# Families, Self-determination, and Disability:
## A Guide to Working Together with Families

## Including a corresponding
## Family Life Experience Project

**Suzanne A. Milbourne, MS, OTR/L**
**Child and Family Studies Research Programs**
**Thomas Jefferson University, Department of OT**
**Spring 2002**

## Table of contents



Note: A special thanks to Gary Mears and Phyllis Guinivan for their inspiration and guidance in preparing this guide which was kindled by a class assignment required for a graduate course at the University of Delaware, College of Human Services, Education, and Public Policy, Department of Individual and Family Studies. The guide was developed for use in student training at Thomas Jefferson University, Department of Occupational Therapy, Child and Family Studies Research Programs. The author encourages use of the guide with students and practitioners enrolled in various institutions of higher education, community-based/non-credit educational opportunities, and continuing education learning contexts.

# Families, Self-determination, and Disability: A Guide to Working Together with Families

This guide is designed to promote family-centered approaches of practice and to introduce students to (1) the philosophy of family support, (2) perspectives on assessing needs and determining supports, and (3) essential competencies for working together with families.

Section 1 of the guide provides a brief introduction to the issues that will be addressed in the rest of the guide. Section 2 – 4 is comprised of various topics specific to promoting family-centered approaches: Philosophy of Family Support, Assessing Family Need and Determining Supports, and Essential Competencies for Working Together with Families.

Section 5 poses and answers the following questions with respect to family support, self-determination, and disability:

- What is the present state of family support, self-determination, and disability?
- What is the vision for the future of family support, self-determination, and disability?
- How can we realize the vision and what are the barriers that must be overcome?

Supplemental readings containing information about families, self-determination, and disability are distributed throughout this guide. Information has been collected from a variety of sources including peer reviewed journal articles, internet-based documents, family presentations, and personal interaction with families. The reader is encouraged to continue collecting additional documents in order to maintain congruency with future research related to the field of family studies and family support. Users of this guide are highly encouraged to review documents prepared both within and outside of their current field of study.

**Family Life Experience**

Text boxes are distributed throughout this guide. The content of each box relates to the complementary project: Family Life Experience. The purpose of the Experience to provide the user with an opportunity to observe the ways in which families lead and live their lives and the impact of having a child with a disability or developmental delay has on the ways in which families manage their daily activities. The Experience is an opportunity to spend time with one family and learn from their perspective "best practice" in providing family-centered care and to synthesize learned knowledge into practice. Each box relates to readings and assignments to fulfill this goal.

**Readings** are assigned in each box, which relate to the content discussed in that section of the guide.
**Supplemental Readings** can be found at the end of each section of the guide.
**Assignments** are to be completed in order in which they are presented in the guide.
**Activity Log:** see appendix B for an example of the activity log to record Family Life Experiences
**Reflection Journal:** see appendix C for a description and guiding questions to enhance clinical reasoning.
Assignments, Activity Log, and the Reflection Journal will all be incorporated into the Family Life Experience final project (page 12).

## Section 1: A brief introduction to the issues that will be addressed in the rest of the guide

The 20th century as been marked by the emergence of increasingly progressive social policy regarding people with disabilities and their families. Two waves of parent and consumer advocacy have achieved unprecedented levels of influence during the second half of the 20th century. The skills, commitment, and perseverance of many families resulted in opportunities for children with disabilities to attend typical schools and become active members in their communities. Advocacy movements have been influential in three major issues that are sources of both tension and opportunity. They are (1) the distinction between being judged as different because of an association of someone who is different and being that someone yourself, (2) the issue of welfare versus autonomy, to some extent the conflict between autonomy and paternalism, and (3) issues of control in the development of policy making (Powers, 1996).

In 1994 Tom Harkin, then chairman of the United States Senate Subcommittee on Disability Policy, supported the delivery of the Families of Children with Disabilities Support Act to President Clinton. The Act was a document recommending and advocating for federal legislation on family support for families of children with disabilities. It became policy that family support must focus on the needs of the entire family. Families must be supported in determining their own needs and in making decisions related to their child, and families should play decision making roles in policies and programs that affect the lives of such families. Also, services and supports must offer options that are flexible and responsive to individual families, and the support is proactive and not solely in response to a crisis. The Act also promoted the integration and inclusion of children with disabilities into all aspects of community life. Additionally, it was expressed in the Act that family support must promote the use of existing social networks, strengthen natural sources of support, and help build connections to existing community resources and services. Finally, services and supports must be provided in a manner that demonstrates respect for individual dignity, personal responsibility, self-determination, personal preferences, and cultural differences of families.

Four years after the Act was instituted three families were invited to present their stories about raising a child with a disability to an audience of both practicing and student early interventionists. A selection of comments expressed on that day illustrated the passion the three parents had for including their children in all aspects of community life. The comments also illustrate the continued efforts and work necessary to honor a family support model where the family is at the core of decision making practices relative to the services and supports accessed by their family. The following three topics will be covered in more detail in the next three sections of this guide and a quote from each of the three families leads the discussion.

**Philosophy of Family Support**

> Tara's mother: "If you don't have a friend in the world, who are you combing your hair for?" when discussing the goals of her child's individualized educational plan (IEP). Family-centered approach philosophy of family support, views individuals and family members as interdependent parts of a family system. Emphasis is placed on strengths and resources that assist families in coping and adjustment, as well as positive contributions of people with disabilities to their families. Families are supported in exercising power and control over the supports they receive and ultimately over their own family lives.

**Assessing Family Need and Determining Supports**

Sean's mother: "He's a regular kid, yea – he has some disabilities, but he is a kid first." A key principle in assessing needs of and determining supports for families is that families are able to identify their own needs and most appropriate supports for their family and child. What is the difference between natural supports and disability-related supports? What is appropriate to ask families? How is a holistic perspective of a family gathered? Each of these questions and more will be discussed in this section.

