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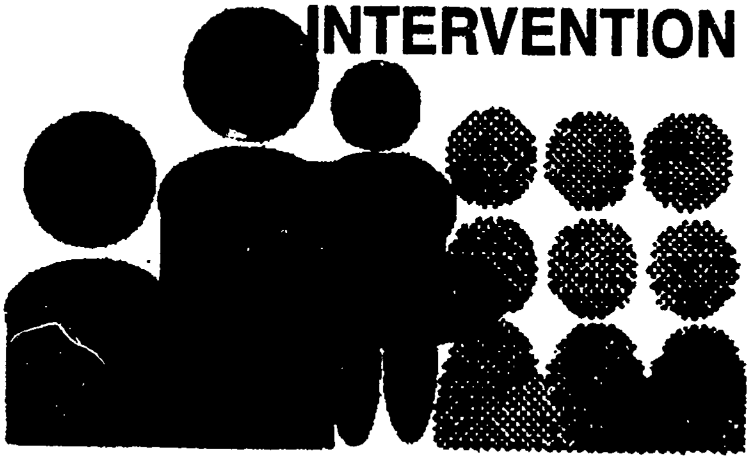
ABSTRACT

Project TIE (Teams in Early Intervention) was conceptualized to meet the need for: (1) involvement of formerly "ancillary" service professionals in early intervention for children with disabilities, (2) high quality family-centered services, and (3) training in the team approach. The project provides training to four groups that might constitute an early intervention team--speech/language pathologists, motor therapists, health care professionals, and family members. This training module emphasizes the importance of the family as the basis in delivering early intervention services. The first section, "Pathways to Teaming," outlines reasons for consulting with families; presents a framework for effective communication; emphasizes the importance of viewing the child from a holistic perspective and taking time to build a relationship between family and professional; and offers family-centered principles for speech/language pathologists, occupational/physical therapists, and health care professionals. The second section, "A Framework for Early Intervention," points out the need to determine what other team members want from families and offers a mechanism whereby family expertise can be applied to the Performance Competence Model to determine how children interact with their environment. Five handouts and overheads are appended. (JDD)

TEAMS IN EARLY INTERVENTION



Family Module

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Family Module

TABLE OF CONTENTS

This module was designed to be used in conjunction with the INTRODUCTORY MODULE which includes the background and philosophical framework for the project as well as the essential information needed to use this module effectively. Read the INTRODUCTORY MODULE before using information in this module.

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Part 2: Pathways to Teaming

I. REASONS FOR CONSULTING WITH FAMILIES

CONTENT SUMMARY: The family is the child's first and primary team. Families are extremely diverse. What a family does for any child is intensified and modified when the child has a disability.

GOAL: Participants will develop an awareness that:

1) families are diverse,

2) families are the most important piece of a child's life, and

3) the early interventionist's role is to support the family as the primary caregivers.

A. Family Diversity

Slides which illustrate different cultures, families, and family groupings.

1

1. American families don't resemble Ozzie & Harriet anymore and probably never did.

2. Professionals must respect the family unit to which the child belongs, no matter what its culture or composition.

Slides which show more examples of families and family groupings.

B. Roles of the Family

1. Family Roles

   a. What do all family members do for their very young children?

Discussion could include how families feed, clothe, nurture, love, discipline, provide health care, teach the culture / religion / traditions, etc. List on flip chart.

   b. What happens to that list (flip chart) when a family learns that their very young child has special needs? How does the news of the diagnosis affect the family's care-giving role and functions?

2. What happens when a child does have special needs? What does this mean for the family?

Group discussion of a specific disability: For example, SLPs - child doesn't talk; OT / PTs -child has serious motor impairments; HCPs - child has Down Syndrome. Use same process as for the discussion of family roles.

3. After the diagnosis, professionals need first to talk with the family and offer both choices and information:

   a. Family to family support

      1) It is often helpful for family members to know that someone else has been through this experience.

