improve (Case-Smith, 1993).

Achieving good interaction and two-way information seems to be a continuing growth process for both parents and professionals. Those who take that challenge seem to think, that the barriers to cooperation are not "bad doctors" or "difficult parents", but just ordinary people with, for example, differing viewpoints. The paradox is, that achieving good interaction usually presumes communication, which may reveal, that "The Bad Dr. Livingstone, I presume" or "The Difficult Parent Butler, I presume" will not be the one supposed.

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Markku Leskinen (toim.)

FAMILY IN FOCUS. New perspectives on early childhood special education.

TIIVISTELMÄ

Tämän kirjan artikkelit kokoavat yhteen Monivammaisuus, perhe, lapsuus -tutkimusprojektin teoreettiset lähtökohdat ja tutkimusteemat. Projekti toimi Jyväskylän yliopiston erityispedagogiikan laitoksella vuodesta 1990 vuoteen 1993. Kaikki kirjoittajat ovat osallistuneet projektin työskentelyyn joko kouluttajina tai tutkijoina. Kirjan luvut tarkastelevat varhaisvuosien erityiskasvatukseen liittyviä kysymyksiä useista eri näkökulmista.

Thomas Weisner ja Ronald Gallimore (University of California, Los Angeles) esittelevät (luku 1) ekokulttuurisen teorian keskeiset periaatteet ja tarkastelevat sen soveltuvuutta käytäntöön. Dianne ja Philip Ferguson (University of Oregon, Eugene) selvittävät (luku 2) vanhempien ja ammatti-ihmisten välisen yhteistyön kysymyksiä. Marika Veisson, Aino Saar ja Ene Mägi (Tallinnan pedagoginen yliopisto) esittävät luvussa 3 alustavia tutkimustuloksia tutkimuksestaan vanhempien tuentarpeista Virossa sekä virolaiset 1990-luvulla perustetut tukijärjestöt.

Markku Leskinen ja Jaana Juvonen esittävät (luku 4) attribuutioteoreettisen mallin, jossa vanhempien vastuullisuustulkinnat ennustavat vammaiseen lapseen liitettyjä tunteita, jotka sitten ennustavat heidän sopeutumistaan. Iiris Mäki tarkastelee (luku 5) vaikeasti vammaisten lasten arviointiin liittyviä ongelmia ja selvittää ekologisen lähestymistavan soveltuvuutta varhaisessa tukemisessa. Marjo-Riitta Mattus tarkastelee (luku 6) erilaisia strategioita tukea perheitä (empowering mielessä). Hän pohtii erityisesti kysymystä, miten haastattelu voisi toimia perhettä tukevana menetelmänä.

Loput artikkeleista liittyvät pienten keskoslasten perheisiin ja keskosten kehitykseen. Maija Virpiranta-Salo selvittää (luku 7) vanhemmuuden kehittymistä tilanteessa, jossa perhe-elämä alkaa lapsen keskosuuden takia erityisolosuhteissa. Annikki Riitesuon artikkeli (luku 8) on kirjallisuuskatsaus keskosten puheen ja kielen kehitykseen liittyvistä kysymyksistä. Viimeisessä luvussa (luku 9) Tuula Laukkanen tarkastelee vanhempien ja ammatti-ihmisten välistä viestintää liittyen lapsen terveyteen.

Avainsanat: varhaisvuosien erityiskasvatus, ekokulttuurinen teoria, vanhempi - ammatti-ihminen yhteistyö, syytulkinnat, arviointi, täysivaltaistuminen (empowerment), vanhemmuus, puheen- ja kielen kehitys, viestintä, vanhemmat, vammaisuus, keskosuus.