Strategies for Developing Family-Directed Outcomes

A Workbook for Service Providers Who Work With Infants and Toddlers, Birth to 3

MACMH

Minnesota Association for Children's Mental Health

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Prepared by
Minnesota Association for Children's Mental Health
Deborah Saxhaug, *Executive Director*

Workbook Development: Kate Shields Stenzinger and Cynthia Moore
Assistance and Support: Wendy Mahoney, Julie Peck, Jane Reilly, and Sara Tinklenberg
Graphic Design: Matt Jenson and April Tighe

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Minnesota Department of Education, Division of Early Learning Services (MDE)
1500 Highway 36 West, Roseville, MN 55113

Minnesota Association for Children's Mental Health MACMH)
165 Western Avenue N, Suite 2, St. Paul, MN 55102 • 651-644-7333 or 800-528-4511 • www.macmh.org

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Free copies of this and related materials available after February 15, 2007, at
http://education.state.mn.us/MDE/Learning_Support/Special_Education/Birth_to_Age_21_Programs_Services/Early_Childhood_Intervention/index.html
and www.macmh.org/publications.

Welcome!

As workers in the field of early childhood intervention, we routinely record what we do—we keep track of how many visits we make, how many minutes we spend with each family, and even how many repetitions of an activity we watch a child perform. At times we even measure how satisfied families are with the services we provide. We don't, however, usually measure what changes occur because of our work with a specific family. As a result, we sometimes have only an anecdotal sense of whether our work has led to positive and meaningful changes for families.

That has changed. New federal accountability standards that accompanied the 2004 reauthorization/revision of IDEA (now IDEIA—the Individuals with Disabilities Education Improvement Act), focus specifically on the outcomes (or benefits) that are reported by families after they have received Part C services. This means that families who receive services funded by Part C dollars will be asked to describe the benefits their family experienced as a result of the services they have received.

Part C
refers to a section of IDEA that directs the provision of early intervention services to infants and toddlers with disabilities and their families. IDEA is the federal law that also provides for a Free Appropriate Public Education for all children with disabilities from 3 - 21.

Is this a good thing, or is it just more paperwork that will take us away from spending time with the families who need our help? Is this, in effect, an early childhood provider's equivalent to "teaching to the test"?

Here's the good news—we believe that this will actually benefit us as providers!

How, you may ask, could a federal mandate be beneficial to both families and providers? "Strategies for Developing Family-Directed Outcomes" uses a family-directed intervention model that emphasizes a proactive, highly responsive approach to working with families. This approach is specifically designed to help you develop strategies and practices that will not only enrich your interactions with families, but also ensure that families you have worked with will report that, YES! their participation in Part C services did lead to significant positive outcomes.

How the Workshop and Workbook Work Together

During this workshop you'll be actively participating, which means you may not have time to write down everything the presenters will discuss, nor will you likely have time to record all the content you see on the screen. Not to worry—this workbook contains all the key points you may want to refer back to when you leave here today, and MORE!

The workbook contains:

- Background information on the research-based strategies and practices recommended in your training, including reprints of articles, references to readings, and related resources
- Additional reflective exercises to help you clarify why and how to use these strategies and build your skills
- Resources to assist your work with parents of young children with disabilities including hearing impairment, autism spectrum disorders, mental health disorders, and fetal alcohol spectrum disorders.

The Workshop

This workshop is designed to give you several tools to help you develop successful family outcomes in your work as an early intervention service provider. These tools will help you increase the number of families participating in Part C who report that early intervention services helped them to effectively communicate their children's needs, to know their rights, and to help their children develop and learn. We will do this by focusing on "family-directed family outcomes." While this may sound repetitive and a little bit clumsy, it is actually a very potent concept. It means that your families' outcomes (or benefits) will be meaningful to the family as a whole and be developed in partnership with the family.

By participating in this workshop you will:

- Learn how to guide a family through the process of developing strategies that will directly benefit their family as a whole
- Understand the importance of including individualized family outcomes in the IFSP
- Receive the research materials used to develop this training, exercises to broaden your skills, and resources for further use.

PLEASE NOTE: This workbook is not intended for stand-alone use. This workbook is a supplement to the workshop "Strategies for Developing Family-Directed Outcomes," which is available from the Minnesota Association for Children's Mental Health or online at *www.macmh.org/publications* or *www.education.mn.us/Learningsupport*.

Why the Focus on Family-Directed Family Outcomes?

Focusing on Family-Directed Family Outcomes

The Research-Based Reason

For an infant or toddler with disabilities, the family is the on-going teacher, advocate, and visionary – it is the family that dreams a future for their child and makes it happen. For this, a family needs assistance, knowledge, and skills, as well as the trust and confidence of the many professionals who are involved in their child's life.

Urie Bronfenbrenner, who researched effective early intervention practices, discovered that interventions focused on the parent and child produced longer-lasting gains than interventions that focused on the child-only (cited in Erickson, Kurz-Riemer, 1999, and Dunst, Trivette, Deal, 1988). Other researchers have also documented that a child's family plays a critical role in a child's overall development; therefore, helping families attain family outcomes has a direct bearing on an individual child's outcomes.

Having a secure family base is vital to overall child development.
For more on the importance of family attachement and security (and for general information about early childhood mental health), visit www.circleofsecurity.org, zerotothree.org, and www.macmh.org.

The Federal Reporting Reason

According to the federally-funded Early Childhood Outcomes Center (ECO), organizations have often measured families' satisfaction with services rather than the outcomes (or benefits) a family has experienced as a result of the services. However, as mentioned earlier, the recently revised and reauthorized IDEA (now known as IDEIA) carries a new reporting requirement: All recipients of Part C funding must submit outcomes data in their annual performance report (APR).

To ensure that the new reporting standard will be beneficial to families, children, and service providers, the U.S. Department of Education, Office of Special Education Programs (OSEP) has worked with the Early Childhood Outcomes Center (ECO) to develop and implement a meaningful measurement system. Whereas previous reporting standards have focused on the process of how a family is served and the satisfaction of the parents with the services, the new reporting standards go a step further and consider whether the services resulted in the family being successful in meeting their child's special needs.

Accountability *increasingly means looking at results – not just process.*

The actual measurement system is based on three family outcomes that are intended to measure whether or not a family's months or years in Part C services have resulted in improvements in the family's ability to help their child develop and learn. Specifically, families participating in Part C will report whether early intervention services have helped their family:

- Understand their child's strengths, abilities, and special needs (effectively communicate their children's needs)
- Know their rights and advocate effectively for their children
- Help their children develop and learn

According to IDEA, the IFSP must contain a statement of the family's resources, priorities and concerns related to enhancing the development of the child with a disability.

OSEP has funded the Early Childhood Outcomes Center (ECO) to make recommendations and to assist states in developing and implementing outcome measurement systems. www.the-eco-center.org

Voilà: Research and Reporting Standards Come Together

Just as independent researchers have found that a child's family plays a critical role in a child's development, the federal government has determined that funding for early intervention programs should be tied to the family's success in understanding their child's unique needs, knowing how to get those needs met, and continually working toward helping their child develop and learn.

What Does This Mean for Minnesota Service Providers?

For Minnesota providers, this means that data relevant to the 3 outcomes stated above will be reported for any child/family who has received services in Minnesota for 6 months or more AND who is exiting services under Part C because:

- Their child is turning 3.
- The family is moving out of the state.
- The family has opted to discontinue services.
- A reevaluation has determined the child is no longer a child with a disability.

The Family Outcomes Survey developed by ECO will be posted on the MDE website in multiple languages. Reading through the survey to get a sense of its depth and breadth will likely be of great value.

Your role in collecting the outcomes data for the state of Minnesota will be this:

- As a child exits Part C, district staff will print a copy of the survey (in the appropriate language) with the MARSS number for the child.
- Staff will deliver the survey and envelope addressed to the Minnesota Department of Education to the parent during a home visit near the time the child is due to exit early intervention services under Part C. The envelope should, of course, already include proper postage.

Getting Started

What is a Family Outcome?

A benefit experienced by families as a result of services and supports received.

An outcome is not the receipt of services or satisfaction with services. An outcome is what happens as a result of services provided to families.
(Bailey, Bruder, & Hebbeler, 2006)

Understanding Outcomes

Because the families you are working with will soon be responding to a survey that asks them to report on the "Outcomes" they achieved while participating in Part C services, we are going to begin by developing a firmer understanding of what is meant by "Outcomes."

Activity 1

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Here are a few outcomes we hope will occur as a result of this training:
You will—

- Understand the importance of keeping services (and therefore outcomes) family-directed.
- Be able to help families turn their concerns into specific statements of need.
- Know how to help families recognize and build on their strengths (and know the value of this).
- Know how to help a family enhance their ability to mobilize resources.
- Know how to use ecomaps to promote untapped resources to insure the availability and adequacy of resources for meeting the identified needs of the family.

To Achieve Family-Directed Family Outcomes We Must Enable, Empower, and Strengthen

You may be wondering why we keep referring to "family-directed family outcomes." It's because we believe that to achieve outcomes that benefit a family, the family themselves must be interested, invested, and involved in the developing the outcomes. In fact, the family-directed model we will explore today emphasizes a proactive, highly responsive approach to working with families.

First, we emphasize both enabling and empowering families. Enabling families means creating opportunities for family members to become more competent, independent, and self-sustaining when it comes to mobilizing their social networks to get their needs met and attain desired goals. Empowering families means carrying out interventions so that family members are able to control how their child's (and their family's needs) are met.

Second, we emphasize strengthening both families and their natural support networks. Our goal is to help families clarify and strengthen their decision-making skills rather than usurping their power; we also want to help families identify their personal social support networks rather than supplant those networks with professional services.

Third, we emphasize enhancing families' acquisitions of a wide variety of competencies that allow them to capably meet the needs of their family by mobilizing their support networks.

Enabling, empowering, and stregthening families constitute the major goals of the family-directed model.

Activity 2

Thinking about the 3 concepts above, answer the following questions:

1. **What are the benefits to you and the programs you support of writing family-directed family outcomes?**

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Activity 2 *(continued)*

2. What are benefits for families?

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3. How will an individual child benefit from family-directed family outcomes?

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Empowering, Enabling, and Strengthening Families—A Shift in Focus

When we empower families, we acknowledge that:

- The families we work with are already competent or have the capacity to become competent.
- A person's failure to display competence at a given moment is not due to deficits in the person, but a failure of the social system to create opportunities for competencies to be displayed.
- Success will be achieved when a parent attributes behavior change to his or her own actions and feels the sense of control necessary to manage family affairs.

Our collective professional goal then must be to ***empower*** and ***enable*** families to achieve their own stated outcomes! But to do that, we may need to shift our focus.

If as a practitioner you typically focus on treating problems and preventing negative outcomes, we invite you to shift your focus.

Developing family-directed family outcomes means having a proactive stance toward families. This means our focus needs to shift away from "treating" problems or "preventing" negative outcomes and instead emphasize ***growth-producing behavior***.

If as a practitioner you typically focus on the needs you as a trained professional believe most need to be met, we invite you to shift your focus.

We will identify and build on family's capabilities in order to strengthen the family. This means we must shift our focus away from professionally identified needs and instead emphasize the family's goals (Dunst, Trivette, and Deal, 2003).

One Example of the Value of Empowerment

One of the three major outcomes OSEP will be tracking is each family's ability to serve as their child's lead advocate. Just because a person has a child with a disability does not mean they necessarily have the skills and temperament to naturally become an advocate for their child. However, as early childhood service providers, we can empower the family members we work with to discover their potential. In fact we know that all of the parents you are working with right now (even the "difficult" ones), each have the capacity to become an advocate for their child.

OUR role is to help families assess
- *THEIR Resources*
- *THEIR Priorities*
- *THEIR Concerns*

A person who feels empowered and who has had the opportunity to develop their confidence and competence will be able to engage the specific activities this kind of advocacy requires. An empowered parent will gather relevant information, seek out and attend appropriate trainings, learn more about their child's disability through books and on-line sources, and perhaps even join or possibly even facilitate a support group.

When a parent learns the information and skills they need to advocate, they can more fully and capably engage the services your program provides.

Some parents may want advocacy skills written as a family outcome; others though may just want to review the basics briefly and be given copies of their district's Procedural Safeguards or other materials provided by your IEIC.

For more information on introducing families to their role on the Early Intervention team, see the article by Joicey Hurth & Paula Goff on the NECTAC website: www.nectac.org/~pdfs/pubs/assuring.pdf.

Watch this website for revisions that reflect the latest versions of Part C regulations now in preparation.

Strategies

Concerns

According to Dunst, Trivette, and Deal (2003), **concerns** *are the recognition that what is and what ought to be are very different. A* ***need*** *is the recognition that* ***something*** *can reduce the distance between what is and what ought to be.*

In the empowered, enabled, and strengthened family ALL family outcomes should be identified by the family. It is the family's rightful role to determine what is best for their family.