**Essential Competencies for Working Together with Families**

Cameron's mother: "the best therapy is life." What is it that parents of children with disabilities identify as a "good" interventionist? What is recognized by the research related to practice in the field of family studies/family intervention? Working together with families requires interventionists to have a variety of essential competencies. This section will assist readers in determining levels of self-competency and to create an action plan identifying competency areas for development.

The journey through this guide will at times comply with and at other times challenge the user's perspective, values, and/or beliefs about children with disabilities and their families. View this discontinuity of perspectives as a source of knowledge enhancement in your workings together with families. Honor the discontinuity as a growth experience, keeping in mind that growing pains fade and result in extension and enhancement of current competencies. Continue with an open-mind, be encouraged and inspired by creative thinking, and fulfill families' advocacy efforts by integrating the key concepts of family-centered practices into your every day encounters with all families.

**Family Life Experience**

Purpose:
To provide users of this guide with an opportunity to observe the ways in which families lead their lives and the impact that having a child with a disability or developmental delay has on the ways in which families manage their day to day activities. The purpose is NOT to provide services for the child or family but, rather, to learn about families who are raising a child with a disability. By understanding about the roles and responsibilities of families themselves and their children and the strategies families use to include the child with a disability or delay, professionals are better able to provide services in ways that support a family's ability to optimize the growth and development of their child.

Spend a total of 35-40 hours of time with a family over 5-6 week time period to understand:

- ✓ Family beliefs and practices about raising children
- ✓ How families implement their roles (as caregiver, nurturer, economic supporter, etc.)
- ✓ How work responsibilities and economic resources of parent(s) impact on family life
- ✓ How the needs of the child with a disability/delay impact on the family in terms of the ways in which they spend their time, responsibilities, stress, etc.
- ✓ How families "perceive" and represent their child with a disability
- ✓ The ways in which early intervention support/does not support the family

## Section 2 Philosophy of Family Support

"If you don't have a friend in the world, who are you combing your hair for?"

Family-centered approach philosophy of family support, views individuals and family members as interdependent parts of a family system. Emphasis is placed on strengths and resources that assist families in coping and adjustment, as well as positive contributions of people with disabilities to their families. Families are supported in exercising power and control over the supports they receive and ultimately over their own family lives.

The main goals of family support are: (Human Services Research Institute, Salem OR, 1993)

- To keep families together until the child chooses to live independently;
- To enhance a family's capacity to meet the multiple needs of the child;
- To improve the quality of supports to families while minimizing the need and cost of out-of-home care;
- To allow the family to participate in integrated leisure, recreational, and social activities; &
- To make a positive difference in the life of the child as well as the lives of all family members.

Characteristics of programs that support the family–centered approach include: (Powers, 1996)

- Consumer and parent collaboration in policy development and program governance
- A focus on the sociopolitical nature of disability
- Emphasis on family strengths, consumer control, and self-direction
- Partnership between and among the varied organizations providing supports to families
- Interventions that promote self-esteem and opportunities for self-help and self-advocacy

Professionals are expected to practice their discipline in family-centered ways particularly when providing early intervention services for young children aged birth through six years of age. Early intervention legislation both federal (Part C of IDEA97) and state (Pennsylvania Act 212, the Early Intervention Services and Systems Act) requires services to be provided in natural environments – defined as the environments in which typically developing children the same age would spend time. For children under the age of six years, this means settings such as child care, stores and shopping centers, museums, organized programs such as Gymboree, amusement parks, parks and playgrounds, doctor's offices etc. – any place where families take their children. The settings in which young children spend time are selected by their parent(s) based on cultural beliefs and backgrounds, work situations, adult preferences of how to spend time, economic resources, community opportunities, and other factors.

### Family Life Experience

**Readings**

-Shelton, T.L., Jeppson, E.S. & Johnson, B.H. (1987). Family centered care for children with special health care needs. Association for the care of children's health, Washington, D.C.

-Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centered services: A conceptual framework and research review. Physical & Occupational Therapy in Pediatrics, 18(1), 1-20.

**Assignment**

-Find 2 additional readings about family life or family-centered approach. Read and summarize key points.

-Watch the video tapes Building a Family Partnership and Exploring Family Strengths from the Listening to Family Videotape Series. Summarize key points on a flip chart and display in an area you use daily.

## Section 3 Assessing Family Need and Determining Supports

"He's a regular kid, yea – he has some disabilities, but he is a kid first"

A key principle in assessing needs of and determining supports for families is that families are able to identify their own needs and most appropriate supports for their family and child. What is the difference between natural supports and disability-related supports? What is appropriate to ask families? How is a holistic perspective of a family gathered? Each of these questions and more will be discussed in this section.

Attitudes and perspectives have been identified as potential barriers to successful inclusion of young children with disabilities in their natural environments. Historically people with disabilities have been represented in terms of their needs, deficiencies, or inabilities. Public policy, designed within the context of this deficite-baed perspective, supports an infrastructure of services and educational systems to address these individual needs through a variety of trained professional people who provide individually tailored programs through specialized early intervention and educational services.

The attitudes, beliefs, and values that individuals hold about a particular issue or situation derive from the individual's knowledge, culture, and experience. Old models of assessing family need and determining supports were based on a deficit orientation which contrasts with a family-centered approach. In a family-centered approach, assessment and planning evolves with a focus on creating visions of an integrated life and determining ways to realize the visions. Example of vision-oriented planning processes include "Lifestyle Planning" process developed by O'Brien and Lyle, the "Personal Futures Planning" model (Mount & Zwernik), and the McGill Action Planning System (MAPS) by Forest & Lusthaus.

Key principles of family-centered assessment and planning include:

- Child-focused goal planning (vs. professional-focused goal planning);
- A resource-orientation focus;
- Consumer-driven planning;
- Partnerships to enhance opportunities;
- Professional contribution to or in support of …; vs professional decision about…
- Outcomes and results vs. numbers;
- Observation in multiple natural settings; and
- Community-based intervention

### Family Life Experience

**Readings**

-Review the early intervention documents available for the child – IFSP, IEP, MDE, contact sheets (families have copies of these documents).

