Recognizing the Centrality of Family through the Family Life Experience Project

Suzanne A. Milbourne
Mike Tabayoyong
Thomas Jefferson University
Child and Family Studies Research Programs
Presentation outline

- Briefly discuss family centered principles
- Describe the Family Life Experience Project
- Visit with Families who participate in the Project
- Journey with a Student
- So what?
- Early Intervention Competencies
Philosophy of Family Support

• Tara’s mother:

“If you don’t have a friend in the world, who are you combing your hair for?”
Sample Family Centered Principles: Philosophy

Characteristics of programs that support the family-centered approach include:

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

(Powers, 1996)
Assessing Family Need and Determining Supports

- Sean’s mother:

  “He’s a regular kid, yea - he has some disabilities, but he is a kid first.”
Sample Family Centered Principles: Assessment

- Key principles of family-centered assessment and planning include:
  - Child-focused goal planning
  - A resource-orientation focus;
  - Consumer-driven planning;
  - Partnerships to enhance opportunities;
  - Professional contribution to or in support of ...; vs professional decision about
  - Outcomes and results vs. numbers
  - Observation in multiple natural settings; and
  - Community-based intervention
Essential Competencies for Working Together with Families

- Cameron’s mother:

  “the best therapy is life.”
Sample Family Centered Principles: Parent Perspective

• Problems of learning how to reenter the real world can be avoided if a child never leave the natural settings for “special” settings in the first place.
• Problems of generalizing skills to the settings where the child needs to use those skills can also be avoided if they are first learned in the natural settings.
• Children with disabilities need even greater exposure to natural environments and experiences so they can learn to function using their disabilities. As with any child, the less exposure to a situation, the less equipped they will be to deal with it.

Colleen Tomko -- kidstogether.org

Special thanks to Gary Mears & Phyllis Guinivan who inspired the development of the

A guide designed to promote family-centered approaches of practice

Introduces students to:

• the philosophy of family support;
• perspectives on assessing needs and determining supports; and
• essential competencies for working together with families.
Components

• Family Life Experience

• Complementary Assignments

• Final Project
Component #1
Family Life Experience

- To provide opportunity to observe the ways in which families lead their lives and the impact that having a child with a disability or developmental delay has on the ways in which families manage their day to day activities.

- By understanding about the roles and responsibilities of families themselves and their children and the strategies families use to include the child with a disability or delay, professionals are better able to provide services in ways that support a family’s ability to optimize the growth and development of their child.
Family Life Experience

• Spend a total of **35-40 hours** of time with a family over 5-6 week time period to understand:
  - Family beliefs and practices about raising children
  - How families implement their roles (as caregiver, nurturer, economic supporter, etc.)
  - How work responsibilities and economic resources of parent(s) impact on family life
  - How the needs of the child with a disability/delay impact on the family in terms of the ways in which they spend their time, responsibilities, stress, etc.
  - How families “perceive” and represent their child with a disability
  - The ways in which early intervention support/does not support the family
Component #2
Complementary Assignments

• Find, read, and summarize 2 articles about family-centered principles
• Create a matrix of EI documents and family-centered principles - analyze
• Create a Community Map with the family
• Complete 2 booklets from the Me Too! Series
• Formal interview with the family - analysis
• Self rating - EI Competencies
• Activity Log and Weekly Reflection Journal
Look What I
Can Do Now

Me Too!
Series
Hanson & Beckman, 2001
Introducing Me

Me Too!
Series
Hanson & Beckman, 2001
Component #3
Final Project

• The goal of the final project is to synthesize and integrate the experience you have had over the course of 35-40 hours spent with one family.