But how exactly can providers who have been working in the "treatment" and "prevention" models move toward the family-directed family outcome model?

Principle 1: Identifying Needs

Outcomes are based on the needs, interests, and strengths of caregivers The greatest impact on child, parent, and family functioning will most likely occur when interventions are based upon the needs, aspirations, and desires that a family considers important and therefore deserving of time and energy.

One of the jobs we have as early childhood professionals is to translate each family's ***concerns*** into ***needs***. Families are usually very able to share their concerns and worries; they are not always able to articulate their needs.

The process of identifying needs can be accomplished through an interview or a formal needs assessment. This is likely done during your intake or initial work together but should continue throughout your work with a family. Use whatever process you have found effective in your work. The ***Family Storybook*** that you'll receive during this workshop is one example of a tool you can use to help you begin the conversation.

Throughout the interview each member of the family should be invited and encouraged to share their concerns, needs, and aspirations. When family members identify concerns, help them clarify the concern and define the precise nature of the need. To do this, you will likely need to ask questions that help the family members more fully understand the nature of their concern.

Identifying Needs

1. *Define for the family the purpose of the interview*
2. *If you will be using a specific tool to guide the interview, describe the tool and explain its purpose or function*
3. *Establish rapport with family members*
4. *Invite each member to share concerns and aspirations*
5. *Help families clarify concerns and define needs*
6. *Deepen the conversation, practice reflective listening*
7. *Restate the family's needs and priorities*

As professionals who are interested in empowering and enabling family members, our goal is not to use this process to give the family our answer to their problem, but to deepen the dialogue so the family will be able to connect the dots and actually understand the path between their concern and their need.

During the interview, use open-ended statements like "What are your ideas about . . . ?" and "Tell me more about . . ."

Respond to verbal and non-verbal communication such as body posture, hesitations, and tone of voice.

Reflect back what you see and hear, for example you may say, "You sounded a little uneasy when you said that Steven doesn't use words to tell us what he wants. Could it be that you are worried about whether his language development is delayed?"

At the end of the interview or discussion of formal assessment results, summarize the needs identified and work with the family to prioritize their needs.

Here are some questions you may want to add to your repertoire

1. *What routines or activities does your child not like? What makes this routine or activity difficult or uncomfortable for your child? What does your child usually do during the activity? What do you do?*
2. *Are there activities you used to do before your child was born that you would like to do again?*
3. *What would you like help with? What supports would be helpful for you and your child?*
4. *What have you thought about doing or trying?*
5. *What would you do if _______ was not a concern? (for example: money, time, transportation, childcare for siblings).*

These questions pertain to concerns about a specific challenge

1. *What have you tried?*
2. *What has worked for you in the past? What hasn't worked?*
3. *I remember when you did _____ for _____? Do you think something like that might work for ______?*
4. *I know a parent who was in a similar position; would you be interested in talking to him, meeting with her, looking at her website/blog?*

The Family Storybook provided as part of this workshop is one example of a routines-based informal interview tool. Like ***The Family Storybook***, formal routines-based assessments—such as the Ounce Scale or the Scale for Assessment of Family Enjoyment within Routines (SAFER)—are used to identify and develop interventions in the child's natural environment. These interventions promote the development of skills and behaviors that a child needs to be successful and independent in daily routines. The goal is to create functional plans that work well in a child's natural learning environments.

Formal Needs Assessment Tools

Family Needs Scale *(Dunst, Cooper, Weeldreyer, Snyder, & Chase)*
Family Needs Survey *(Goldfarb, Brotherson, Summers & Turnbull)*
Family Resource Scale *(Dunst & Leet)*
Ounce Scale *(Meisels, Marsden, Dombro, Weston, & Jewkes)*
Parent Needs Inventory *(Fewell, Meyer & Schell)*
Personal Projects Scale *(Little)*
Scale for Assessment of Family Enjoyment within Routines *(Scott & McWilliam)*
Support Functions Scale *(Dunst & Trivette)*

Activity 3

Family-Identified Needs

In the empowered, enabled, and strengthened family, ALL family outcomes should be identified by the family. It is the ***family's*** role to determine what is best for their family. As early childhood professionals who have had years of training and even more years of experience in the field, we often have very clear ideas of what, in the ideal world, a family ***should*** do (after all we are the professionals!).

But we need to avoid getting stuck in the thinking that we know what is best for a family and their child. Our job is to empower and strengthen the families we work with so that they have the confidence and capacity to make the best decisions for their family. It's not about right or wrong; it's about what works for each family. According to Dunst et al.,

> Sooner or later the professional will see him or herself as right and the family as wrong and try to convince or even coerce the family into doing what the help-giver considers appropriate or right. We describe such situations as *oppositional encounters*. How many of us have seen others or even seen ourselves consider a child to have developmental needs that require intervention when the child's parents did not think there was anything wrong? And how many times have we felt obligated to inform parents that unless they intervened, their child might become more retarded or delayed? . . . We engage in oppositional encounters where there are no winners, only losers.

One way to avoid getting stuck is to train ourselves to see multiple options and opportunities for each family. Sometimes we have to step back, be more creative, and broaden our understanding of the possible interventions.

To truly empower and strengthen a family, we, the professionals, must also spend some time learning: we have to take time to learn what the ***family*** identifies as being worthy of their time and effort. Sometimes this may mean that we have to respect a family's right to say that they just are not ready for a specific intervention that we, in our professional opinion, would like them to try. Each family and each family member will accept a child's disability in their own time and in their own way.

Principle 2: Recognizing Family Strengths

Once a family has identified their concerns and prioritized their needs, they need to figure out how to get their needs met. In the family-directed model where families are empowered, enabled, and strengthened, the family must (with your professional guidance) discover what they do well and use their strengths to develop a plan of action to get their family's needs met.

NOTE: This will be easier for some families than for others. *Unfortunately some families may not be used to hearing about or talking about their own strengths because they have been focusing for too long on what's been going wrong. Some families may not think their family has any strengths.*

According to VanDenBerg & Grealish (1997) some people are raised to view talking about strengths as bragging. They report, "Some family members may be so focused on the negative information that they find it difficult to address strengths. Thus it may be necessary to let a person talk about their concerns and fears before they will talk about their strengths. However, it is important to be persistent and thorough about moving as quickly as possible into a discussion of the good news."

- To do this, the family will need your support and encouragement to think creatively about how their current situation can be used to promote positive family changes.

- They will also need your trust as they develop a plan of action that will create opportunities for their family members to display their competencies or develop the competencies they need to put their plan into action.

A family is a system of interconnected individuals who provide support and resources for each other. Use the family's existing strengths and capabilities (family functioning style) to help them recognize what they do well. Then help them to apply these strengths to the tasks that need to be done to get their needs met.

To begin to recognize what a family's strengths are, ask yourself, "How does this family deal with life's challenges? What things are the family already doing well?"

Questions to Ask

1. *What are your favorite things to do together?*
2. *Do you have any hobbies or interests that you enjoy or find relaxing? Use observation as well, notice books, crafts, gardens, etc… as a sign of strengths.*
3. *What are the best things about you? Your family? Your community?*
4. *What difficult decisions have you made that make you proud now?*

Activity 4

In order to recognize family strengths in the families we work with, we need to generally define healthy family characteristics. List 12.

Healthy Family Characteristics

1. ____________________

2. ____________________

3. ____________________

4. ____________________

5. ____________________

6. ____________________

7. ____________________

8. ____________________

9. ____________________

10. ____________________

11. ____________________

12. ____________________

Research suggests the following 12 characteristics (Dunst, Trivette, & Deal, 2003):

Healthy Families...

1. Have a sense of commitment toward promoting the well-being and growth of individual family members and the family system.
2. Appreciate individual family members' strengths in the family, the big and small things.
3. Spend time together.
4. Have a sense of purpose.
5. Agree on the value and importance of assigning time and energy to meet needs.
6. Communicate in ways that encourages positive interactions.
7. Have clear rules, values and/or beliefs that guide expectations of acceptable and desired behavior.
8. Solve problems together.
9. Have varied coping strategies to deal with everyday and unusual life events.
10. Have a positive outlook and can view challenges as a chance to learn and grow.
11. Flex and adapt to changing roles as they pursue resources.
12. Use a balance of internal and external family resources for coping and adapting to life events and planning for the future.

Formal Family Strengths Assessment Tools

Family Functioning Style Scale *(Deal, Trivette, & Dunst)*

Family Strengths Inventory *(Stinnett & DeFrain)*

Family Strengths *Questionnaire (Otto)*

Family Strengths Scale *(Olson, Larsen, & McCubbin)*

Formal family strengths assessment tools can also be used. When you use these tools to determine a family's strengths, use the results as a starting point for discussing specific family strengths.

As you are working with family members, keep these 12 qualities in mind (feel free to use chart on next page). As you are listening to the stories the family tells, listen especially for examples of positive family traits that you can point out to the family. Notice and share with the family the strengths you observe. You can even suggest that the parents add these to the Storybook on the "Gifts I Give My Child" page.

Remember that some families are not used to hearing about or talking about their own strengths because they have been focused on what's been going wrong. All too often, by the time family members become involved with Part C services, they have been told in no uncertain terms what is wrong with their family and what their family's weaknesses are.

When you see a family who has this perspective, let them know, in no uncertain terms, that they do have strengths! Rephrase and reframe negative comments into positive ones. Offer the family a new way of looking at their own behaviors. For example, say to an indecisive or hesitating parent, "You are taking this decision very seriously and trying not to make a mistake," and to a father who denies his son's need for services, "Johnny is so lucky to have a dad who sees all his strengths."

Enable every family you work with to recognize their family's strengths, talents, skills, and positive characteristics.

Share with families the strengths you observe.
Encourage parents to add them to the "Gifts I Give My Child" page of the ***Family Storybook****.*

Family Strengths Profile

(from Dunst, Trivette & Deal, 2003)

												Family Behavior	
												Commitment	Family Strengths
												Appreciation	
												Time	
												Sense of Purpose	
												Congruence	
												Communication	
												Role Expectations	
												Coping Strategies	
												Problem Solving	
												Positivism	
												Flexibility	
												Balance	
												Intrafamily	Type of Resource
												Extrafamily	

Diversity and Family Strengths

Sometimes our cultural background leads us to overlook or even see as negative, a parent trait that may, in fact, be a strength. When we cannot find strengths, we often need to step back and look from another viewpoint. This may mean asking yourself "How am I different from this parent?" It may require reframing your analysis. Often, it is helpful to try to uncover the meaning the parent applies to an action – it may mean something completely different than your first impression.

Activity 5

Think about how it feels to be described by your deficits and then think about how it feels to be described by your strengths.

1. **Using deficit-based descriptive terms or words, describe yourself.**
   For example, *I am a procrastinator. I am late for meetings. I don't know enough about… The inside of my car is a mess.*

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Activity 5 (continued)

2. **Now turn each of those into a strengths-based description about yourself.**
   For example, *I think through tasks before beginning them. I like to be fully prepared before I jump in. I value the opinion and expertise of others and I know where to look when I don't have the answer to something. I keep many resources with me when I make home visits.*

Principle 3:
Identifying Sources of Support and Resources

In the family-directed model, the support and resources a family will come to rely on will be ones that they are comfortable using. Families who see themselves as empowered, enabled, and strengthend will be able to—with your support, encouragement, and trust—identify reliable, appropriate resources.

Our job is to open our mind and to think creatively about a wide range of supports that may be available. We can first help the family to realize that they may already have developed a personal social network. But we can also help families scope out untapped sources of aid and assistance.

When we talk about support, we include emotional, physical, informational, and services-oriented resources. Each family will need their own unique blend of supports. For example, some families may need someone to talk to about rasing a child with a disablity, others may need information about medical care, still others may need help with transportation, child care, or meeting basic needs.

Identifying Resources

The process of identifying resouces can be accomplished through an ecomap or a social support scale. (A list of social support scales is included at the end of this section.)

An ecomap is a picture of a family and their environment. Have the family make a list of people, community organizations and agencies that they have contact with on a regular basis. Think about the stories the family members have shared with you and ask about people or resources you have heard them talk about. Ask family members who they first spoke with when they had a concern about their child. And, if you don't already know, ask about medical professionals and specialists the family is already working with. The ecomap should create a picture of the family and their community.