      2) Ask participants if they are familiar with any family support groups.

   b. Information about the disability

   c. Information about resources and/or early intervention

C. Family Relationships

1. Having a child with special needs can lead to new relationships for the family and a new way of "operating" in the world.

2. Family with a child with special needs must enter unfamiliar territory to access resources.

   a. Must build relationships with many types of professionals.

   b. Instead of contacts with a pediatrician or preschool teacher, which the family may have expected, they are now meeting with a variety of specialists (sheer numbers, as well as "impressive" degrees may feel overwhelming and intimidating.)

   For example, families may expect:

   1) conference with preschool or Kindergarten teacher

   2) 3rd grade CTBS (California Test of Basic Skills) or other nationally standard test scores

   But what they may get are:

   1) "diagnostic evaluation" or multiple diagnostic tests

   2) Individual Educational Plan (IEP) meetings

2. Families must learn to work with an array of professionals and to advocate for their child with them.

a. It can be intimidating for parents regardless of their background to deal with professionals.

b. It can be intimidating to learn and to access the systems. (For example, not only is the structure of the system confusing, it is often hard to find the right offices or transportation to the right offices at the right time.)

c. A layer of anger and/or sadness often colors these relationships for the family, especially in the earliest stages.

D. Impact of the Child's Disability on the Family's Life

Ask for positive and negative anecdotes.

1. What is the impact on:

   a. Parents/marriage/relationships

   b. Brother & sisters

   c. Grandparents

   d. Finances

   e. Jobs

   f. The family's schedule

   g. Modifications to the home

2. **Where** early intervention is delivered is important. Give choices, such as in the home, at the center, etc. What does it mean to have professionals in one's home? It may not feel personally comfortable or be culturally appropriate to have professionals in the home.

II. FRAMEWORK FOR EFFECTIVE COMMUNICATION

CONTENT SUMMARY: To care for children with special needs, families find themselves part of many different teams and yet, the family itself is also a team. The types of teams with which a family interacts depends upon the individual child's special needs. (Some parent advocates believe that the "family team" has a hard time being on other teams - even when professionals believe that families should be part of such teams.)

GOAL: Participants will learn that they (as individuals) are just one element of a constellation of services that families must access. They will also understand:

1. the importance of good communication with the family and other team members;
2. the impact on a family of having to interact with so many different teams; and,
3. that families are generally not part of the professional team's culture.

A. Early Intervention Teams

1

1. Each "group" that is part of this constellation (physicians, therapists, early interventionists) has its own team. It is hard, if not impossible, for the family to belong to each team.
2. Family members expect professionals to take an integrated approach to the family; the family doesn't want to feel fragmented.
3. Early intervention often begins in the home with home visits (if the family wants) and later with a transition to preschool classes.

Family Module

Selection of slides depicting an array of early intervention services; professionals and families in your community.

4. Professionals need to listen carefully to families. Families have continuous access to their children; professionals see them for brief periods of time.

5. Services with early intervention programs often go beyond the child with special needs. They may have a parent library, sibling groups, counselor, etc.

6. It is important to invite families to participate in the program. Let them know you believe they each have something to offer.

1

B. Medical Teams

1. Depending on the child's disability, a variety of health care professionals may constitute a team.

2. Communication is a key issue. Good communication ensures that a family need not duplicate tests, forms, etc.

3. Family often becomes the conduit between the early intervention team (or other teams) and the medical team.

III. WHAT CAN BE EXPECTED FROM FAMILY-CENTERED CARE

CONTENT SUMMARY: Family-centered care is what makes sense for families as they care for their children in partnership with professionals. Family-centered care does not compromise a profession.

GOAL: Participants will develop an awareness of how to make services family-centered, and will learn to measure their success by asking if they have made the family's life simpler rather than more complex.

A. Viewing the Child from a Holistic Perspective

1. The child is not a "diagnosis." Describe attributes of the child first. Ask the question, "What does this child need to participate in the culture of childhood?" (Kjerland, 1992)

What does this mean?

2. Consider the family's culture. Ask what you, as a professional, can do to support the culture of childhood within that family because childhood's definition and expectations vary from culture to culture.