**Assignment**

-Create a matrix including the following items: documentation date; type of EI document; perceived purpose of document; contributing professions; type of information included in the document; strength/deficit-based approach and examples; comments on the language.

-Analyze the level of family-centered assessment and planning you can infer from the documents.

-Discuss your findings with the family and ask for their perspective or expectations.

**What is the difference between natural supports and disability-related supports?**

If you ask Carl Dunst, researcher at the Orelena Hawks Puckett Institute in North Carolina, about families he would state that research has confirmed a basic fact: Parents do a very good job of engaging their children in a rich array of everyday learning activities. There is a particular research focus on infants, toddlers, and preschoolers who have are at risk for delays in their development – the goal being to identify, develop, and evaluate ways of using family and community life as sources of learning activities and opportunities promoting child abilities. Findings from the research indicate that everyday family and community activity settings are real life, natural learning environments that make the most sense in terms of learning important life skills.

Based on the work of Dunst and colleagues, categories of family and community activity settings and learning opportunities include: (Connections in Special Education, number 9, Fall 2001).

Family Life
- Family routines
- Parenting routines
- Child routines
- Literacy activities
- Physical play
- Play activities
- Entertainment activities
- Family rituals
- Family celebrations
- Socialization activities
- Outside activities

Community Life:
- Family excursions
- Family outings
- Play activities
- Community events
- Outdoor activities
- Recreation activities
- Children's attractions
- Art/Entertainment activities
- Church/Religious groups
- Organizations/Groups
- Sports activities/events

**Family Life Experience**

**Readings**

-Olson, J & Esdaile, S. (2000). Mothering young children with disabilities in a challenging urban environment. AJOT, 54(3), 307-314.

**Assignment**

-Watch selected videos from the Marriage and Family series –Building a Family Partnership & Exploring Family Strengths.

-Create a community map with the family to define their community/neighborhood. Find out about the ways they spend time, what activities they engage in, what community resources they access.

-Spend a 3-4 block of time with the family to observe what they do during the selected portion of a day and write up your objective observations in relation to Family Life and Community Life experiences.

**How is a holistic perspective of a family gathered?**

An interventionist using a natural-supports approach to collecting information from a family would avoid using the word behavior or talking about problems the child may have. Instead, they would talk with families about what the child likes to do, what the child likes, and what makes the child smile. Part of the conversation would focus on what an ordinary day in the family entails with a focus always on opportunities for the child to be involved with the family. For example, the family states that the child loves mealtime with the family, and the child is usually talkative during mealtime. So, it may be decided to enhance the child's language production during mealtime. This process is collaborative and acknowledges family knowledge and expertise.

Holistic perspectives can be best gathered by using an open-ended question format when engaged in dialog with the family. Open-ended questioning enables the family an opportunity to guide the dialog and provide as much rich information they feel is relevant or important for the interventionist to know about. Examples of open-ended questions:

Fill me in on the background of…
Tell me more about…
What was your reaction to…
What would you like to do about…
How do you think things stand right now…
What is you ultimate goal…
What would it take to do that…
Where do you think this will lead…
What do you (your family) think is best…
Who have you talked with about…

Active listening skills complement the use of open-ended questioning. Active listening means trying to understand exactly what another person is saying and letting the person know that you have understood. When using active listening, pay attention to both what is being said and to the feelings expressed. The basic elements of active listening are:

Be attentive
Be impartial
Reflect back
Listen for feelings
Summarize

**Family Life Experience**

**Readings**

-Campbell, P.H., Milbourne, S.A., & Silverman, C. (2001). Strengths-based child portfolios: A professional development activity to alter perspectives of children with special needs. Pro-ed, 21(3), 152-161.

**Assignment**

-In collaboration with the family, complete the Introducing Me booklet from the Me Too series (Brooks Publishers). The booklet will be returned to the family at your last visit.
-Again, in collaboration with the family, complete the Look What I Can Do booklet.
-Using the booklet as a guide, and integrating information you have gathered from the family, formulate at least 5 suggestions for adaptations to make it easier for the child to participate in family activities and routines.
-Discuss the adaptations with the family and asks if you can implement at least 3 of them.

**What is appropriate to ask families?**

People tend to provide information in a way they believe will make themselves and their families more acceptable to others. In an open-ended dialog with a family an interventionist should be willing to follow tangents in whatever direction the family's interest seem to dictate. For example, a parent may address other topics in the process of addressing one, in such a case avoid repetition by "formally" bringing up the same topic at a later time. As much as possible avoid a formal "interview" approach, seeking instead to create a discussion or conversation with shared interest and goals. In other words, let the family "tell their story".

It is appropriate to gather information about (examples are certainly not comprehensive):

Family Characteristics:
- Names and ages of the immediate family and ages of siblings
- Other persons (not necessarily relatives) and the role they play in the family
- The way work outside the home influences involvement with the family/child

Family Interactions:
- Most and least enjoyable aspects of interacting with the child for different family members
- Interest and activities of family members
- Ways in which decisions are made in the family

Family Functions:
- What the family does for fun together
- The community activities in which the family is involved
- The families strengths in carrying out responsibilities

Family Life Cycle:
- The most difficult and most enjoyable times the family has had with the child
- The family's short and long term goals for the child and for other family members
- Hopes for the child's life 5 years from now and 10 years from now

**Family Life Experience**

**Readings**

-Section on interviews from the PA, IFSP Guidelines (Campbell, 1995).

**Assignment**

-Conduct an interview with the family using the Family Interview format found at the back of this guide. Audio-tape the interview with permission from the family. The audio-tape is for you to listen to as a self-evaluation and a back-up for your notes.

-Compare and contrast the type and content of the information you gathered using previous assignments of information gathering and the interview.

-Discuss with the family their response to the interview. How did it feel to them? Is this an experience they are used to? How would the family prefer to provide information about their child/family – interview or story telling? Can they give you feedback or suggestions for improving your interview skills? Etc.

## Section 4 Essential Competencies for Working Together with Families

"The best therapy is life."