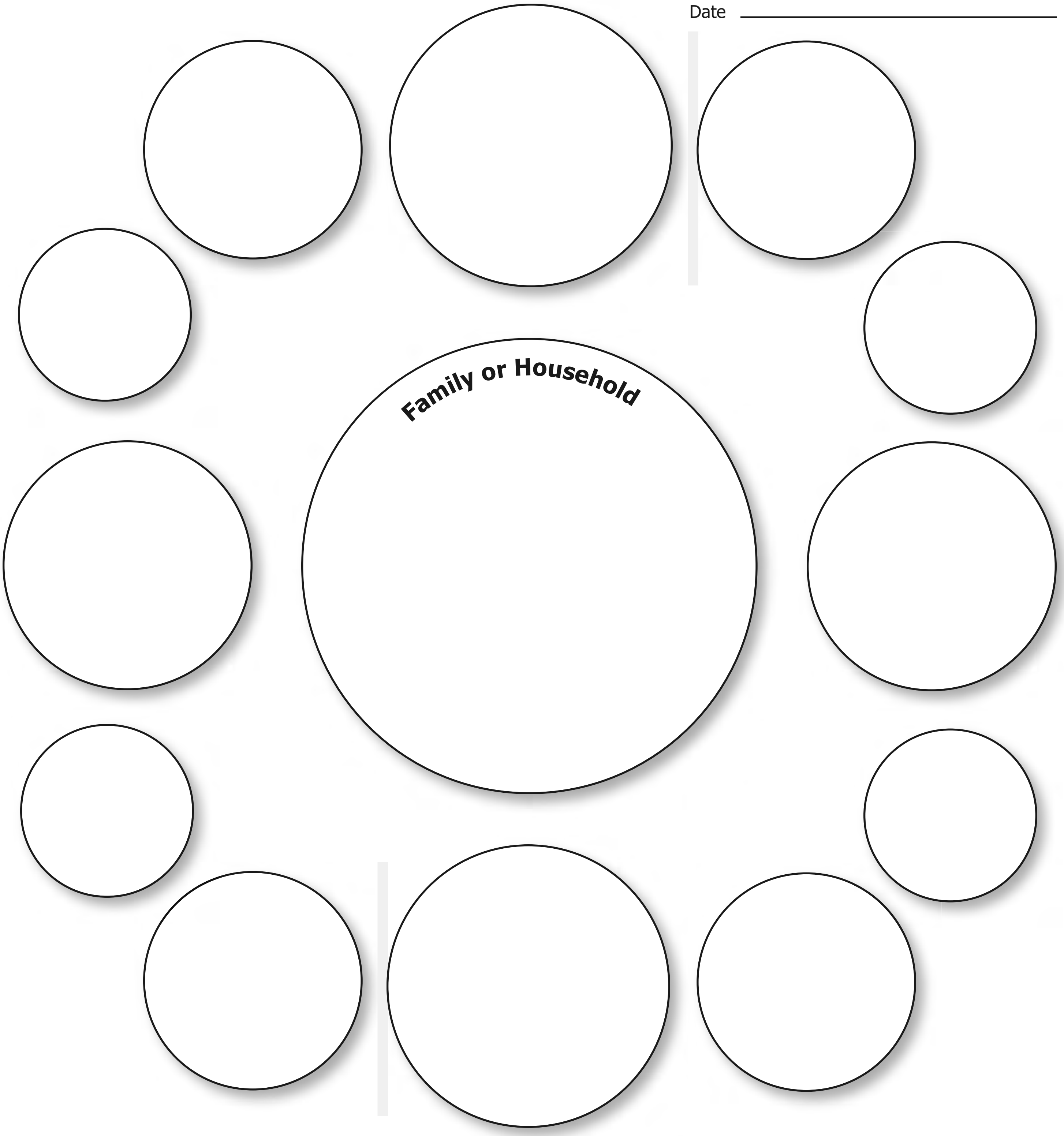
Simply creating the list can be useful in locating resources to support the family. Sometimes creating the list will be enough to move you and the family to the next step, which is to match the resources with priorities. However, it can be benificial and a richer experience to use the list to create an an ecomap picture (see pages 28-30). With the ecomap picture, the family can identify whether the relationship is strong (denoted with a solid line), weak (denoted with a dashed line), or tense (denoted with x's for the line xxxx).

This additional information aids in understanding relationships that exist among the family members and those who are listed as possible resources. The information can be especially beneficial in helping a family to determine if a resource is likely to be able to meet the family's needs. A tense relationship with a brother-in-law, for example, may help the family to realize that the brother-in-law may not be a good choice for transporting the family members to and from appointments.

Eco-Map

Name ______________________________

Date ______________________________



━━━━━━━━━━ **Strong and Supportive Relationship**

━ ━ ━ ━ ━ **Weak Relationship**

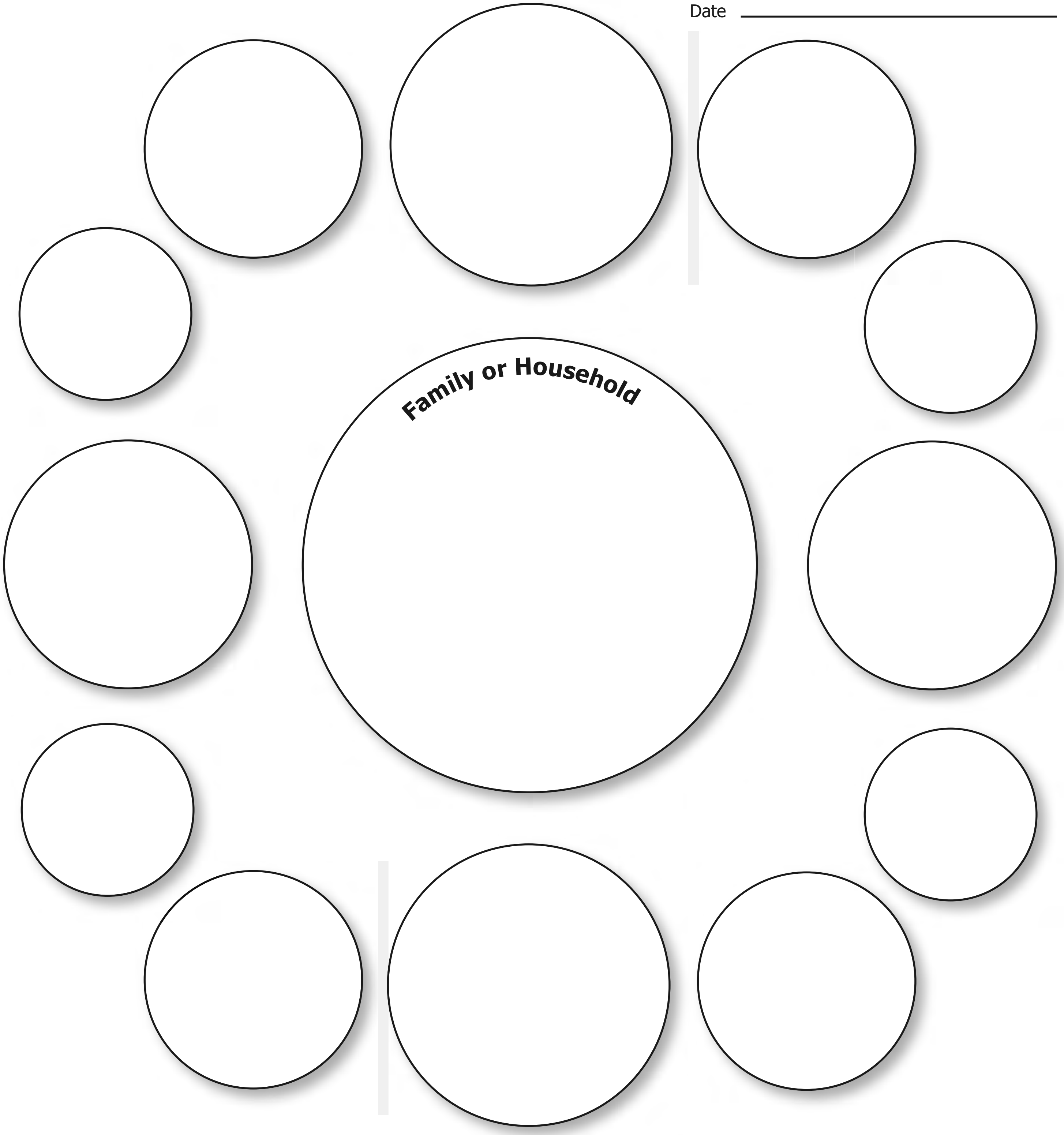
X X X X X X X X X X **Stressful Relationship**

28

Eco-Map

Name ______________________

Date ______________________

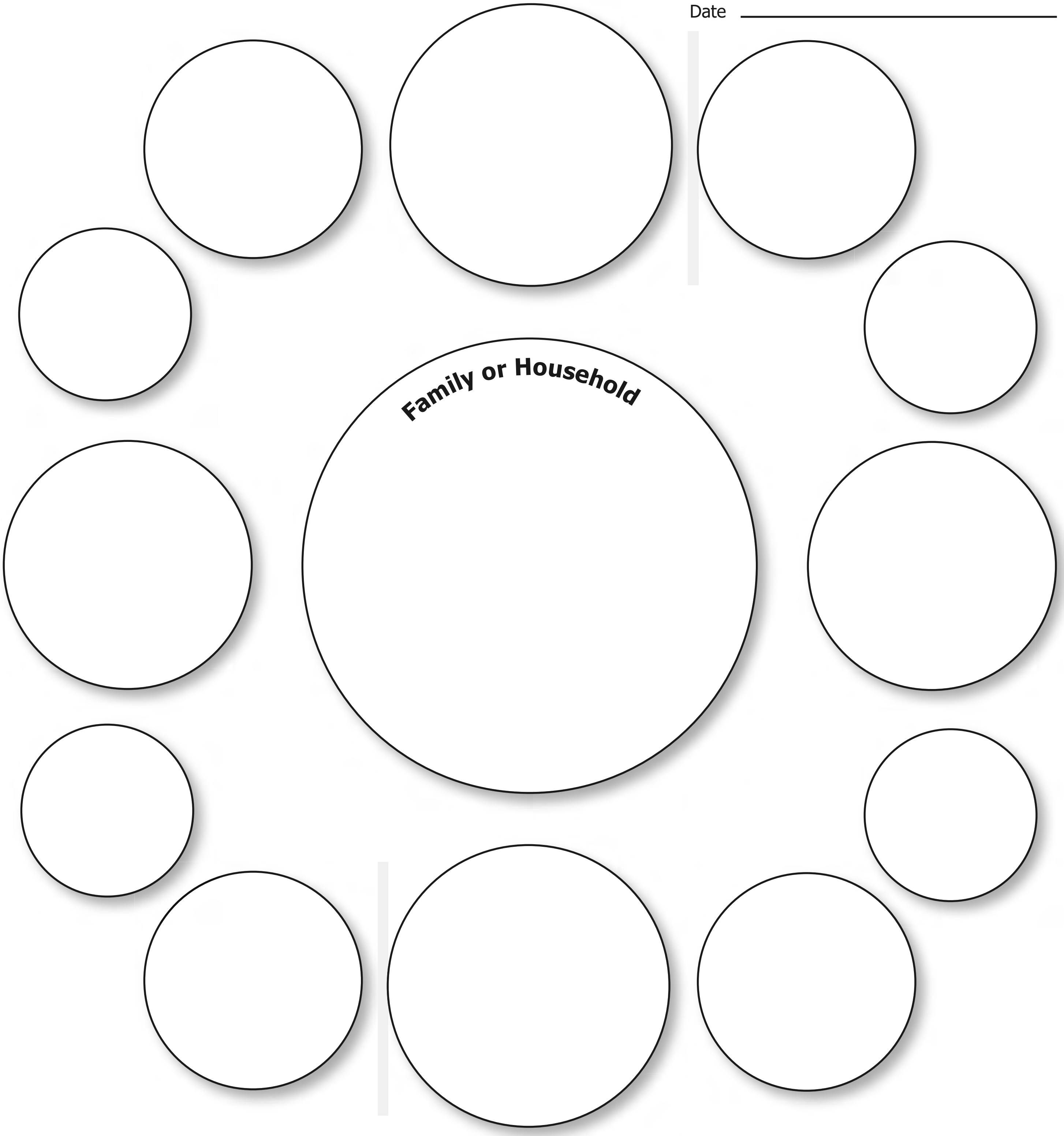


▬▬▬▬▬▬▬	**Strong and Supportive Relationship**
▬ ▬ ▬ ▬ ▬	**Weak Relationship**
X X X X X X X X X X	**Stressful Relationship**

Eco-Map

Name ______________________________

Date ______________________________



▬▬▬▬▬▬	**Strong and Supportive Relationship**
▬ ▬ ▬ ▬ ▬	**Weak Relationship**
X X X X X X X X X X	**Stressful Relationship**

Matching Resouces with Priorities

The next step is to review the family's needs in order of priority. What has the ***family determined*** to be the most pressing need? Once this need is articulated, help the family to use their ecomap to identify which resources will best address the need. Before looking at the ecomap, you may want to brainstorm with the family different ways the need could be met, then work with the family to identify resources available to them based on their ecomap. Start with resources within the family and move through the ecomap.