B. Take Time To Build A Relationship Between Family and Professionals

1. Building trust is a good investment in time.

2. Relationships among family members and early intervention professionals may be very intense. Often friendships develop.

IV. FAMILY-CENTERED PRINCIPLES FOR SLP, OT/PT, HCP

CONTENT SUMMARY: All professionals can implement family-centered principles through good communication skills, sensitivity, and collaboration.

GOAL: Participants will identify what they can do to support families...going back to what families <u>do</u> for kids

Discuss with each group of professionals, "What do <u>you</u> need from families?" Look for themes.

POST the responses generated in the earlier discussion about family roles.

Ask these questions and try to elicit information in A, B, C below. Weave these points into their responses.

1. *What do professionals want ...*
2. *What can professionals do that is supportive of families?*

A. Recognize that the Family is the Constant in the Child's Life

B. Collaborate with Families

   1. Listen carefully to their questions and concerns.
   2. Ask for their help in solving problems.
   3. In working with the family to set goals for the child, ask what makes <u>sense</u> to the family.
      a. Ask what the family wants for the child.
      b. Avoid giving families a list of activities to do with the child.

c. In planning therapies and interventions, keep in mind that <u>more</u> isn't always better. (Remember the idea of the culture of childhood.)

2

C. Share Unbiased, Complete Information

1. Level with families when they ask for information.

2. Give information in understandable, everyday language.

Discussion with various disciplines:

D. HCP - A Child with Down Syndrome

1. Keeping in mind the family-centered principles, how can you help the family accomplish one of their tasks (use earlier flip chart pages on what all families do for their young children) for this particular child?

2. How might you support placement in inclusive settings?

E. OT/PT - A Child with Serious Motor Impairments

1. Keeping in mind the family-centered principles, how can you help the family accomplish one of their tasks (use earlier flip chart pages on what all families do for their young children) for this particular child?

2. How might you support placement in inclusive settings?

F. SLP - A Child with Serious Language Disorder.

1. Keeping in mind the family-centered principles, how can you help the family accomplish one of their tasks (use earlier flip charts on what all families do for their young children) for this particular child?
2. How might you support placement in inclusive settings?

Family Module

Part 3: A Framework for Early Intervention

I. SYNOPSIS OF INFORMATION SHARED IN OTHER GROUPS

CONTENT SUMMARY: A condensed version of the major points covered in the Family content for the other three areas (OT/PT, SLP and HCP) will be discussed.

1

GOAL: Family members will learn the information that was shared with each of the groups of professionals.

A. Family Diversity

B. Roles and Relationships for Families with Children with Special Needs

Display examples of what all families do for young children.

Flip chart pages from earlier discussion.

C. The Culture of Childhood

D. Constellation of Teams

E. Elements of Family-Centered Care

II. WHAT DO OTHER TEAM MEMBERS WANT FROM FAMILIES?

CONTENT SUMMARY: Content will depend upon the discussion with each of the groups.

GOAL: Family members will understand and discuss what professionals need from them in order to make a team that is supportive of families.

Fill in outline below with notes from discussion.

Display flip chart pages that were posted in each discipline group.

A. OT/PT

B. Health Care Professionals

C. Speech/Language Pathologists

\# 3

D. What Did the Family Group Hear from Others During Part II? *(Fill in discussion, above.)*

III. APPLICATION OF FAMILY EXPERTISE TO PERFORMANCE COMPETENCE MODEL

CONTENT SUMMARY: The Performance Competence Model provides us with windows to understand how children interact with their environment. The family's influence is pervasive; family is not a "factor" in the model, but it is the basis for the model.

GOAL: Families will be given the same framework as all other professionals for asking questions about how to support a child's performance.