What is it that parents of children with disabilities identify as a "good" interventionist? What is recognized by the research related to practice in the field of family studies/family intervention? Working together with families requires early interventionists to have a variety of essential competencies. This section will assist readers in determining levels of self-competency and to create an action plan identifying competency areas for development.

Colleen Tomko, a mother of a child with a disability, represents many families on her web site, KidsTogether.org. According to Colleen, what is important for interventionist to know is the point that problems of learning how to reenter the real world can be avoided if a child never leave the natural settings for "special" settings in the first place. Problems of generalizing skills to the settings where the child needs to use those skills can also be avoided if they are first learned in the natural settings. Children with disabilities need even greater exposure to natural environments and experiences so they can learn to function using their disabilities. As with any child, the less exposure to a situation, the less equipped they will be to deal with it.

Appendix A includes a list of competencies relevant for early interventionists working together with families and their child(ren) with disabilities. It also includes a blank action plan for the user. The competencies were developed as a part of a personnel preparation grant from the Department of Education No. H029G970066-98. Content of the competencies was gathered from pre-existing professional publications, focus groups with both occupational and physical therapists and focus groups with families of children with disabilities. The document is for self-evaluation purposes for both practicing therapists and students entering the field of early intervention. The action-plan is for personal professional planning.

### Family Life Experience

**Readings**
Review the Early Intervention Competencies in Appendix A.

**Assignment**
-Complete the competency self-rating document found in Appendix A.
-Using the competencies as a guide, create a personal professional development plan using the Action Plan found in Appendix A.

## Section 5 Family Support, Self-determination, and Disability

**What is the present state of family support, self-determination, and disability?**

Current practice models are inadequate; there is a paucity of good research that may better inform models of practice; and the dilemmas facing early interventionists and families are deeply intertwined with institutional and cultural structures of practice. Four models of family-support, self-determination, and disability (professional partnership) have been described by Turbull et al. (2000):

| | |
|---|---|
| Parent counseling/psychotherapy | Family-centered services |
| Family involvement | Collective empowerment |

The models span the time frame from the 1950's to the time of the publication. The type of power - power-over, power-with, and power-through – that are inherent in each model demonstrate the change of family-support practices during the 50 years, and illustrate how each model may have been brought to bear on individual families. Power is described as the ability and willingness to affect the behavior, thoughts, physical wellbeing, and/or feelings of another and is a critical element of all relationships. Parent-professional relationships have traditionally been marked by the presence of dominant-subordinate power structures – power-over. In recent years, relationships and the power distribution between professionals and parents in early intervention have begun to change. Power-with partnerships arose when collaborative decision-making emerged as the recognized value that each person(s) bring to the relationship. Professionals respect family members' competence, listen to their perspectives, and are influenced by the knowledge and resources inherent in the family system and community ecology. Power-through partnerships, referred to as collective empowerment, incorporate synergistic decision making among all of the partners involved in the relationship. Power is defined in terms of capacity rather than control and is characterized by openness, responsiveness, dignity, personal empowerment for each member, alternative influence, and cooperation.

So, where are we now. As one parent states "we've come a long way baby" in parent-professional partnerships. However, in reality all four models continue to be used in early intervention. Potentially the reason may be that because family needs and resources change, preferences for their relationships with early interventionists change. If family choice is the reason for the continued use of the various models, this change may indicate the use of family-centeredness or collective empowerment. On the other hand, more often than not, the decision on the partnership model, as suggested by Turnbull et al., is made unilaterally by the early intervention provider. Early interventionists need to reflect on their partnerships with families and ensure that families truly have choices in how the relationships evolve and impact their themselves and their child(ren).

**What is the vision for the future of family support, self-determination, and disability?**

The vision for the future is that early interventionists will embrace the collective empowerment model and take advantage of this point in history to answer questions such as:

- ✓ How do families develop the resources, the motivation, and the supportive environment they need in order to participate in a collective empowerment model?
- ✓ How do the early interventionists learn to embrace the inherent values of collective empowerment and associated skills?

- ✓ How can the philosophy be initiated and by whom?

According to Turnbull et al., As families and professionals actualize the collective empowerment model it has been demonstrated that families and professionals develop effective partnerships. They find ways to work together, to attend to one another's needs and concerns, and come to understand (and even appreciate) the other's differing points of view.

**How can we realize the vision and what are the barriers that must be overcome?**

The vision of successful, supportive, strength-based, and constructive family-professional partnerships can be realized through the collective perspective that:

The main goals of family support are:
- ✓ To keep families together until the child chooses to live independently;
- ✓ To enhance a family's capacity to meet the multiple needs of the child;
- ✓ To improve the quality of supports to families while minimizing the need and cost of out-of-home care;
- ✓ To allow the family to participate in integrated leisure, recreational, and social activities; &
- ✓ To make a positive difference in the life of the child as well as the lives of all family members.

(Human Services Research Institute, Salem OR, 1993)

And

Characteristics of programs that support the family–centered approach include:
- ✓ Consumer and parent collaboration in policy development and program governance;
- ✓ A focus on the sociopolitical nature of disability;
- ✓ Emphasis on family strengths, consumer control, and self-direction;
- ✓ Partnership between and among the varied organizations providing supports to families; &
- ✓ Interventions that promote self-esteem and opportunities for self-help and self-advocacy.

(Powers, 1996)

Challenges continue to include:
- ✓ Inconsistencies in public attitudes and policies toward different disability groups have influenced the parent and consumer activism, promoted categorical approaches, and acted as disincentives to collaboration;
- ✓ Parent activism has historically emphasized caregiving and well being, whereas consumer activism has focused on civil rights and promoting autonomy;
- ✓ There are difference in perspectives among some parent and consumer activists related to disability stigma, welfare and autonomy, and control over decision making;
- ✓ Understanding of family-centered practices lags considerably behind our attempts to implement responsive and efficacious services;
- ✓ Many professionals remain uncertain about exactly what family-centered practice means; &
- ✓ Findings of current research need to be replicated, and longitudinal studies are needed to determine the long-term effectiveness of family-centered practices on families and their children.