In some cases, the needed resource may not be on the ecomap. It may be necessary to suggest additional resources to the family. When this is necessary, keep in mind that the resouce must be one that the family will be comfortable using. Sometimes it can be helpful for us to share resources and information we are aware of.

Additional Considerations

An individual or family's willingness to ask for help is, according to Dunst et al., influenced by 5 qualitiative features. Determing which feature is ***most important*** will vary depending on a each family's situation, but keep in mind all 5 features when identifying resources for families:

Response Cost	The cost of seeking and accepting help compared to benefit
Dependability	The extent to which the family can depend on the resource and that resource's willingness to provide assistance
Indebtedness	The extent to which there is a personal or psychological obligation
Reciprocity	The extent to which the exchange of help is welcome but not expected
Satisfaction	The extent to which one is satisfied with the help

Social Support Scales

Family Support Scale *(Dunst, Jenkins & Trivette)*

Inventory of Social Support *(Trivette, & Dunst)*

Perceived Support Network Inventory *(Oritt, Paul, & Behram)*

Personal Network Matrix *(Trivette, & Dunst)*

Psychosocial Kinship Inventory *(Pattison, DeFrancisco, Wood, Frazier, & Crowder)*

*Social Support Scales can also be used to identify family resources.
The results should be used as a starting point
for matching resources with priorities.*

Develop a Plan

The final step is to develop a plan of action with the family that is contingent on the family playing an active role. Define the steps of what the family is going to do to meet their needs. Remember we are building on their strengths—when we enable caregivers to support their families, we are strentghening the family. Your goal is to create the opportunity for the family to actualize the plan and meet their identified needs. We do not wish to usurp their decision-making power, nor replace their personal social support networks with professional services.

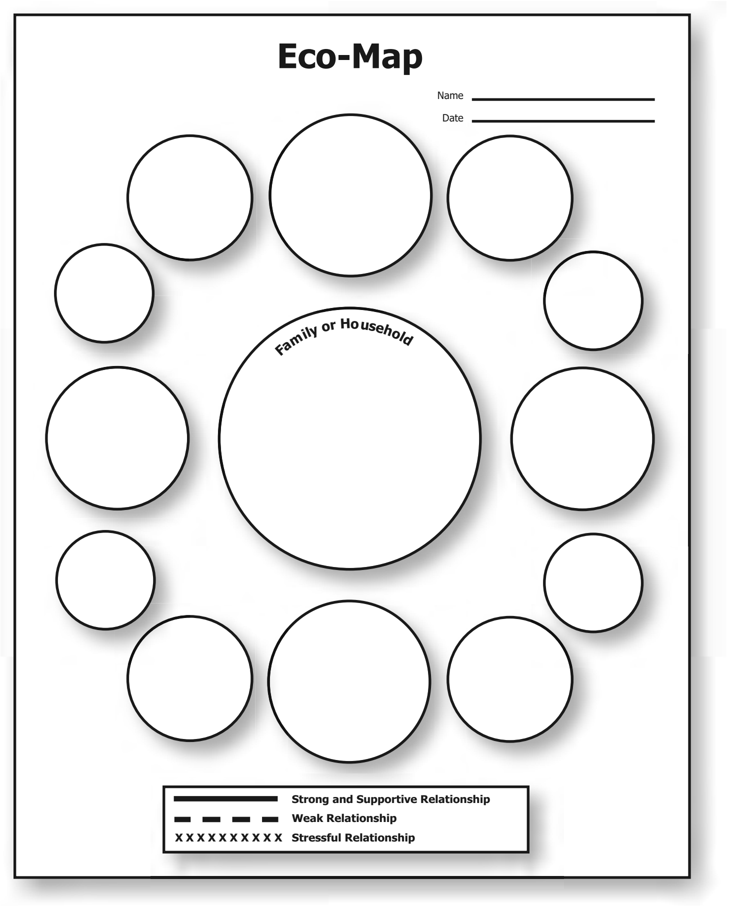
The Final, Final Step

What happens when you identify the need, listen carefully and develop a really good ecomap, have a workable plan, but then the family member doesn't follow through.

If a family member says they are interested in a resource but fail to follow-up, most likely one of the 5 qualitative factors (listed earlier) has interfered. Rather than assume that a family member is just not interested or is non-compliant, assume that something got in the way. Then use ***supportive*** questions (derived from the 5 qualitative features) to discover why the family member didn't follow-up.

Activity 6

Practicing ecomaps, using our case families



Principle 4:
The Early Childhood Professional's Role

Throughout our work with families, we play many roles and we wear many hats. In advocating the family-directed model, we are not advocating that early childhood professionals be passive. In fact, quite the contrary is true. This model requires us to actively listen instead of lecture; it requires us to actively observe and support instead of instruct; and it requires us to wisely advise and consult instead of direct and dictate. It also requires us to encourage and to support and to trust so that we will ensure a sense of confidence and competence.

Not only are we each family's guide through this process, we are also their source of constant support, information, and motivation.

If we are able to do all of this, the families we serve will develop

- an understanding of their rights and responsibilities
- learning to advocate for their child, and
- finding ways to help their child grow and learn

Here are some of the important roles we play:

Empathetic Listener:

Teacher:

Consultant:

Resource:

Enabler:

Mobilizer:

Mediator:

Advocate:

Active Listening

Demonstrate interest and concern about what is important to the family and how each member feels or perceives family circumstances.

Reflective Listening

Rephrase what the family said and reflect feelings you observe in order to clarify meaning and improve mutual understanding.

Activity 7

Think about the various roles you play during your workday. Which comes easiest to you? Which is difficult? – hint, it is often overlooked. Write a goal of what to do in order to expand your knowledge/comfort level playing that role.

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Support Parents in Making the Right Decision for Their Family

The families we work with are faced with many decisions. Even as they are reeling from the impact of news from their child's doctor or developmental specialist, they are faced instantly with making decisions that will have a lifelong impact.

Empathetic, resourceful, and confident professionals can offer families an enormous service—not by making or even suggesting decisions, but merely by being an understanding presence. Use skillful questioning to help a family consider their options. Early childhood professionals who incorporate the family-directed model will work carefully to avoid promoting their own attitudes and values.

The process a family uses to solve problems and make decisions is usually very specific to a family and it can be very complex.

As early childhood specialists, our role is to help families realize how and why they make their decisions. We also can help them to gain an understanding of the long-range impact of their decisions.

Consider looking at http://www.mindtools.com. This site has an excerpt from Edward de Bono's Six Thinking Hats that describes 6 different styles of decision-making.

Personal strategies for problem-solving and making decisions vary widely between individuals, and sometimes even reflect cultural and individual experiences. Ask yourself:

- What are the family's preferred strategies for problem-solving? Do these vary depending on the situation or the problem or do the strategies remain the same regardless of the situation?
- Is decision-making done independently? Is it a cooperative process within the family? Is the wider community involved? Is the decision left an authority figure?
- Are the family's strategies linear? Circular? Global? Intuitive or based on data collection?
- Are the solutions derived from the family's predetermined goals or do they drive the goal-setting?

Most families have a preferred method of solving problems and making decisions. The family-directed model can help families to understand the process they use to make decisions and solve problems. Highlight for families the strengths you see in their decision-making style. Using your "reflective listening skills," you may even try describing to a family what their decision-making style looks like to you. This can help families move forward to make those important decisions.

Decision-Making and Very Young Parents

Research into decision-making among teens is very slim. But what has been done reveals that teens generally generate either/or choices rather than a full range of options. And, surprisingly, research shows that maturity level is high among 6th graders, then drops to a low among 9th-11th graders, when it increases to a plateau during young adulthood.

Mature decision-making requires a person to carefully weigh all their options and the still-developing brain of a teen may not be completely ready to take on this task. While the capacity for abstract reasoning, reasoning from premises that are not true, systematic reasoning and looking at probabilities are all growing, they have not yet reached maturity. In addition, the adolescent is not yet fully able to coordinate independent bits of information and attend to all data relevant to their choices.

In the expanding world of social experiences, the teen parent is making important decisions under a set of circumstances that are difficult sometimes even for the adult brain to handle: unfamiliar tasks, choices whose outcomes cannot be predicted, and ambiguous situations. Teens may also show limited maturity of judgment, which includes being self-reliant with a sense of autonomy, taking a long-term view, showing concern for others, and being able to limit impulsivity.

When working with teen parents, use friendly, open questioning to draw out and encourage consideration of additional options, looking "through another's eyes," and persistence in reviewing possible results of the choices made.
(retrieved from http://aspe.hhs.gov/hsp/adolescent99/decision.htm, on 12/6/06.)

When It's Time to Write Family-Directed Family Outcomes

By the time it's time to write down outcomes for the families you work with, you will likely know a great deal about them: their position in the community, their priorities, and their aspirations, values, and needs.

Remember that the outcomes that are written down will govern the interventions this family receives. ***This is perhaps the most crucial time to be mindful of the family-directed model.*** No outcome should ever be written without the agreement of the family or over their protest. Even during team meetings, keep the dialogue open--especially if you see signs of hesitation or uncertainty. It is our job to make sure that a family's values, beliefs, and priorities are honored and respected.

For example, if you have learned through your work with a family that it is their practice to consult someone in authority before making important decisions, be sure that the family has the opportunity to do this when their IFSP outcomes are being formulated. There are many ways you could facilitate this need; here are just two: 1) send a draft copy of the outcomes home so that the necessary person can be consulted before the outcomes are agreed upon or 2) include the person in authority in the team meeting.

The format and language you use when writing outcomes is also very important. It should be straightforward, clear, and concise. The model we recommend is one that was formulated by Deal, Dunst, and Trivette. We like it because it provides both clarity and measurability.

This model first describes what is to occur (the process) then explains what is to be expected (the outcome). These two statements are then combined with an "in order to" phrase to show the relationship between the process and the outcome. For example, "Germaine and Jeremy's foster mother will review daily journals outlining Jeremy's activities and development at each visit, in order to help Germaine understand Jeremy's growth and development."

Working Together

Building Empathic Relationships

The family-directed model has enormous potential to positively influence both families and professionals. Because this model requires both parties to operate on the assumption that all people have strengths and the capacity to become competent, practitioners who use the family-directed model experience both personal and professional growth. For example, many report enhanced wellbeing and health, better adaptive functioning, and improved social competence (Dunst, Trivette, and Thompson 1995).

And yet, the parent/professional relationship can also be fraught with tension. What factors make it so difficult? Early intervention trainer and parent of an adult child with special needs, Janice Fialka, examines this question in "The Dance of Partnership: Why Do My Feet Hurt?" (The full text is reprinted in your training workbook.)

Fialka does a wonderful job of exploring the parent/practitioner partnership in depth, but for our discussion of family-directed family outcomes we will focus specifically on the 5 "dimensions," as she calls them, of the parent/professional relationship that can lead to problems.

1. Most professionals make a conscious decision to work with young children and their families. Most families, however, would prefer to have a life that did not require such support.

2. Many parents feel that this relationship is not only uninvited, but awkwardly intimate. While parents are in pain, confused, and vulnerable, they are forced into a relationship where all of this is revealed to someone who is essentially a stranger.

3. Professionals are always committed to the growth of the child. Too often, parents feel left out or set aside when they want to be and should be the primary partner. Most children will benefit from the involvement of an early childhood provider; but the child cannot survive without the parents' involvement.

4. Lack of clarity is another point of confusion where "the dance" can lead to awkward stumbles and trod-upon toes. Traditionally, the professional is the expert; now, the parent might find their provider calling her the expert when she feels at a total loss. Ideally, each is contributing ideas, resources, and knowledge in different areas – a partnership with two contributors.

5. The 5th dimension is the differing sets of priorities caused by different views of life. Fialka mentions the bittersweet pain of watching the neighbor's child grow and develop skills her son never achieved. The professional she told about this pain had only seen a potential playmate in the next yard, and was gracious enough to thank the mom for sharing her own unique viewpoint.

Truly listening to family members' needs, dreams and projects builds trust. When a trusting relationship is established, family members will be more willing to increase their awareness of and involvement in systems such as state intervention programs. When you invite parents to share the "music" of their daily life, you can use those notes to guide you and avoid stepping on your partner's toes.

Now here's how Fialka's 5 dimensions would sound if they were used to propose a new activity to a family. The following questions come from a therapist who was especially good at "dancing."

> "I realize this proposal is something new for you,
> - What have I missed?
> - How will this change or disrupt your life?
> - Will this complicate your daily living?
> - What do I need to understand from your point of view?"

These questions are a comfortable, respectful invitation to parents to share their perspective. And this is crucial to the successful incorporation of the family-directed model. These questions say to family members, "I need your participation so what I recommend will be relevant, practical, and manageable."