4

A. Givens
   1. Predispositions
   2. Basic biological drives

B. Underlying Factors for Producing an Efficient Adaptive Response
   1. Internal self-regulatory functions
   2. Purposive system
   3. Ability to achieve, change, and maintain state of arousal
   4. Freedom and control of movement
   5. Orientation to stimulus
   6. Discrimination
   7. Attention (or selective attention)
   8. Integration of multiple sensory input

C. Developmental Sequence
   1. Comfort/safety
   2. Confidence
   3. Risk-taking
   4. Competence

D. What We Think, Feel and Do
   1. Spiritual
   2. Emotional
   3. Intellectual
   4. Physical

E. Environment and Culture
   1. Quality of life
   2. Membership
   3. Personal sense of competence

F. Families are Related to Every Aspect of the Model
   1. Professionals need to take into consideration the family's pervasive influence on the model. If they don't, the family will feel frustrated.
   2. By taking the family's influence into consideration, professionals will be able to implement family-centered principles.

IV. CASE STUDY APPLICATION TO THE PERFORMANCE COMPETENCE MODEL

CONTENT SUMMARY: Participants will discuss specific aspects of three different children's performance in relation to the Performance Competence Model. (See game cards in Introductory Module.)

GOAL: Families will use mini-case studies to practice the use of the model to provide information about the performance of young children for other team members within a common framework.

A. Newborn—A Child Prenataly Exposed to Drugs/Alcohol

B. 1 year old—A Child with Down Syndrome

C. 2 year old—A Child with Delayed Language Development

OVERHEADS

&

HANDOUTS

FAMILY

We all come from families. Families are big, small, extended, nuclear, multi-generational, with one parent, two parents, and grandparents. We live under one roof or many. A family can be as temporary as a few weeks, as permanent as forever. We become part of a family by birth, adoption, marriage, or from a desire for mutual support. As family members, we nurture, protect, and influence one another. Families are dynamic and are cultures unto themselves, with different values and unique ways of realizing dreams. Together, our families become the source of our rich cultural heritage and spiritual diversity. Each family has strengths and qualities that flow from individual members and from the family as a unit. Our families create neighborhoods, communities, states, and nations.

Developed and adopted by New Mexico's House Memorial 5 Task Force on Children and Families and the Coalition for Children. 1990.

WHEN PARENTS AND PROFESSIONALS COMMUNICATE...

Tips for Professionals

1. Make sure that the meeting is being held at a time and in a place that is convenient for parents. That might mean after school, at night, in the family home. In arranging the meeting with parents, ask, "Where would you like to meet? When would it be best to meet?" A note that says, "There will be a meeting a 9:00am on January 23. Please be present," does not send a message of teamwork or cooperation. Be flexible. Think about the setting -- a principal's office is intimidating.

2. Remember that you and the parents are part of a team. The atmosphere that you set is crucial, and initial arrangements and remarks set a tone that will affect all future interactions. You have specific knowledge and expertise, but so do the parents. This meeting is a time to share your individual perspectives and insights on behalf of a child.

3. Let the parents speak. Give them time to talk about their child, to tell you what he does on Saturday mornings or with his grandfather. Let them explain how they are feeling about his progress and what they think a next step should include.

4. Be sensitive to family dynamics and traditions. If the family is Spanish-speaking and is most comfortable conversing in Spanish, make sure that the primary spokesperson for your team speaks Spanish (or Keres or Navajo). Important documents and instructions should be written in the family's language or should be translated appropriately.

5. Make sure that enough time has been set aside for the message. If this is a first meeting, when a great deal of information will be shared, set aside a half hour or more. If you just need "a moment" to speak with a parent, make sure that she also has "a moment" to spare, and that a few minutes is all that it will take to absorb and respond to your concern.

6. Speak in ordinary English. Educators and health professionals tend to talk in a jargon that only their colleagues understand. Avoid acronyms (IEP, LEA, PT).

7. Have you made an assumption or reached a decision about the child already? If you have, tell the parents immediately! Is the purpose of the meeting to bring the parents to the same conclusion? Or is it to discuss the child and together reach a decision? Do not pressure the parents to make an immediate decision unless it is absolutely clear that everyone agrees on a course of action. Be prepared to arrange for a later meeting or discussion.