(Lawlor & Mattingly, 1997; Powers, 1996; Rosenbaum et al., 1998; and Turnball, et al., 2000)

**Family Life Experience**
**Final project**

**Assignment**

The goal of the final project is to synthesize and integrate the experience you have had over the course of 35-40 hours spent with one family. Secondly, to generalize the information to your everyday relationships with families and the partnerships you create together.

**IMPORTANT**

**IMBED ALL OF THE PREVIOUS ASSIGNMENT CONTENT AND PRODUCTS INTO THE FINAL FAMILY LIFE EXPERIENCE PROJECT (SECTIONS 1-5 BELOW). THE FINAL PROJECT SHOULD ALSO INCLUDE YOUR COMPETENCIES & ACTION PLAN (APPENDIX A), ACTIVITY LOG (APPENDIX B) AND REFLECTION JOURNAL (APPENDIX C).**

Section 1:
Family beliefs and practices about raising children
How the family implements their roles (as caregiver, nurturer, economic supporter, etc.)
How work responsibilities and economic resources of parent(s) impact on family life

Section 2:
How the needs of the child with a disability/delay impact on the family in terms of the ways in which they spend time, responsibilities, stress, etc.

Section 3:
How the family perceives and represents their child

Section 4:
Reflection on the ways in which current early intervention services support/do not support the family in optimizing the development of their child
Include a description of the ways in which early intervention supports the family's goals for their child and assists the family in implementing their roles and responsibilities and ways in which current early intervention does not do this. In instances where there are services not maximally supportive to the family, provide examples of ways in which they might be restructured using a family support approach to address family strengths, needs, and priorities.

Section 5:
Implications for you as a practicing or new interventionist in regard to the way you see yourself working together and partnering with families. In other words, discuss how this experience may influence the ways in which you will do things day to day in your work with families.

**References**

Agosta, J., Melda, K., Kelsch, R., & Becker-Green, J. Family Support Policy Brief #2. 1999. National Center for Family Support @HSRI. Ref Type: Pamphlet

Campbell, P. H. Guide for Individual Family Service Planning in Pennsylvania: A resource for families and professionals. Pennsylvania Department of Public Welfare. 1995. Ref Type: Unpublished Work

Campbell, P. H., Milbourne, S. A., & Silverman, C. (2001). Strengths-based child portfolios: A professional development activity to alter perspectives of children with special needs. Pro-ed, 21, 152-161.

Commitee on Labor and Human Resources (94 A.D.). United States Senate Washington, DC: Committee on Labor and Human Resources.

Cooley, W. C. & McAllister, J. W. (1999). Putting family-centered care into practice-A response to the adaptive practice model. In I.Lipincott Williams & Wilkins (Ed.), Developmental and Behavioral Pediatrics (pp. 120-122).

Cripe, J. W. & Venn, M. L. (1997). Family-guided routines for early intervention services. In Valdosta State University (Ed.), Young Exceptional Children (pp. 18-26). Georgia.

Edelman, L. E., Greenland, B. M., Mills, B., & L (1992). Family-centered communicating skills: Facilitator's guide . St. Paul, MN: Pathfinder Resources.

Feldman, H. M., Ploof, D., & Cohen, W. (1999). Physician-Family Partnerships: the adaptive practice model. In I.Lipincott Williams & Wilkins (Ed.), Developmental and Behavioral Pediatrics (pp. 111-123). Lippincott Williams & Wilkins, Inc.

Hanft, B. E. & Pilkington, K. O. (2000). Therapy in natural environments: the means or end goal for early intervention? Infant Young Children, 12, 1-13.

Human Services Research Institute. Expecting Excellence in Family Support. 2002. Salem, Oregon. Ref Type: Pamphlet

Johnson, B. S. (2000). Mother's perceptions of parenting children with disabilities. MCN, 25, 127-131.

Kellegrew, D. H. (2000). Constructing daily routines: A qualitative examination of mothers with young children with disabilities. American Journal of Occupational Therapy, 54, 252-259.

Kohlen, C., Beier, J., & Danzer, G. (2000). "They don't leave you on your own:" A qualitative study of the home care of chronically ill children . Pediatric Nursing, 26, 364-371.

Laurie E.Powers (2002). Family and Consumer Activism in Disability Policy. In Powers (pp. 413-433).

Lawlor, M. C. & Mattingly, C. F. (1998). The complexities embedded in family-centered care . American Journal of Occupational Therapy, 52, 259-267.

Lewis, P (87 A.D., December). My Other Brother Daryl. Tash Newsletter.

Linder. Old/New Thinking. 1995. Ref Type: Unpublished Work

Mandi S.Newton (2000). Family-Centered Care: Current realities in parent participation. Pediatric Nursing, 26, 164-168.

McCroskey, J. & Meezan, W. (2002). Family-centered services: Approaches and effectiveness . The Future of Children Protecting Children From Abuse and Neglect, 8, 54-70.

Olsen, J. & Esdaile, S. (2000). Mothering young children with disabilities in a challenging urban environment. American Journal of Occupational Therapy, 54, 307-314.

Rosenbam, P., King, S., Law, M., King, G., & Evans, J. (2002). Family-centered services: A conceptual framework and research review. Physical& Occupational Therapy in Pediatrics, 18, 1--20.

Schaaf, R. & Mulrooney, L. L. (1989). Occupational therapy in early intervention: A family-centered approach. American Journal of Occupational Therapy, 43, 745-754.

Shelton, T. L., Jeffson, E. S., & Johnson, B. H. (1 A.D.). Family centered care for children with special health care needs. Washington, D.C.: Association for the care of children's health.

Shelton, T. L., Johnson, B. H., & Jeppson, E. S. (1987). Family-Centered Care for Children with Special Health Care Needs: AN Overview. In Division of Maternal and Child Health (Ed.), Family -centered care for children with special health care needs (2 ed., pp. 1-5). Washington, Dc: Association for the Care of Children's Health.