Fialka's 5 dimensions also give voice to the fact that we do ask families to stretch – a lot. But sometimes we forget just how much stretching we ask families to do. As Fialka reminds us, we are in each family's life out of necessity—most families would prefer to not need us. They would prefer to have a perfect child who they can brag to all their friends about. They would prefer to not have to know about all the special services out there that can help them. They would prefer to go to the park instead of early intervention services.

This is not to say that early intervention services are a burden to families—they are not. They are a blessing to most families. But they are a blessing in disguise. The families we work with do need us and they are grateful for the services we provide, but they also are working very hard to want to have us in their lives.

We need to make sure the families we work with don't think we are saying that they are incompetent—we need to make sure they hear us say we want to work with them to develop ***additiona***l competencies. We are empowering and enabling them to advocate, care for, support, and teach their child who has ***special*** needs.

Dealing with Grief

A big trigger for our emotional stress is dealing with the grief reactions of the parents we serve. Parents whose children are being assessed for early intervention are walking through minefields of new experiences, emotions, and adjustments. Because we care, and because we are not and cannot pretend to be, therapists, we are often left wondering just what we can and should do if a parent breaks down. We are usually urged to show empathy, or "relate" to the parents' feelings. But how? And how do we get back to the task we are there to accomplish?

One answer comes from Dr. Ken Moses, a psychologist who specializes in the unique grieving process of parents whose children have disabilities. He himself is such a parent, and his work has lead him to believe that grieving is not only a natural process but a necessary one, resulting in personal growth. Our job is not to comfort or soothe (make the parent feel better), but to help them feel better. That is, if we stay available while the parent truly experiences and expresses the pain of the moment, they can move beyond that grief-filled moment into the future.

Moses says, for instance, about the depression state in grieving, that:

> A common response to loss often is characterized by profound and painful sobbing. Parents report that at times it feels as though the tears will never stop. There is a rest, but then for no apparent reason, waves of despair and anguish wash over the parent once more. Between the tears, one can sit alone, staring silently. Those periods of silence can last well beyond the periods of tears. The thoughts of depression take over, thoughts like: "What's the use of trying, it's all over." or "Nothing I do matters, because nothing will change what has happened to my child!"
>
> Depression is subtly rejected and judged as pathological by much of our culture. When people display such feelings, they are often told to "cheer up", given medication, or offered distractions. Such responses are inappropriate, for depression is part of normal, necessary, and growth-ful grieving. It attends to another aspect of a basic human struggle that loss stirs.
>
> As we mature, we develop and modify our definitions of the following words: competence, capability, value, and potency. They are words of profound personal significance. They are the criteria that people use to decide if they are OK or not. What criteria does a person have to meet to feel like a competent parent, a capable worker, a valued friend, or a strong person? Each person determines these standards privately, even secretly.
>
> When parents are confronted with an impaired child, whatever definitions they held for competency, capability, value, and potency usually no longer apply. How does a mother feel competent when she has a retarded daughter? She can't use the measures of her peers, like having a daughter graduate from college, or become homecoming queen. What is the worth of a father who cannot "fix" what is broken in his impaired son?

> Out of this struggle of defining one's worth come the frightening feelings of helplessness, hopelessness, and haplessness. Faced with loss, a parent feels unable to act effectively (helpless), unable to imagine that things will ever get better (hopelessness), and unable to believe that their lives are touched by good luck (hapless).
>
> Such feelings are terrifying for both the parents and those around them. For that reason, it is hard to see that depression is a normal and necessary part of the grieving process. Depression is the medium that helps parents come to new definitions of what it takes to be competent, capable, valuable and strong people, even though their child has impairments that they cannot cure.
>
> **For a full description of Moses' concept of grieving and growth, use this link:** www.macmh.org/publications/Unlocking_mysteries/higher1.pdf.

What, then, can we do when a parent is caught up in such strong emotions? Moses recommends that we briefly interrupt our process for one he calls ENUF, which stands for the essential elements of the provider's stance: Empathy, Non-judgment, Unconditionality, and Feeling-focus. The goal: to help the parent accurately share the feeling state they are in, and move on. Thus, when a parent moves from sadness to anger, or anger to denial, the growth step is completed for now. Use this as a signal that you can move back to the content your task dictates without fear that you are cutting off the process or helping a parent "stuff" his or her feelings.

Activity 8

What are some questions or comments that you could use to help a parent who becomes overwhelmed by sadness during your interview? What about a parent who is suddenly filled with anger when discussing part of his/her child's story?

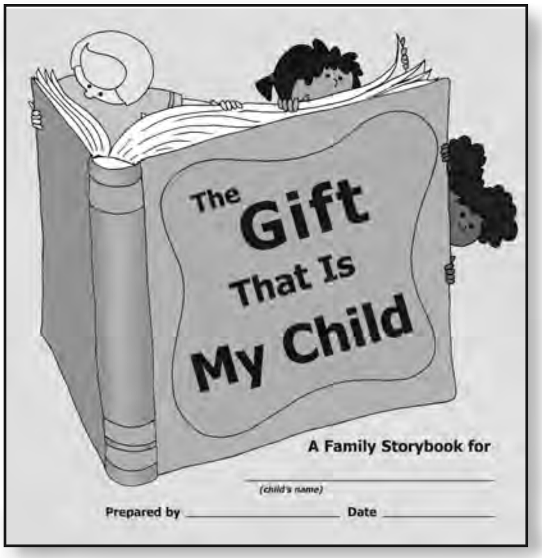
Considering Cultural "Difference"

Sometimes it appears that cultural differences wreak the most havoc in the "dance" between parents and professionals. In actual fact, there are cultural differences between any two people. And all these differences need to be handled with honesty and respect. Notice we are not saying that Persons are different. We are saying that when two persons come together, inevitably difference exists between them. This is because each person has a unique set of values, expectations, and histories that create the basis from which they act.

Some differences are common to many of us (we don't eat this food, we don't work on that day). Others seem to be more unique or are "just the way we are." For example, Dad hates accepting help from any service because his dad remembers the embarrassment of growing up 'on the dole' in the depression; Mom may get angry and threaten to stop the intervention if she feels shamed because of her lack of education.

It takes patience, creativity, and often some thoughtful discussion among colleagues to negotiate these "culture bumps." Isaura Barrera and Robert Corso, authors of "*Skilled Dialogue: Strategies for Responding to Cultural Diversity in Early Childhood*," use this term to suggest that these issues can be thought of like "speed bumps"—they may interfere with our work but they don't pose an insurmountable barrier.

To accommodate these bumps, Barrera and Corso suggest a three-step process. First, both sides need to develop an understanding of the cultural meanings behind the perceived "bump." Step two requires time and what the authors call "skilled dialogue" to discover what impact the "bump" will have on the relationship. As always, this dialogue must be based on respect, reciprocity, and responsiveness. Step three requires openness, creativity, and flexibility to develop a "third space" to stand in to restart the dialogue.



The Family Storybook *is designed to help you get to know a family's unique set of values, expectations and history.*

Activity 9

Let's evaluate our solutions.

- Was the provider responsive to the parent without taking responsibility for her actions?
- Did the provider maintain appropriate boundaries with the mother?
- Does the solution acknowledge the cultural differences and accomplish the task of preparing the child for more advanced finger control and self-feeding?

Based on these criteria, it appears our solutions provide a way for both parties to maintain the integrity of their beliefs while accomplishing the joint goal they agree upon for the child.

Inevitably, responsive professional solutions clarify boundaries, because you, the professional, are no longer going to feel as if you are the only source of strength and knowledge for this family. You are responsive, but not responsible, for the family's decisions and well-being.

Establishing and Respecting Boundaries

Firm and clear boundaries "establish a common understanding of what it means to provide care and services to children and their families," according to the ZERO TO THREE Center for Program Excellence. Boundaries also help us maintain objectivity—boundaries allow professionals to reflect back what they see and allow families to accept comments that might be unacceptable from others, such as extended family members.

Sometimes a family may make a request that does not necessarily violate boundaries but it does set up an expectation that would interfere with a professional's objectivity in the future. One method for maintaining boundaries is to ask yourself these questions:

- What is the impact on the family if I fulfill this request?
- Will my relationship with the family begin to resemble a friendship if I fulfill this request?
- Would fulfilling this request reduce my ability to be objective about this family? (from ZERO TO THREE Center for Program Excellence.)

The difference between friendship and a professional relationship...

Friendship *is a reciprocal, long-term relationship with emotional give-and-take and a sharing of resources.*

A professional relationship *is one of limited duration designed so that the provider supports the family's achievement of specific goals.*

Because every parent and every relationship is different, there is no formula to determine if a relationship is too-close or too-distant. What there should be, though, during the beginning stages of the relationship is a joint discussion where both the practitioner(s) and the family member(s) describe what they perceive their roles and expectations to be. During that discussion, it would also be a good idea to openly discuss your program's ethical guidelines, such as data privacy, avoiding conflicts of interest when making referrals, and avoiding any action that could be interpreted as attempting to further religious, business, or political interests.

Activity 10

How do you re-charge?

Activity 11

Facilitated Communications

As Minnesota's immigrant population grows, more and more early intervention providers find themselves immersed in dialogues that are, in fact, three-way rather than two-way. Parent-Professional-Interpreter discussions require important extra skills to ensure that the family's voice remains the driving force when developing family-directed family outcomes.

In these situations, the interpreter is being expected to perform a fairly complex act. They don't just substitute words, but they must convey thoughts, attitudes, and feelings. A sentence's practical, social meaning and any subtle variations must also be transferred for a successful transaction. If a practitioner refers to something that is unknown in the family's native culture, it may be nearly impossible for an interpreter to "assign" a word to that thing or concept. In fact, sometimes interpreters may have to elaborate on what is being said. They must first explain the concept and then make it understandable to the listener.

American Sign Language

This is not the same situation as working with an interpreter of American Sign Language who has been trained professionally and works to a code of ethics that requires them to convey a word-for-word equivalent of what is spoken or signed.

Do all early childhood practitioners have such a trained and talented interpreter? Sometimes, but not always. Your "voice" for a family might be someone who is offering interpretation as an informal support. This person may be a school employee who happens to know the language, a community volunteer, or a member of the child's extended family. We say "informal" because often these people are not trained in the unique vocabulary and concepts that are specific to early childhood intervention. In fact (through no fault of their own), informal interpreters may have virtually no background knowledge of the concepts being discussed. In addition, they are most likely not being paid for their time and effort. This means that the early childhood intervention worker (that's you!) must know ***how*** to work with the interpreter to make sure they are conveying exactly what you intend to convey. You also may need to learn how to use the information you receive from them.

Finally, if there ever appears to be a disagreement between the interpreter and a family member, if either party takes extended time to begin speaking, or if nonverbal cues indicate anger or frustration, feel free to ask the interpreter if there is a problem you can clarify. It is also important to ensure that an interpreter's own values, beliefs, and feelings do not creep into any explanations and that the information they present is not changed or distorted. If this does happen, encourage the interpreter to offer information only.

Helpful Hints When Involving an Interpreter

1. *Allow at least twice the time as usual for an interpreted interview or meeting.*

2. *When you are talking with a family make eye contact and express yourself to the family, not the interpreter.*

3. *Speak as clearly as possible and ask if your speaking speed is too fast or slow.*

4. *Use the definition of any specialized terms, rather than the term itself. For example, say "skills he will use every day" instead of "functional living skills."*

5. *Use simple sentences, especially when asking questions; adding clauses or questions in a series may lead to misinterpretation.*

6. *Try to use the same interpreter with a family so they can become familiar and trusting of each other. Try to talk to the interpreter after the session and get feedback on how accurate he/she believes the session was, what problems were encountered, and what could be improved next time.*

7. *Because parents may be reluctant to share very personal or controversial information with yet one more stranger, have a brief initial discussion between the three of you about confidentiality before you begin.*

8. *Include the Interpreter as a team member whenever necessary (and feasible). If the interpreter's focus is directed toward the family's and child's outcomes, there is less likelihood they will fall into a pattern of covering up inadequacies on either side or see their role as an imposition.*

9. *Discuss team duties and acknowledge the interpreter's role as a cultural specialist. Encourage the interpreter to be aware of any cultural "bumps" such as greetings, visiting rituals, and where and when to sit.*

Before We Go:
The Importance of Reflective Practice

We have covered a wide range of topics over the course of the day and our guiding principle has been "family-directed family outcomes." We have talked at length about the importance of supporting our families, understanding them, encouraging them, empowering them, enabling them, and strengthening them. This is hard work and it takes skill, patience, creativity, compassion, objectivity, and a good deal of selflessness.

At times we may feel frustrated, confident, confused, and victorious. On the days when we feel confident and victorious, we could work forever. But on the days when we feed frustrated and confused, we wonder if we are in the right line of work. It's these days where we most need a way to reconnect with our own hopes, values, and aspirations.