8. Talk about the child in positive terms. Everyone knows what she cannot do. She cannot walk or button her coat. But she can light up a room with her smile or clean the art table. If you cannot think of a positive thing to say about the child, you should not be working with her.

9. Understand the child's life experiences. A child who cannot speak will have a different way of dealing with things than a child who talks. A child who can move only with an electric chair will have experienced social situations in a different way. Try to see things from the child's perspective.

10. Be cautious about making predictions. Someone who says, "She will never read," must be absolutely certain of that knowledge or all future credibility will be lost. On the other had, don't avoid a certainty -- chances are the parents long ago reached the same conclusion.

11. Do not overwhelm the family with information and paperwork. When eyes start to glaze over or questions cease, stop the meeting and plan another one.

12. Thank the parents for their help and their commitment to their child.

New Mexico Parents Reaching Out (PRO)
1127 University Blvd. NE, Albuquerque, NM
(505) 842-9045 or (800) 524-5176

WHEN PARENTS AND PROFESSIONALS COMMUNICATE...
Tips for Parents

1. If you are going to a meeting with health or education professionals, bring your spouse, a friend, or a relative who knows your child well. It is always wise NOT to go alone. If the meeting concerns major educational or medical issues, it is especially important that someone else be there to hear what you may not want to hear, to say what you might be afraid to say. There are often many educators or other professionals at these meetings, and feeling "outnumbered" is uncomfortable.

2. Try to feel at ease. This is not easy to do. Make sure the meeting place and time are convenient for you, your spouse, the professionals. Try to get to the meeting in plenty of time. Leave younger children at home so that you will not be distracted. Wear something that makes you feel good. Have documents and papers that you think might be helpful. Find a comfortable place to sit. Keep in mind that you are there for your child and you know him best.

3. Consider yourself the captain of a team that has come together to discuss your child. Because you know her better than anyone else, your role is critical. On the other hand, the teachers or health professionals who are present have a special expertise that you lack. It is this unique combination of knowledge, training, and experience that creates the team that works with your child.

4. Talk about your child. If the meeting has gotten underway and you have not yet been asked to speak, find an opportunity soon and say, "Let's talk a little about what Jesse's like at home." Your insights and ideas about you child will help in the larger discussion. "Jesse" may have some skills and behaviors at home that the professionals will find enlightening.

5. Bring paper and pencil and take notes. This will be helpful when you get home and talk things over with your spouse, a friend, or later on with a teacher. You can also take notes to remind yourself to ask specific questions later in the meeting.

6. Ask questions, even if you feel stupid asking them. Educators and health professionals have languages of their own -- stop and say, "What is mid-line?" or "What do you mean by dyplegia?"

7. If things are going too fast, ask people to slow down, to repeat, to give you time to think. Having a friend or spouse there who might also find things moving too fast will help.

8. Do not feel pressured to make a decision on that day. If you are asked to sign something, give yourself time, either during the meeting or later on at home, to think about the decision. You may need to ask your spouse what he or she thinks. Maybe your pediatrician has asked that you talk things over with her. On the other hand, if the discussion makes sense to you and you have all come to the same conclusion, then it is logical to make a decision at the meeting.

9. If you think you need another meeting, make arrangements for a follow-up. This is especially sensible if you and the professionals at the meeting have to make a decision that will have a major impact on your child.