Shonkoff, J. & Meisels, S. J. (2002). Guide for gathering family information through discussion. In Handbook of Early Childhood Intervention (2 ed., pp. 227-232). Cambridge University.

Singer, G. H. & Powers, L. E. (2002). Contributing to resilience in families: An overview . In Singer and Powers (pp. 1-25).

Tomko, C. Kids Together, Inc. Tips for Getting What Your Child Needs. 1998.
Ref Type: Unpublished Work

Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2002). Collective empowerment as the model for the early twenty-first century. In Evolution of family-Professional Partnerships (pp. 630-650).

University of Kansas. Beach Center How To: Give Family-Centered Care. 2002. The University of Kansas: The Beach Center on Families and Disability. Ref Type: Pamphlet

University of Kansas. How To : Honor Cultural Diversity. 2002. The University of Kansas, The Beach Center on Families and Disability. Ref Type: Pamphlet

Vandercook, t., York, J., & Forest, M. (1989). The Mcgill action planning system(MAPS): A Strategy for building Vision. JASH, 14, 205-215.

## Appendix A

Appendix A is a list of competencies relevant for early interventionists working together with families and their child(ren) with disabilities. These competencies were developed as a part of a personnel preparation grant from the Department of Education No. H029G970066-98. Content of the competencies was gathered from pre-existing professional publications, focus groups with both occupational and physical therapists and focus groups with families of children with disabilities. The document is for self-evaluation purposes for both practicing therapists and students entering the field of early intervention.

Following the competencies, a blank Action Plan is included to develop a personal professional development plan. Be realistic and plan for a one-year time frame when creating the plan. If possible use the Action Plan with your supervisor or a colleague to discuss resources available to support your plan.

**MCP Hahnemann University**
**Department of Rehabilitation Sciences**
**Programs in Pediatric Physical The rapy**
Lisa Ann Chiarello, PT, PhD

**Thomas Jefferson University**
**Department of Occupational Therapy**
**Child & Family Studies Research Programs**
Suzanne A. Milbourne, MS, OTR/L