And it's on these days when reflective practices are most welcome. In fact, early childhood programs are increasingly confronting the problems of ethics, boundaries, burnout, and staff turnover proactively by implementing reflective practices, which include things like instituting staff study groups, encouraging case consultations with peers or consultants, and providing on-going staff training based on case-specific questions.

The University of Minnesota's Center for Early Education and Development (CEED) puts it this way:

> Working with infants, toddlers, and their parents is rewarding and challenging, evoking powerful feelings in the professionals who deliver these relationship-based services. By "stepping back" to explore our observations, feelings, and actions, we can begin to understand our emotional responses. This practice of reflection helps us to remain emotionally available and connected to families—within appropriate professional boundaries—so we can develop interventions that support the evolving relationship between the parents and the child. (CEED, 2006)

One reflective practice you can implement on your own is to journal about your readings and your efforts to implement the practice strategies in this training. For optimum value, we recommend that you begin your own informal peer discussion or even set up a formal study group to share these discussions and exercises with your colleagues.

Wrap-Up

The OSEP Family Survey in Minnesota

As we mentioned at the beginning of this workshop, the Office of Special Education Programs (OSEP) is requiring states to submit outcomes data in their Annual Performance Report (APR). Three family outcomes have been developed to ensure that a family's participation in Early Intervention services under Part C results in improvements in a family's ability to raise a child with successful outcomes as well as specific improvements in the child's abilities.

The survey asks families if their early intervention services helped them:

- understand their child's strengths, abilities, and special needs (effectively communicate their children's needs).
- know their rights and know how to advocate effectively for their children.
- help their children to develop and learn.

The Family Outcomes Survey, developed by the Early Childhood Outcomes Center (ECO), will be posted on the Minnesota Department of Education (MDE) website in multiple languages. As a child exits Part C, copy and paste the child's MARSS number onto the survey (in the appropriate language for the family) and print it out. Bring the survey to the family during a home visit, assure families that their answers are private and will not be shared directly with program staff. Provide stamped envelope addressed to MDE and encourage the family to provide feedback.

A copy of the Family Survey is provided in this workbook for your information and as an example. The survey is rated on a 7-point scale.

Rating Levels for Family Outcomes

The rating scale is 1-7, with levels 1-3-5-7 defined as follows and 2-4-6 available without definition:

1. We are just beginning to understand where our child is developmentally. There is a lot we need to learn about our child's special needs or disability, and we need to find out where we can go to get this information.

3. Our family has a basic understanding about where our child is developmentally, but we still have a lot to learn. We know some things about our child's special needs or disability, but there is a lot of information out there that we still need to find. We have some ideas about where to go to get this information, but could use some help. We think we can help professionals know whether things they are doing are making a difference with our child, but will be able to do this better once we learn more. We are not yet ready to be a resource for other families, as we still have a lot to learn ourselves.

5. Our family has a pretty good understanding about our child's development, but we occasionally find that we still have questions. We know a fair amount about our child's special needs or disability, but there are still some questions that we are trying to find the answers to, and we are not always sure exactly where to go to find those answers. We're pretty confident in our ability to help professionals know whether things they are doing are making a difference with our child. We might be willing to share all of this information with other families, but we're not sure that we are quite ready to do this.

7. We fully understand our child's development and how it compares with typical development. We have a clear idea about our child's health, behavior, and learning needs. We know a lot about our child's special needs or disability, and how to find more information when we need it. When new treatments are tried with our child, we can help professionals know whether they are really working or not. We know all of this information well enough that we would feel very comfortable helping other families learn it.

Activity 12

Look back to **Activity 1** and rate that activity using this 7-point scale.
Please circle one.

1 2 3 4 5 6 7

References & Resources

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Disorder-Specific Resources

Deaf/Hard of Hearing

With the advent of universal newborn screening for hearing loss, most Part C providers have more infants with diagnosed hearing loss on their caseloads. Because communication plays such a vital role in shaping a young child's brain development and emotional well being, providers must be able to help families make difficult decisions both quickly and confidently. The decision about which communication system to use will influence a child and their family for their lifetime.

> *Giving birth to a deaf child forces you into a very small world. Each decision you make about what to do makes that world even smaller. You will need your whole family to move into that world with you, so be sure they all understand the options and the implications of their choices.*
>
> *—Julie, mom of two deaf teen-agers*

Alsop, L., Blaha, R., & Kloos, E. (2000). *The intervener in early intervention and educational settings for children and youth with deafblindness.* [Briefing Paper]. Retrieved December 10, 2006, from NTAC (National Technical Assistance Consortium for Children and Young Adults Who Are Deaf-Blind) Web site: www.tr.wou.edu/ntac/documents/spotlight/intervener.pdf

Centers for Disease Control (CDC). (n.d.). *Hearing loss fact sheet.* Retrieved December 6, 2006, from www.cdc.gov/ncbddd/autism/actearly/hearing_loss.html

Fact sheet emphasizes the need for early intervention and provides additional resources.

Centers for Disease Control (CDC). (n.d.). *A parent's guide to hearing loss*. Retrieved December 31, 2006, from www.cdc.gov/ncbddd/ehdi

The EHDI (Early Hearing Detection & Intervention) Web site has a wealth of information on a variety of topics.

Cued Speech Association of Minnesota. (n.d.). Cued speech: Seeing spoken language! [Brochure]. Edina, MN: Author.

This nonprofit advocacy organization provides brochures, classes, and information on cued speech; their Web site is www.cuedspeechminnesota.org.

Lifetrack Resources. (n.d.). *Resource directory for parents of children who are deaf or hard of hearing.* (2005). St. Paul, MN: Author.

Lifetrack Resources provides first-contact family support, classes, referrals, and other family supports. Twin Cities: 651-265-2435 or 651-265-2379 (TTY); toll free: 866-346-4543 or 866-857-2379 (TTY). Their Web site, www.familysupportconnection.org, includes a valuable list of resources about various communication choices.

Minnesota Early Hearing Detection & Intervention Network. (2006). *Program/contact information.* Retrieved December 31, 2006, from www.education.state.mn.us/mdeprod/groups/specialEd/documents/announcement/000844.pdf

Minnesota Department of Health (MDH). (n.d.). *Minnesota guidelines of care for families with children who have a hearing loss*. Retrieved December 11, 2006, from www.health.state.mn.us/divs/fh/mch/unhs/resources/guidelines/index.html

Infant/Toddler Mental Health

Research and decades of experience have confirmed the life-long importance of healthy social and emotional development in children during the earliest months and years of life. Understanding early brain development and the prenatal and postnatal environment is essential to working with children in today's families. This is especially important when an infant or toddler's behaviors warn us that a mental health disorder may be present.

While early childhood workers should not attempt to diagnose a child, their observations can often provide valuable information to a mental health professional. This may be a sensitive topic to discuss, but research shows that early, effective intervention can reduce a child's symptoms and lessen the impact on the family as a whole.

Backer, L., Hunt, M., & Smith, M. (2006, August). *Measuring early childhood & family outcomes + reporting transition.* Oral presentation for the Minnesota Department of Education, St. Paul, MN.

Chew, J. (July 2003). Review. [Review of the book *Out of the darkened room: When a parent is depressed: Protecting the children and the family*]. [Electronic version retrieved December 31, 2006, from www.findarticles.com/p/articles/mi_qa3658/is_200307/ai_n9254967] *Journal of Marital and Family Therapy*. 29(3).

Children, Youth, and Family Consortium. (2002). *Mental health in infancy and early childhood.* (Public Policy Brief, 2nd in a series). Minneapolis, MN: University of Minnesota.

Edwall, G. (n.d.). *Early childhood mental health: The continuum of care*. Retrieved October 6, 2006, from www.macmh.org/info_resources/articles/glenace_article.php

Minnesota Association for Children's Mental Health (MACMH). (2006). *Parent fact sheets on infant and early childhood mental health*. Retrieved December 8, 2006, from www.macmh.org/publications/ecgfactsheets/ecgfact_sheets.php

Minnesota Association for Children's Mental Health (MACMH). (2005). *Guide to infant and early childhood mental health*. St. Paul, MN: Author.

Research and Training Center for Family Support and Children's Mental Health. (2006, April). Assessing children's mental health: Validity across cultural groups. *Data Trends, No. 132*. Retrieved January 3, 2007, from Portland State University, Research and Training Center for Family Support and Children's Mental Health Web site: www.rtc.pdx.edu/PDF/dt132.pdf

Research and Training Center for Family Support and Children's Mental Health. (2004, May). The effects of having a child with ADHD on family members and family management. *Data Trends, No. 98.* Retrieved January 3, 2007, from Portland State University, Research and Training Center for Family Support and Children's Mental Health Web site: www.rtc.pdx.edu/PDF/dt98.pdf

Research and Training Center for Family Support and Children's Mental Health. (2003, December). Stress reduction interventions for parents as treatment enhancement. *Data Trends, No. 89*. Retrieved June 10, 2006, from Portland State University, Research and Training Center for Family Support and Children's Mental Health Web site: www.rtc.pdx.edu/pgData Trends2003.shtml

Autism Spectrum Disorders (ASD)

Note: The term ASD is used to describe diagnoses that may include Autism, Asperger's Syndrome, High-Functioning Autism, and Pervasive Developmental Delay, Not Otherwise Specified (PDD-NOS).

The diagnosis of Pervasive Developmental Delays (PDD), more commonly called Autism Spectrum Disorders, continues to rise at an alarming rate. While some young children seem to develop normally and then lose skills, others show early signs that cause parents to seek out diagnosis and early treatment. Research supports early and intense treatment as a means to better outcomes. There is a wide range of intervention theories/programs; some are described in the resources below.

Clemmensen, D., & Merzer, S. (2006, November 15). *Promoting resilience in children with autism spectrum disorder.* Oral Presentation at St. David's Forum, Minnetonka, MN.

Minnesota Autism Project. (2000, November). *Promising practices for the identification of individuals with autism spectrum disorder*s. Retrieved August 10, 2006, from Minnesota Department of Education Web site: http://education.state.mn.us/mdeprod/groups/SpecialEd/documents/Manual/000824.pdf

Wallis, Claudia. (2006, May 15). Inside the autistic mind. *Time*, 167(20), 43–48.

Wallis, Claudia. (2006, May 15). A tale of two schools. *Time*, 167(20), 49–51.

Williams, K. R., & Wishart, J. G. (2003, May). The Son-Rise Program intervention for autism: An investigation into family experiences. [Electronic abstract retrieved January 3, 2007, from www.ingentaconnect.com/content/bsc/jidr/2003/00000047/F0020004/art00009]. *Journal of Intellectual Disability Research, 47(4-5)*, 291.

Wiseman, N. D. (2006). *Could it be autism? A parent's guide to the first signs and next steps.* New York: Broadway Books.

Written by the founder and president of First Signs, Inc. and available from www.Firstsigns.org

Woods, J. J., & Wetherby, A. M. (2003, July). Early identification of and intervention for infants and toddlers who are at risk for autism spectrum disorder. *Language, Speech & Hearing Services in Schools, 34(3)*, 180–193.

The entire issue deals with autism spectrum disorders—mainly in infants and young children.

Yapko, D. (2003). *Understanding autism spectrum disorders: Frequently asked questions.* New York: Jessica Kingsley Publishers.

Fetal Alcohol Spectrum Disorders (FASD)

> *Note: The acronym FASD is used to encompass the range of possible diagnoses caused by prenatal exposure to alcohol. These diagnoses may include Fetal Alcohol Syndrome (FAS), Fetal Alcohol Effects (FAE), Alcohol Related Neuro-development Disorder (ARND), Alcohol Related Birth Defects (ARBD), Prenatal Exposure to Alcohol (PEA), or Static Encephalopathy Alcohol Exposure (SE).*

Prenatal exposure to alcohol is the world's leading preventable cause for mental retardation. The effects, however, are varied and may be more severe and more disruptive to the life of the child and its family, when no typical developmental delay is present. Early signs may be physical or behavioral as well as developmental. In the absence of documented maternal drinking, early screening may not reveal any signs and may have to be repeated after age 3.

Arc Northland. (n.d.). *Fact sheets on fetal alcohol spectrum disorders and other mental health topics*. Duluth, MN: Arc Northland.

> *Arc Northland has a variety of fact sheets on topics including health/medical concerns, parents who have fetal alcohol syndrome/effect, Minnesota resource list, red flags for professionals, sleeping and eating concerns, and caregiving/family issues. To request copies, contact Arc Northland, 201 Ordean Building, Duluth, MN, 55802; 800-317-6475 (toll free), 218-726-4725; or e-mail arcdu@aol.com.*

Kleinfeld, J., & Wescott, S. (Eds.). (1993). *Fantastic Antone succeeds! Experiences in educating children with fetal alcohol syndrome*. Juneau, AK: University of Alaska Press.