10. Thank everyone present for their help and their interest in your child.

Prepared by Polly Arango for New Mexico Parents Reaching Out (PRO)
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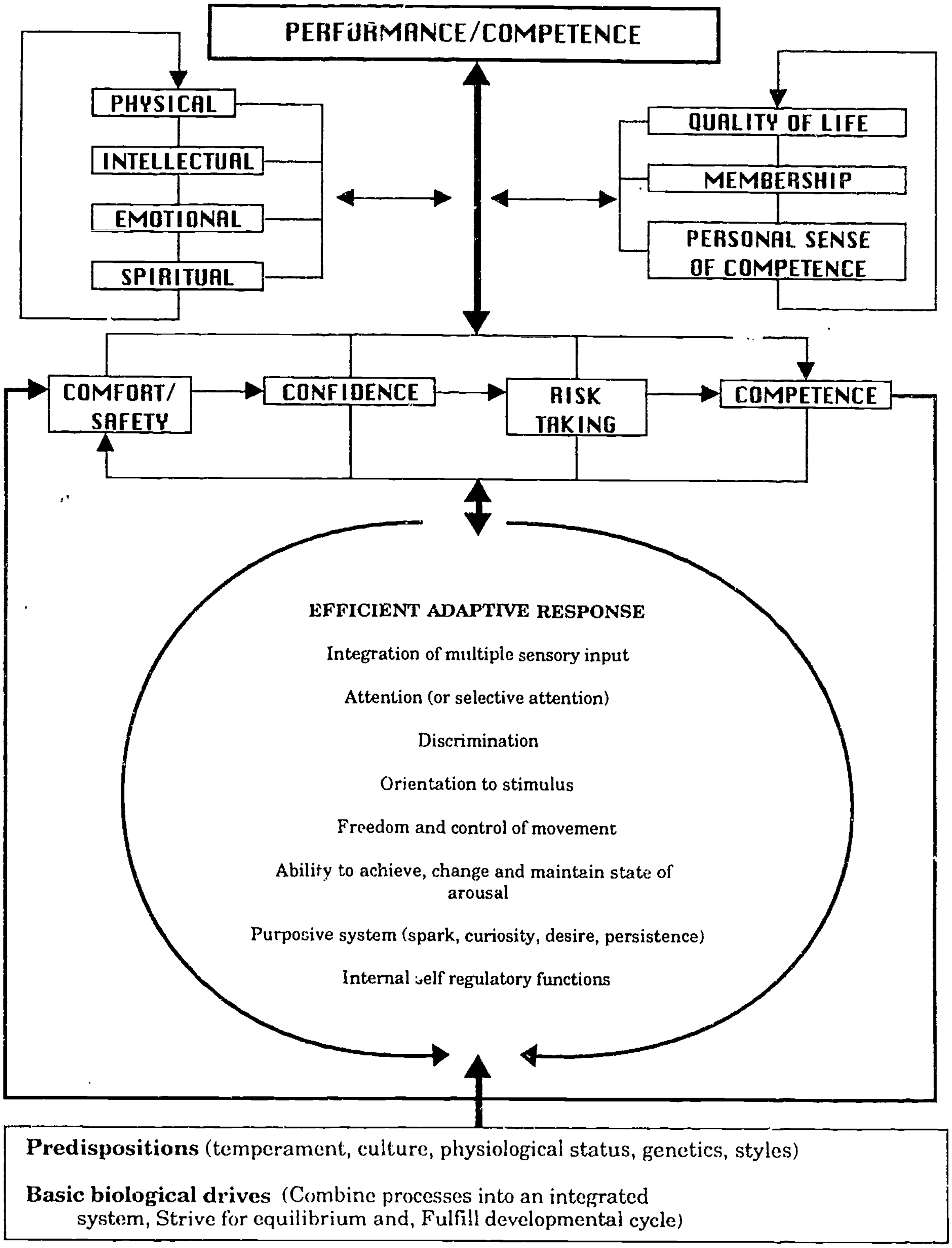


EFFICIENT ADAPTIVE RESPONSE

Integration of multiple sensory input

Attention (or selective attention)

Discrimination

Orientation to stimulus

Freedom and control of movement

Ability to achieve, change and maintain state of arousal

Purposive system (spark, curiosity, desire, persistence)