## Specialty Certificate Program in Early Intervention DOE Grant # H029G970066-98

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| **Content Area A**<br>**The context of therapy in early intervention settings** | | | |
| 1. *Knowledge of local, state and federal laws, rules and regulations regarding service delivery<br>*a) discuss the implications of PL 94-142, PL 99-457, and PL 105-17 and their reauthorizations*<br>*b) apply the guidelines of federal, state and local regulations*<br>*c) identify and use information sources for federal, state, and local legislation and regulation changes*<br>*d) discuss and demonstrate professional behavior regarding ethical and legal responsibilities*<br>*e) discuss professional competencies as defined by professional organizations and state regulations*<br>*f) advocate to support family and child entitlements* | **1 2 3 4** | | |
| 2. *Knowledge of the central importance of family and is able to provide family-centered services<br>*a) conduct a family interview using active listening skills to gather information on: family's knowledge, strengths, concerns, and priorities regarding their*<br>*i. child*<br>*ii. family lifestyle and beliefs*<br>*iii. services and outcomes desired*<br>*b) respect the family and acknowledge that the family is the most significant member of the team*<br>*c) recognize that children are best understood in the contexts of family, culture, and community* | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| | | | |
| 3. Knowledge of family systems theory and its application to practice<br>a) Identify and discuss how the following factors may affect a child's and family's experience with an early intervention program:<br>*i. cultural*<br>*ii. socioeconomic*<br>*iii. ethical*<br>*iv. historical*<br>*v. personal values* | **1 2 3 4** | | |
| 4. *Recognize the impact of a child with special needs on a family unit throughout the family life cycle<br>a) describe a typical daily routine and activities that families may encounter<br>b) implement basic strategies to support the family unit, including the parents, parent-child relationships, and sibling subsystems | **1 2 3 4** | | |
| 5. *Support the parents' primary roles as mother and father to the child<br>*a) assist the family in identifying and developing:*<br>*i. internal and external resources*<br>*ii. a social support network*<br>*iii. advocacy skills*<br>b) advocate the right of parents to be decision makers in the early intervention process<br>c) provide parents with the information and options needed for informed decisions<br>*d) respect parents' choices and goals for their children* | **1 2 3 4** | | |
| 6. *Collaborate and encourage family involvement with the early intervention process | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| *a) implement, a range of family-oriented services based on the family's identified resources, priorities, and concerns*<br>*b) provide information on family oriented conferences and support groups in the community*<br>*c) demonstrate people first and family friendly communication and interaction skills*<br>*d) communicate effectively with parents about curriculum and child's progress* | | | |
| **Content Area B**<br>**Wellness and prevention in early intervention settings** | | | |
| 1. Promote public awareness of early intervention services<br>*a) disseminate information about the availability, criteria for eligibility, and methods of referral*<br>*b) collect and use data from multiple sources for child-find systems* | **1 2 3 4** | | |
| 2. Design and implement a screening program to identify infants and toddlers at risk for developmental delay<br>*a) demonstrate knowledge of genetic and cultural differences in standards of growth and development*<br>*b) identify the etiology, signs & symptoms, and classifications of common pediatric disabilities*<br>*c) identify established biological and environmental factors that affect children's development and learning*<br>d) *demonstrate understanding of developmental consequences of maternal health & nutrition, social supports, and stress* | **1 2 3 4** | | |
| 3. *Select, administer, and interpret a variety of screening instruments and standardized measurement tools<br>*Apply knowledge of:*<br>*a) child development from cognitive, adaptive, motor, social-emotional, and communication perspectives*<br>*b) the interrelationship among developmental areas*<br>*c) the range of normal variations of development* | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| *d) the difference between delayed and atypical development* | | | |
| 4. Promote child safety by educating caregivers on:<br>*a) child development*<br>*b) environmental and toy hazards and safety measures*<br>*c) accident prevention*<br>d) recognition of child neglect and abuse | **1 2 3 4** | | |
| **Content Area C**<br>**Coordinated care in early intervention settings** | | | |
| 1. *Form a partnership and work collaboratively with other team members, especially the child's family<br>*a) refer and coordinate services among family, other professionals, community agencies, day care programs*<br>*b) demonstrate effective and appropriate interpersonal communication skills*<br>*c) implement strategies for team development and management*<br>*d) develop mechanism for ongoing team coordination*<br>*e) function as an interdisciplinary or transdisciplinary team member*<br>*f) if applicable, serve as a service coordinator* | **1 2 3 4** | | |
| 2. Function as a consultant<br>a) identify the administrative and interpersonal factors that influence the effectiveness of a consultant<br>b) provide technical assistance to other early intervention team members, community agencies, and medical facilities | **1 2 3 4** | | |
| 3. Supervise personnel and professional students<br>*a) monitor the implementation of therapy recommendations by other team members*<br>*b) establish a student clinical affiliation*<br>*c) formally and informally teach/train therapy staff* | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| **Content Area D**<br>**Examination and evaluation in the early intervention setting** | | | |
| 1. *Individualize the examination and evaluation for child, team, and family needs.<br>*a) offer flexible scheduling*<br>*b) provide options for multiple settings*<br>*c) solicit input on the process*<br>*d) establish consensus of content including domains of child development and family routines* | **1 2 3 4** | | |
| *2.* *Evaluate family strengths, resources, concerns, and priorities<br>*a) conduct family interview*<br>*b) select and administersupplemental family surveys* | **1 2 3 4** | | |
| 3. Selectively gather, interpret, and report information from available medical/developmental records | **1 2 3 4** | | |
| 4. *Examine and evaluate child abilities and strengths:<br>*a) functional ability including activities of daily living, play, and gross motor, fine motor, perceptual motor, and oral motor skills,*<br>*b) musculoskeletal status*<br>*c) neuromotor status*<br>*d) sensory status*<br>e) *cardiopulmonary status* | **1 2 3 4** | | |
| 5. *Utilize valid, reliable, and nondiscriminatory examination instruments and procedures for:<br>*a) identification & eligibility*<br>*b) diagnostic evaluation*<br>*c) individual program planning*<br>d) *documentation of child progress, family outcomes, and program impact* | **1 2 3 4** | | |
| 6. Function as a team leader and/or member in a multidisciplinary, | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| interdisciplinary, or transdisciplinary assessment<br>*a) organization*<br>*b) time management*<br>*c) timeliness*<br>*d) constructive feedback*<br>*e) consensus building*<br>*f) wrap-up* | | | |
| **Content Area E**<br>**Planning** | | | |
| 1. *Actively participate in the development of the Individualized Family Service Plan:<br>*a) accurately interpret and communicate examination findings to the family and other team members*<br>*b) discuss and integrate examination findings from family and other team members*<br>*c) solicit from family their goals of the early intervention process*<br>*d) Prioritize needs identified during examination according to:*<br>*i. family preference and goals*<br>*ii. environmental demand*<br>*iii. future environmental demands*<br>*iv. resources*<br>*v. developmental level*<br>*vi. past history*<br>*e) collaboratively establish IFSP outcomes that are meaningful to the child and family*<br>*f) communicate options for strategies, programs and services to family*<br>*g) establish consensus on strategies, programs and services* | **1 2 3 4** | | |
| 2. *Integrate an interdisciplinary understanding of the home, child care, medical and social community of the child and family into | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| the IFSP:<br>*a) inquire about family routines and activities*<br>*b) establish contact and with permission consult with day care / preschool providers*<br>*c) establish collaborative relationship with any relevant medical personnel*<br>*d) inquire about community resources from local interagency coordinating council*<br>*e) gather with family information on community activities, programs, services, and resources* | | | |
| 3. *Develop mechanism for ongoing coordination and collaboration regarding the IFSP<br>*a) implementation of the IFSP*<br>*b) update or modify IFSP*<br>*c) transition planning & implementation of the transition plan*<br>*d) interagency activities* | **1 2 3 4** | | |
| **Content Area F**<br>**Intervention** | | | |
| 1. *Develop and implement appropriate intervention programs and strategies that address or incorporate:<br>*a) self-care, mobility, learning and play*<br>*b) values of the family and child's culture*<br>*c) developmentally and individually appropriate activities*<br>*d) environmental adaptations in the home and community*<br>*e) information and strategies from multiple disciplines*<br>*f) medical care of infants and toddlers*<br>g) *methods of behavior support and management* | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| 2. *Assist families in accessing services that promote full inclusion of child and family into the community<br>*a) provide services in the child's natural environments*<br>*b) communicate with, and educate, family/caregivers, teachers, and others regarding intervention strategies*<br>*c) implement small group parent-child and peer activities when appropriate for a particular community setting*<br>*d) link current intervention plan with the next educational setting* | **1 2 3 4** | | |
| 3. *Integrate therapy intervention strategies into home and community settings:<br>*a) support and facilitate family child interaction as primary context for learning and development*<br>*b) utilize daily routines including child care activities such as feeding, bathing, dressing, and playing*<br>*c) utilize parent and child mediated activities during intervention*<br>*d) modify intervention strategies according to changes in the child's interests, functional level, medical status, or family needs* | **1 2 3 4** | | |
| **Content Area G**<br>**Documentation issues in early intervention settings** | | | |
| 1. Produce useful written documentation by:<br>*a) utilizing commonly understood and meaningful terms*<br>*b) maintaining timely and consistent records*<br>*c) concisely summarizing relevant information*<br>*d) sharing records with family and other team members* | **1 2 3 4** | | |
| 2. *Demonstrate the ability to write the IFSP document, including:<br>*a) current developmental and functional status of the child*<br>*b) long-and short-term child and family objectives that are meaningful, functional and measurable*<br>*c) objective means of monitoring progress*<br>*d) description of the early intervention and community services*<br>*e) justification for frequency, intensity, location, & service delivery* | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| 3. Document to convey information to family, other team members, and funding agencies including:<br>*a)* summary of intervention session<br>*b)* child' s response<br>*c)* ideas for daily activities and routines<br>*d)* plans for new intervention strategies and resources | **1 2 3 4** | | |
| *4.* *Collaboratively monitor and modify child's intervention plan<br>*a) establish a mechanism for ongoing communication with family and other team members*<br>*b) record summary of communications with family and other team members*<br>*c) establish a plan for re-evaluation*<br>*d) schedule pre-established team meetings to review child's progress* | **1 2 3 4** | | |
| 5. *Evaluate and document the effectiveness of therapy intervention strategies and therapeutic procedures<br>*a) establish baseline of child's developmental and functional status*<br>*b) collect ongoing data on the child's progress toward stated IFSP outcomes*<br>*c) summarize data to determine child's progress*<br>*d) make recommendations for modifications of IFSP* | **1 2 3 4** | | |
| **Content Area H**<br>**Administration issues in early intervention settings** | | | |
| 1. Function as an administrator:<br>*a) identify the philosophy, goals, structure and function, and administrative needs of the early intervention program and therapy services*<br>*b) apply knowledge of other disciplines' roles and functions for program planning and policy formation*<br>*c) develop and implement criteria and procedures for job* | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| *descriptions, recruitment, staff selection, supervision, and performance appraisals*<br>*d) develop therapy policies and procedures*<br>*e) direct therapy services and delegate appropriate responsibilities*<br>*f) establish appropriate and manageable caseloads*<br>*g) meet deadlines in order to be able to provide services in a timely and efficient manner*<br>*h) identify and develop appropriate referral mechanisms*<br>*i) develop procedures for documenting service in accordance with Codes of Ethics, funding agency policies, and federal, state, and local regulations* | | | |
| 2. Demonstrate the ability to assist and support the professional development of early intervention personnel<br>*a) identify and access intramural and extramural funding sources and resources*<br>*i. community*<br>*ii. state*<br>*iii. national*<br>*b) provide onsite inservice training*<br>*c) establish intra-agency mentoring program*<br>*d) implement individualized professional development plan* | **1 2 3 4** | | |
| 3. Demonstrate leadership abilities in promoting effective team processes<br>*a) facilitate regularly scheduled staff meetings*<br>*b) implement mentor program*<br>*c) provide opportunity for staff inservices*<br>*d) selectively delegate responsibilities*<br>*e) allocate time for team collaboration*<br>*f) mediate team differences* | **1 2 3 4** | | |
| **Content Area I**<br>**Research in early intervention settings** | | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| 1. *Demonstrate knowledge of current research relating to infant development, medical care, and developmental intervention for infants and toddlers<br>*a) conduct a literature review using such reference materials as Index Medicus, or other data base sources*<br>*b) seek assistance from experienced researchers in interpreting published research*<br>*c) critically evaluate published research* | **1 2 3 4** | | |
| 2. *Apply knowledge of research to the selection of therapy intervention strategies, service delivery systems, and therapeutic procedures in early intervention<br>*a) use objective criteria for evaluation*<br>*b) justify rationale for clinical decision making*<br>*c) expand clinical treatment cases into single-subject studies* | **1 2 3 4** | | |
| 3. Partake in program evaluation and clinical research activities with the appropriate supervision<br>*a) identify topics in early intervention in which research efforts are needed*<br>*b) secure resources to support clinical research*<br>*c) implement clinical research projects*<br>*d) disseminate research findings* | **1 2 3 4** | | |
| Content Area J<br>**Professional Development** | | | |
| 1. Utilize opportunities and resources available to enhance professional knowledge, skills, and attitudes | **1 2 3 4** | | |
| 2. Attend study groups, conferences, workshops, and continuing education courses | **1 2 3 4** | | |
| 3. Serve on committees, advisory boards, work groups and task forces | **1 2 3 4** | | |