Malbin, D. (2006). *Fetal alcohol spectrum disorders: A collection of information for parents and professionals* (2nd ed.). Author.

Malbin, D. (2002). *Trying rather than harder* (2nd ed.). Author.

> *Copies of Malbin's books are available at www.fascets.org/market_place.html*

Minnesota Organization on Fetal Alcohol Syndrome (MOFAS). (n.d.). Project SOS: Seeds of success, creating success [Parent advocacy workbook]. St. Paul, MN: Author.

Shaw, E., & Goode, S. (Eds.). (2005, December). *Policy issues and intervention strategies for young children prenatally exposed to drugs or alcohol: Selected resources.* Retrieved August 10, 2006, from www.nectac.org/pubs/titlelist.asp#prenatalexp

Waller, A. (Ed.). (1999). *The best of F.A.S. Times.* Tacoma, WA: Crawford Publishing.

> *A compilation of articles (including stories from birth and adoptive families) reflecting 10 years of the newsletter published by the Fetal Alcohol Syndrome-Family Resource Institute.*

Additional Reading:

The Dance of Partnership: Why do my feet hurt?

Strengthening the parent-professional partnership

The Dance of Partnership: Why do my feet hurt?

Strengthening the parent-professional partnership

Janice Fialka, M.S.W., A.C.S.W

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Keynote address delivered at the Division of Early Childhood's (DEC) Thirteenth Annual Conference on Children with Special Needs New Orleans, November 20, 1997

There is no escaping it these days. "Partnership" is a recurrent buzzword in the fields of education, health, and human services. "Parents and professionals must be partners. Collaboration is the name of the game." This is the refrain sung by administrators, policy makers, direct service providers, and parents. Indeed, partnership is a noble goal and, on the surface, seems fairly reasonable to achieve. "Let us sit at this table together, create the best plan of action for three-year-old Sally---and be partners." Seems relatively easy. Yet, regardless of the hat you wear, you know that being partners is often challenging beyond words. At times, forming partnerships is more challenging than parenting my son, Micah, who has developmental disabilities. I did not anticipate that the partnering with professionals would be at times this hard.

Several years ago, I began a journey to gain understanding about what complicates this partnership. My first step was to consult the dictionary for the definition of "partners." I found "Either of two persons dancing together." (Webster's New World Dictionary, 1968). This image of dancing fit perfectly. Forming partnerships with the myriad of professionals who have entered my life via Micah is like learning to dance. At first, my professional partners and I often do not glide together gracefully across the floor. Our movements feel stiff, awkward, and out of sync. We sometimes seem to be listening to different music with conflicting beats and rhythms. Our toes--and feelings- -get stepped on as we try to maneuver around unspoken worries.

What is it that complicates this parent-professional partnership, this dance? Why do we often collide in our attempts to help our children and students reach their fullest potential? I have identified five distinct features, or dimensions, which both entangle and enhance our partnership dance. These ideas are based on my own personal experiences. My impressions on partnerships may not match those of all parents. However, the universality is found in the desire of all parents to have their uniqueness recognized and valued. The following is what I have learned about my partnership dances as Micah's mom.

First Dimension — Choice: Do You Wanna dance?

The first dimension pertains to choice. For most parents, this is not a chosen relationship. In spite of the many gifts given to me by the scores of professionals I have met because of my son's disability, I would rather not know them under these circumstances. I would rather not have a child with a disability. I did not choose this.

On the other hand, most professionals made a very conscious choice to work with children. Many of you chose this work because of a strong sense of connection with these little people, and a passion for teaching. You anticipated that this work would give you some sense of meaning to your life and a sense of self-esteem and mastery, maybe not every day, but often. Many of you were drawn to make a difference in the lives of a child.

Let's look at this issue of choice using this dance image. Here you are, the professional, eagerly awaiting your new dance partner. Your arms are stretched out inviting us, parents, to enter your world of interventions, appointments, activities, forms, and (maybe) hope. You beckon us into your brightly decorated offices and classroom. "Please come in and see what is here. I'm excited to share these toys and opportunities. Welcome."

We, as parents, having not chosen this dance, are usually not as eager to join you. We may approach you not with open arms but with tightly folded ones clutched to our chest. Sometimes, it is as if our backs are turned to your welcoming arms, eliminating all opportunities for engagement. We may feel reluctant, ambivalent, and often unwilling. For one thing, if we choose to join you, we have to acknowledge that our child has special needs. We have to acknowledge that we are entering your world--one that is initially unfamiliar and frightening. Entering into our partnership with you demands that we let go of our dreams and begin to build new ones. So we may not appear too eager or too willingly to join you in this partnership dance.

To your open, welcoming arms, we parents may appear arrogant, withdrawn, hostile, uninvolved, or defensive. Some might refer to us as being "in denial." It is easy to see how you, as the professional might personalize our distancing attitude we seem to project with our folded arms and defensive posture. You may find yourself silently crying out to us, "I'm only trying to be helpful!"

I recall the story of one mother whose young son was unable to walk. The idea of a wheelchair was introduced to the family. A freshly graduated social worker met this mother at her home eager to take her to select her son's first brand-new wheelchair. The mother hardly shared the worker's enthusiasm. To the mother, this was another shattering of a dream. She wanted to be selecting a tricycle for her son, not a wheelchair.

One of your tasks as a professional is to not personalize our distancing attitude, and to understand, that in most cases, our reluctance to connect with you and your program is not about YOU, but rather about the situation and circumstances forced upon us, our families, and our child. Your acceptance and sensitivity toward our worries and fears help to relax our tightly folded arms. When you can see our ambivalence from our side of this partnership dance, then maybe you're less likely to be offended by our unintended, and sometimes challenging, dispositions. You maybe able to see that our lack of enthusiasm for one more meeting, one more phone call, one more form, one more test, one more transition is less about YOU and more about our worries and uncertainties.

Second Dimension — Forced Intimacy: Too Close for Comfort

The second dimension unique to our partnership deals with intimacy. Because we are sitting with you during one of the most painful and confusing times of our life, we feel thrust into an uninvited and awkward closeness with you. We sit before you at one of our most vulnerable times. You enter our hearts. You hear our guilt and shame. You listen to our inadequacies. You are stung by our salty tears. You are witness to our pain. We may welcome the tender support and practical interventions, but the nature of the circumstances forces an immediate intimacy that is awkward. At times, it is as if we are forced into a slam-dance popular among the younger generation a few years ago.

Most relationships evolve gradually over time. In this unique parent-professional partnership dance, we often are forced into an instant closeness bringing us nose-to- nose with strangers long before there is a foundation of trust to cushion the strong feelings. I'm struck by the fact that we parents sometimes cry in front of people whose last names we don't know. Our unexpected display of our feelings of sadness, rage, or frustration sometimes makes it hard to return to your office. We're not sure what you think of us and our strong emotions.

Many of us are rather awkward with feelings in general. In many of our relationships we try to avoid expressing and acknowledging them. I refer to feelings as the "F" word in partnerships--something to avoid at all costs. Consider Jeff, a friend of mine. Jeff's four-year-old daughter had an immune deficiency problem and was struggling to stay alive. The family teetered on the edge of life and death on a daily basis, sometimes on a moment-to- moment basis. One night Jeff decided to spend the evening at home away from the hospital, now his daughter's home. He hoped for a good night's sleep, but was rudely disturbed by a haunting dream in which his daughter died. Her death felt so real to him that he traveled to the hospital in the middle of the night hoping to be reassured by her warm, rhythmic breathing. He maneuvered his way through New York City's night traffic, rushed through the hospital's long hallways, shoved open his daughter's door and knelt down close to her soft cheeks. He burst into sobs as he felt her warm, reassuring breaths on his face.

A nurse observed Jeff's unexpected arrival and later sat next to him offering supportive words. She commented that she was surprised to see this strong reaction from him as she had grown accustomed to his consistent positive attitude. "Jeff, I didn't know you felt this way." She remarked. Jeff looked at her and responded, "I always feel that way. It's just that I can't walk around falling apart all the time."

You as professionals have the opportunity to allow us our feelings, even to invite us to "fall apart" once in awhile in the presence of someone who understands and cares. Your compassion and non-judgmental attitude can be a gift that decreases our sense of isolation, softens our stress, and decreases the number of times we unintentionally step on toes!

Third dimension — Identification of Partners: Will the Real Partner(s) Please Come Forward?

The third dimension to our partnership deals with identifying who is the partner on the family side. You as professionals often enter this work because you enjoy children; you are drawn to the "little people." Additionally your education and training emphasized the child, focusing on how to arrive at the proper diagnosis of and intervention for the child. Thus, you as the professional enter this dance ready to partner with the child.

"Let's dance, little one. You are my partner. I'm ready to play with you and teach you. Let's begin together."

Parents, however, want and should be primary partners in this dance. I am reminded of the words of Kristen Birkmeier (1993), a physical therapist and national speaker, as she addressed an audience of early intervention therapists. She said, "Put the parents first, for it is their lives that have been changed. The child is who she is, and needs your expertise, but not without the active involvement of the parents who live with this child 24 hours a day."

"Thank you! Thank you!" I remember whispering under my breath as I listened to Kristen. I was recalling Micah's early childhood days when I took him to his every-Thursday speech therapy sessions. I would hand him over to the speech pathologist, but I found myself wishing I could hand me over to her as well. He needed to learn how to stimulate his oral motor muscles, but I needed to learn how to live with a child who did not have words or a familiar way to communicate his needs. Micah and I both needed to dance with our professional partner.

This rearranging of partners to include the parents is often awkward and new for the professional. It is a shift away from the "old ways" where the focus was primarily on the child to a more inclusive perspective which invites parents in on the work. For me, some of the most meaningful sessions with Micah's therapists were the ones when the professionals momentarily put aside the big, green, bouncy ball and turned to me to ask, "What are you concerned about? What have we neglected to think about for Micah? How are you doing?" Those questions felt wonderful and truly engaged me in this partnership dance.

Another aspect to this third dimension deals with the sheer number of partners. Earlier I stated that the definition of partners was "either of two persons dancing together." As we all know, we are not talking about a partnership of two when dealing with our child. On the parent's side there may be two, but more likely there are others, including significant loved ones, siblings, extended family members, and friends. On the professional side, there's the speech therapist, the occupational therapist, the physical therapist, the social worker, the teacher, the nurse, the paraprofessional, and on and on. I didn't just give birth to Micah; I gave birth to an entire ballroom. And at any time, any one of those partners can change faces, as the professionals move in and out of jobs or assignments. Sometimes we are dancing with more people than is manageable.

I am a strong proponent of meetings that include all members of the team. It is in this setting that the creative problem solving is invigorating and reassuring. At our recent school meeting to plan for my son, one teacher learned from another teacher ways to involve his peers in assisting Micah with written assignments. Then, the speech therapist offered suggestions about new software to enhance his participation and we, his parents, reminded the team about the importance of using current events to engage Micah in the class discussions. The partnership dance was working!

Not all meetings of the entire team flow this evenly, however. Negotiation with two people can be challenging, but with eight, nine or ten it can feel cumbersome and unproductive. Sometimes it makes sense to meet with only two or three members, especially when the issues are volatile or complicated. Most of us talk more freely and risk sharing our worries when we work with fewer people.

There are times when a large square dance is needed and other times when dancing cheek-to-cheek makes all the sense in the world. All partners do not need to be at every dance, at every meeting. Knowing which meetings should be small and which should involve the entire team is another way to reduce the amount of times that toes get stepped on. Sometimes more is not better.

Fourth Dimension — Role Expectations: Who’s Leading This Dance?

The fourth dimension is the lack of clarity to our distinct roles; that is, who is leading this partnership dance. Historically, based on the medical model, the professionals were viewed as the experts. They lead this dance. They gave the direction to the dance and decided on the music. Now we hear more talk about parents being the experts. "Parents know their child best." In many ways, I agree with this approach. My husband and I do know a tremendous amount about Micah, especially now that we’ve been his parents for 16 years. We know what grabs his attention---politics and sports. We know he often repeats himself when he wants to keep your attention and doesn’t know what else to say. We know that he needs coaching about ways to engage his peers. We know that he has an exquisite ability to read people’s moods and respond with compassion and insight.

At the same time, there is so much that we still don't know and understand about him and his mind, especially as we face his future as an adult. There are so many processes that are not clear to us. Our uncertainty was more prominent during his early childhood years. I was less likely to trust my “mother instinct.” During those early years, when professionals used that well-meaning but pat phrase “You are the expert, Ms. Fialka,” my mind would go as blank as a freshly cleaned chalkboard and I would shiver at my inability to say something profound or at least coherent. In the beginning I knew more about what he didn’t do, then what he could do. For me the use of the phrase “You are the expert” pulled me away from my familiar role of everyday-mom who giggled with Micah as we splashed in the bath tub, and instead shoved me behind the professional’s desk piled high with thick reports and foreign acronyms. “Expert? What do you mean by that?”