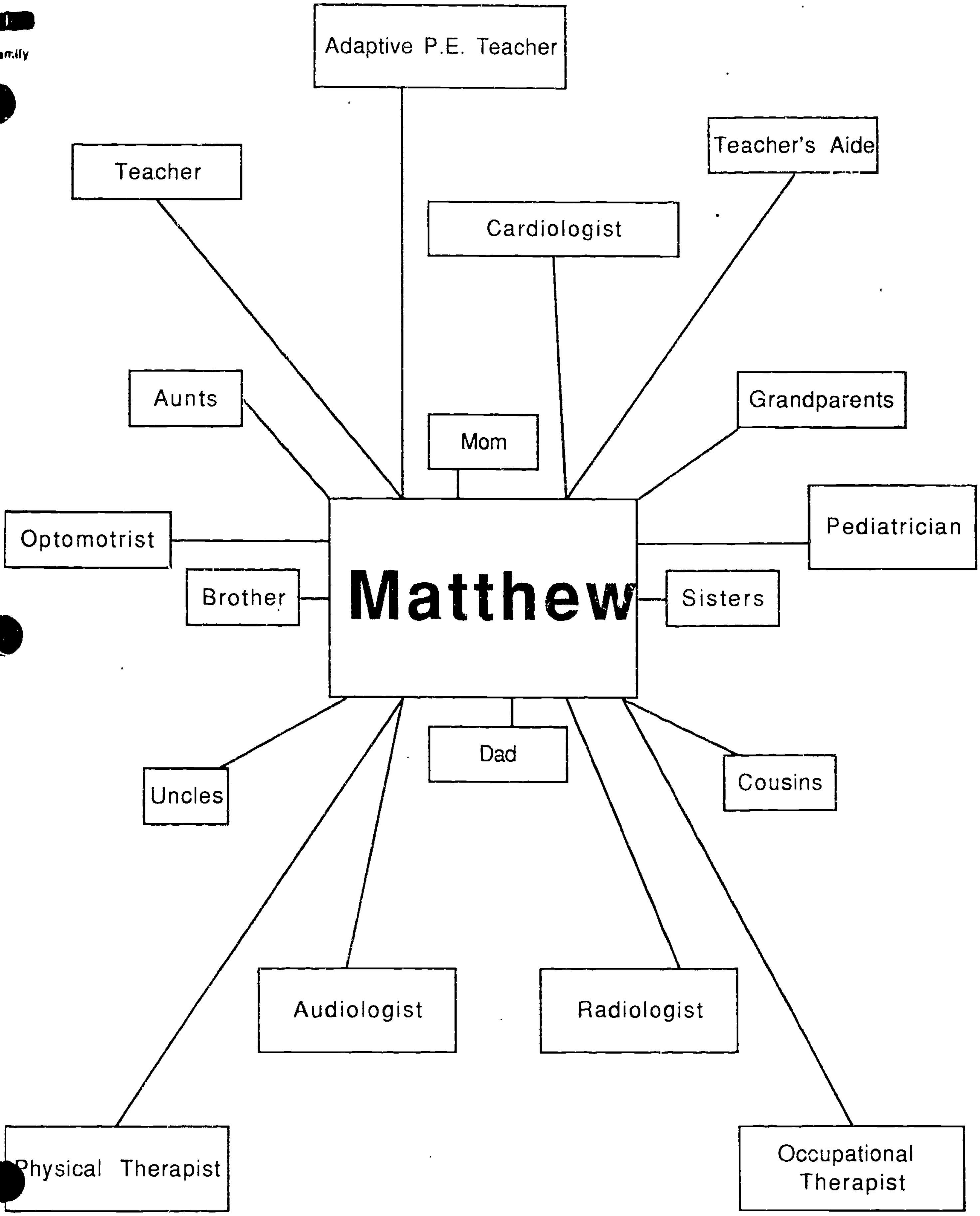
Internal self regulatory functions

Predispositions (temperament, culture, physiological status, genetics, styles)

Basic biological drives (Combine processes into an integrated system, Strive for equilibrium and, Fulfill developmental cycle)

Oetter & StevensDominguez, 1991, Training Unit, UAP/UNM

Family


Adaptive P.E. Teacher
Teacher
Teacher's Aide
Cardiologist
Aunts
Mom
Grandparents
Optomotrist
Pediatrician
Brother
Matthew
Sisters
Uncles
Dad
Cousins
Audiologist
Radiologist
Physical Therapist
Occupational Therapist