| **Content Area**<br>Competency<br>*Indicator* | **Self Rating** | **Action Plan** | **Evidence for Achievement** |
|---|---|---|---|
| 4. Present at inservices, conferences, workshops, and courses | **1 2 3 4** | | |
| 5. Publish on current issues | **1 2 3 4** | | |
| 6. Enroll in post professional certification or degree programs | **1 2 3 4** | | |

This document provides a comprehensive list of professional competencies for therapists in early intervention. The competencies that are noted with an * are specifically addressed in MCP Hahnemann University, Department of Rehabilitation Sciences, Specialty Certificate Program. The document can assist you in your overall professional development.

Self Rating Scale for Competencies: Review the suggested behavioral indicators associated with each competency to determine your individual level of achievement.
1 = No experience
2 = Minimal competence
3 = Emerging competence
4 = Achieved

Action Plan: Steps to be taken and resources to be accessed in order to achieve competency. May include: plans to take a course, a specific course assignment, a job-related activity, inservices and other continuing education, literature analysis, consulting with an expert in the area, shadowing an expert in the area, etc.

Evidence of Achievement: Objective documentation which demonstrates that you have achieved the competency. This may include: actual client reports (ie. IFSP documents), videotapes of family interview or intervention, handouts from a presentation that you developed, written assignments/papers, etc. This documentation should be included in your student portfolio.

3/3/00

**Appendix B**

**Activity Log** **Name** _____

| Date | Time of day spent with the family | Description of the activities and routines experienced with the family |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

**The activity log can be typed or hand recorded. This form may be copied and used. The description of activity column should include objective, specific information about the activities and routines. Refrain from personal reflection or interpretation, that is to be included in your reflection journal (appendix C).**

**Appendix C**

**Reflection Journal – guiding questions**

What happened during the day/week that you expected to happen?

What did you not expect?

From the unexpected outcomes, what did you learn?

What new questions or thoughts do you have?

What are some things that challenged you to think about your own judgements, perceptions, values, beliefs, etc.?

What are some things you learned from the family visit that will impact how you work with families as an early interventionists?

If you were providing intervention to this family what would you focus on? Why?

What are some things that you need to find out about the family/child? What is the significance of acquiring this information? How will you acquire this information?