I prefer to move away from this idea of expert and in its place use the word contributor. Each dancer, professional and parent, contributes to the understanding of the child. Our unique contributions evolve and build on each other as we offer differing sides and perspectives about this child. There is the playground-side, the art class-side, the dinnertime-eating-side, the bouncing-on-daddy’s-knee-side.

Each of our contributions is critical. Ann Hartman (1993) captured this spirit when she wrote to professionals, "We must relinquish the role of expert so that our clients' narratives and experiences can be validated. . . .We do not discard our knowledge, we cease to privilege it, and we apply our knowledge with caution and humility, with the recognition that it is one of many truths. . ."

A square dance comes to mind as I see the partners circling in and around, over and through these many "truths," relying on the hand of the next partner to guide us to the next place in our dance.

Fifth Dimension — Differing Priorities: Do You Hear What I Hear?

The fifth dimension deals with priorities. Priorities for parents and professionals often differ. It is as if we each have on our own set of headphones and are listening to our own music with its own tune, words, and rhythm. There's the mother-song, the father-song, the speech pathologist-song, the neurologist-song, and the teacher-song. Sometimes the only song we can momentarily agree on is "Hit the road Jack, and don't you come back no more, no more!"

When Micah was about two years old, a teacher consultant made weekly visits to our home for "fun and therapy!" One beautiful spring day, we decided to play outdoors. As we moved to our back lawn, we saw our next door neighbor and her young daughter playing outside on their swing set. The teacher consultant, noticing that the little girl seemed to be about the same age as Micah commented, "It must be nice to have a playmate for Micah right next door."

I understood her thinking, but offered my own experience. "Some days it is pleasant." I tentatively continued. "But more days than not, that sweet, unknowing girl is the constant reminder of what Micah can't do, no matter how much exercising, and pushing and pulling of his low muscle tone arms and legs we do! Many days that innocent girl is a reminder of our lost dream." The teacher consultant maintained her eye contact with me and respectfully acknowledged my perspective. "I never thought about it that way. I'm glad that you mentioned it to me. You helped me to see your world." The teacher consultant, in essence, took off her professional-headphones, put on my parent-headphones and listened to my music and words. This interaction reminds me that as partnership-dancers we must be willing to take risks, offer our headphones to our partners and be willing to listen to each other's music and experiences. We won't be able to do it all of the time, but when we can, I believe we will be more effective in strengthening the parent professional partnership.

When the physical therapist suggests to a mother that she begin helping her child focus on proper hand-positioning of eating utensils, it is critical that the therapist also be mindful that this seemingly innocent recommendation may wreak havoc during the family meal time. When making new recommendations to families, one therapist asks the family a series of questions, "Now that I have suggested some new approaches at home, what have I missed? How will this change or disrupt your life? How will this complicate your daily living? What do I need to understand from your side as the parent?"

This type of questioning respectfully invites parents to share their music, their perspective so that recommendations can be relevant, practical, and manageable. This gives the message to parents that "I need your participation."

These five dimension--choice, forced intimacy, partnership roles, number of partners, and priorities--are present in all our dances, in all our parent-professional partnerships. When we are experiencing difficulties, when we step on each others toes, when we feel we'd rather not be at this dance--at this meeting--then it is time to examine these five issues to determine which one might need to be further explored or addressed. The issue is not will these dimensions creep into our partnerships, because they obviously will. The issue is are we willing to recognize these dimensions and be courageous enough to discuss them and work on them together.

Maybe our theme song for our partnerships should at least begin with the refrain, "Getting to know you, getting to know all about you." I believe that if parents and professionals are to be effective in creating marvelous opportunities for our children, then both sets of partners must carve out time to get to know each other's dreams, hopes, fears, constraints, and perspectives. We must take off our own sets of headphones and be willing to hear each other's music, with special attention to and inclusion of the parent's music and unique dance steps. To truly get to know the child, we must also get to know each other, not just as parents and professionals (more labels) but as people. This is hard work requiring patience, trust, and lots of getting to know each other, as well as ourselves. It is one of the most significant ways that we can make a difference in the lives of our children who are indeed the star dancers of this relationship.

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Notes

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You can reach Janice Fialka at ruaw@aol.com or www.danceofpartnership.com.

Family Survey

Family Outcomes Survey

Part C Version

The Family Outcomes Survey is designed to provide a way for you to describe your family and the ways you support your child’s needs.

Instructions:

- This survey should be filled out by the person in your family who has the most interaction with early intervention.
- All of the responses include the word “we” or “our.” This refers to your family. Usually this means parents and others who support and care for your child. But every family is different, so think of what “family” means to you when answering.
- On every page, you will be asked to answer questions like the example below:

How much does your family know about dinosaurs?

1	2	3	4	5	6	7
We know a **little** about dinosaurs		We know **some** about dinosaurs		We know **a good amount** about dinosaurs		We know **a great deal** about dinosaurs

- Read each question and circle the number that best describes your family right now.
- If a statement almost describes your family, but not quite, circle the number just to the left or the right. For example if you feel that the statement 5 “We know **a good amount** about dinosaurs” almost describes your family, but not quite—circle the 4.

  If you do not know how to answer a question, or if you are not comfortable answering the question, skip it and go to the next question.

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Family Outcomes Survey

UNDERSTANDING YOUR CHILD'S STRENGTHS, ABILITIES, AND SPECIAL NEEDS

1. *Your child is growing and learning. How much does your family understand about your child's development?*

1	2	3	4	5	6	7
We are **just beginning** to understand our child's development		We understand **some** about our child's development		We understand **a good amount** about our child's development		We understand **a great deal** about our child's development

2. *Some children have special health needs, a disability, or are delayed in their development. These are often referred to as "special needs." How familiar is your family with your child's special needs?*

1	2	3	4	5	6	7
We are **just beginning** to understand our child's special needs		We understand **some** about our child's special needs		We understand **a good amount** about our child's special needs		We understand **a great deal** about our child's special needs

3. *Professionals who work with you and your child want to know if the things they do are working. How often is your family able to tell if your child is making progress?*

1	2	3	4	5	6	7
We **seldom** can tell if our child is making progress		We **sometimes** can tell if our child is making progress		We **usually** can tell if our child is making progress		We **almost always** can tell if our child is making progress

KNOWING YOUR RIGHTS AND ADVOCATING FOR YOUR CHILD

4. *A variety of programs and services may be available to help your child and family. How much does your family know about the programs and services that are available?*

1	2	3	4	5	6	7
We are **just beginning** to learn about the programs and services that are available		We know **some** about the programs and services that are available		We know **a good amount** about the programs and services that are available		We know **a great deal** about the programs and services that are available

5. *Families often meet with early intervention professionals to plan services or activities. How comfortable is your family participating in these meetings?*

1	2	3	4	5	6	7
We are **just beginning** to feel comfortable participating in meetings		We are **somewhat** comfortable participating in meetings		We are **generally** comfortable participating in meetings		We are **very** comfortable participating in meetings

6. *Families of children with special needs have rights, including what to do if you are not satisfied. How familiar is your family with your rights?*

1	2	3	4	5	6	7
We are **just beginning** to understand our rights		We understand **some** about our rights		We understand **a good amount** about our rights		We understand **a great deal** about our rights

HELPING YOUR CHILD DEVELOP AND LEARN

7. *Families help their children develop and learn. How much does your family know about how to help your child develop and learn?*

1	**2**	**3**	**4**	**5**	**6**	**7**
We are **just beginning** to know how to help our child develop and learn		We know **some** about how to help our child develop and learn		We know **a good amount** about how to help our child develop and learn		We know **a great deal** about how to help our child develop and learn

8. *Families try to help their children learn to behave the way they would like. How much does your family know about how to help your child learn to behave the way your family would like?*

1	**2**	**3**	**4**	**5**	**6**	**7**
We are **just beginning** to know how to help our child behave the way we want		We know **some** about how to help our child behave the way we want		We know **a good amount** about how to help our child behave the way we want		We know **a great deal** about how to help our child behave the way we want

9. *Families work with professionals to help their children learn and practice new skills at home or in their communities. How often does your family help your child learn and practice these new skills?*

1	**2**	**3**	**4**	**5**	**6**	**7**
We are **just beginning** to help our child learn and practice these skills		We **sometimes** help our child learn and practice these skills		We **usually** help our child learn and practice these skills		We **routinely** help our child learn and practice these skills

HAVING SUPPORT SYSTEMS

10. *Many people feel that talking with another person helps them deal with problems or celebrate when good things happen. How often does your family have someone your family trusts to listen and talk with when they need it?*

1	**2**	**3**	**4**	**5**	**6**	**7**
We **seldom** have someone to talk with about things when we need it		We **sometimes** have someone to talk with about things when we need it		We **usually** have someone to talk with about things when we need it		We **almost always** have someone to talk with about things when we need it

11. *Families sometimes must rely on other people for help when they need it, for example to provide a ride, run an errand, or watch their child for a short period of time. How often does your family have someone you can rely on for help when your family needs it?*

1	**2**	**3**	**4**	**5**	**6**	**7**
We **seldom** have someone we can rely on for help when we need it		We **sometimes** have someone we can rely on for help when we need it		We **usually** have someone we can rely on for help when we need it		We **almost always** have someone we can rely on for help when we need it

12. *Most families have things they enjoy doing. How often is your family able to do the things your family enjoys?*

1	**2**	**3**	**4**	**5**	**6**	**7**
We **seldom** are able to do the things we enjoy		We **sometimes** are able to do the things we enjoy		We **usually** are able to do the things we enjoy		We **almost always** are able to do the things we enjoy

ACCESSING YOUR COMMUNITY

13. All children need medical care. How well does your family's medical care meet your child's special needs?

1	**2**	**3**	**4**	**5**	**6**	**7**
Our medical care meets **few** of our child's needs		Our medical care meets **some** of our child's needs		Our medical care meets **many** of our child's needs		Our medical care meets **almost all** of our child's needs

14. Many families have a need for quality childcare. By this, we do not mean occasional babysitting, but regular childcare, either part-day or full-day. How well does your family's childcare meet your child's needs?

☐ CHECK HERE IF YOUR FAMILY HAS NOT WANTED CHILD CARE, AND GO TO QUESTION 15.

☐ CHECK HERE IF YOUR FAMILY HAS WANTED CHILD CARE BUT IT IS NOT CURRENTLY AVAILABLE, AND GO TO QUESTION 15.

1	**2**	**3**	**4**	**5**	**6**	**7**
Our childcare meets **few** of our child's needs		Our childcare meets **some** of our child's needs		Our childcare meets **many** of our child's needs		Our childcare meets **almost all** of our child's needs

15. Many families want their child to play with other children or participate in religious, community, or social activities. How often does your child participate in these activities right now?

☐ CHECK HERE IF YOUR FAMILY HAS NOT WANTED YOUR CHILD TO PARTICIPATE IN SUCH ACTIVITIES AND GO TO QUESTION 16.

1	**2**	**3**	**4**	**5**	**6**	**7**
Our child **seldom** participates in the activities we want		Our child **sometimes** participates in the activities we want		Our child **usually** participates in the activities we want		Our child **almost always** participates in the activities we want

THE HELPFULNESS OF EARLY INTERVENTION

The next questions ask how well early intervention has helped your family. When answering, think about the early intervention services you have received.

16. To what extent has early intervention helped your family *<u>know and understand your rights</u>*?

1	**2**	**3**	**4**	**5**	**6**	**7**
Early intervention has done a **poor** job of helping us know our rights		Early intervention has done a **fair** job of helping us know our rights		Early intervention has done a **good** job of helping us know our rights		Early intervention has done an **excellent** job of helping us know our rights

17. To what extent has early intervention helped your family *<u>effectively communicate your child's needs</u>*?

1	**2**	**3**	**4**	**5**	**6**	**7**
Early intervention has done a **poor** job of helping us communicate our child's needs		Early intervention has done a **fair** job of helping us communicate our child's needs		Early intervention has done a **good** job of helping us communicate our child's needs		Early intervention has done an **excellent** job of helping us communicate our child's needs

18. To what extent has early intervention helped your family be able to *<u>help your child develop and learn</u>*?

1	**2**	**3**	**4**	**5**	**6**	**7**
Early intervention has done a **poor** job of helping us help our child develop and learn		Early intervention has done a **fair** job of helping us help our child develop and learn		Early intervention has done a **good** job of helping us help our child develop and learn		Early intervention has done an **excellent** job of helping us help our child develop and learn

Thank you for completing this survey!

Minnesota Association
for Children's Mental Health
165 Western Avenue N, Suite 2
St. Paul, MN 55102
651-644-7333 • 800-528-4511 • www.macmh.org