• Secondly, to generalize the information to everyday relationships with families and the partnerships created together.
Visit with Families who Participated in the Project
All families spend 35-40 hours with an OT student in various settings

- home
- parent to parent meetings
- swim meet
- neighborhood shopping
- childcare
- IEP/IFSP meeting
- dance class
- Grandma’s house
Family Interview Focus

- Partnering with families / teamwork
- Understanding of Family Centered Principles
- Affect on future practice
- Advantages for the student
- Open ended - anything to add
Rayfield Family

- It made the student be more aware of the stressors that are on the family because it put her right with us. She saw how stressful it was to do the appointments and it wasn’t like a typical family...
McGee Family

- I think it gave him an inside look at how it really is in family life of a child with a disability - how very busy, very crazy it is... I really don’t think a therapist is able to grasp what the family is like on the hour they are here.
McGrath Family

- I don't think that people appreciate sometimes all the things that a family goes though ... sometimes the daily schedule becomes difficult... I think it was beneficial for the student to see how to adapt and make things work
McGee Family

• He came to a swim meet with us... It gave him a great sense of the family life of a child with a disability... if your always thinking about a child with a disability you don’t always know how they function in the family. I think it is a great way to see how much he does fit into our family.
Rayfield Family

• Because it wasn’t just geared to the child. Also, she dealt with my feelings, what I was going through and she tried to help. And that is important...
McGee Family

- The student switched his schedule once... Then the other time he switched to go to the Down Syndrome meeting. I think that was good that he recognized that these meetings were important to us... So the meetings were very important and he took the time to go to a meeting and just hear families network and figure out what’s best.
McGee Family

- ... just sometimes the heaviness of having a child with a disability. The everyday dealing with the child. You know the good and the bad. Just their whole life. I think he [the student] got sensitive toward that. When he goes into the home he may be more sensitive to the parents and impact on their life.
[He learned] that not everything is clear cut. There are things the family runs into. Difficulties that you’re not going to experience in a textbook. You’re only going to learn when you meet a family that has this situation... I don’t think you can learn stuff like that from a textbook.
McGee Family

- ... he actually went to school with Nicolas... it was great for him [the student] to come home and tell what his eyes saw... he was able to say how he felt Nick did in the classroom. He was able to give me feedback about the school... I think that if people are going... to be a therapist, I think it’s good to understand what the whole family is about - that it is about the dynamics of the family.
Journey with a Student
Student Journal Comments

What have you gained from this experience:

- The importance of involving the family and others present in therapy sessions...
- I need to keep in mind that their lives are above and beyond our therapy sessions together.
- I will focus on listening to family on a continued basis to what the family wants to address... and what they need as a whole.

- Focus on parents’ priorities when developing interventions
- Realize that you are not the most important part of a family’s life
- Importance of being prepared for each therapy session
- Being aware of boundaries but also making connections with the family at the same time
- Respect family requests - flexibility to change intervention plan
Student reflection

• Most families are just trying to do the typical things that a family needs to do and when they have a child or children with a disability, they are still trying to do these typical things, in addition to the special services that they are receiving.

• ... always be mindful of being as flexible as possible with my schedule... and to always be on time and use the time with the family wisely... show them respect that their time is important.

• ... even though some families and children may have to take a different road... they all have hopes and concerns for their children (with and without disabilities)
So What?
Family as Faculty - they can teach what no textbook can!

Personnel Preparation

Competent Early Intervention Providers

EI Competencies
<table>
<thead>
<tr>
<th>Content Area C</th>
<th>Individualize – be “in-tune” with “my” child</th>
<th>Knowledge that “I don’t have” as a parent</th>
<th>Be flexible and adaptable – responsive to our family</th>
<th>Include the family as part of the team</th>
<th>Be committed to what you are doing - dedication</th>
<th>Sensitive and respectful of individual families</th>
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</thead>
<tbody>
<tr>
<td>Coordinated care in early intervention settings</td>
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<tr>
<td>1. *Form a partnership and work collaboratively with other team members, especially the child’s family</td>
<td></td>
<td></td>
<td>X</td>
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<td>X</td>
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<tr>
<td>2. Function as a consultant</td>
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<td></td>
<td>X</td>
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<tr>
<td>3. Supervise personnel and professional students</td>
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<tr>
<td>Content Area D</td>
<td>Examination and evaluation in the early intervention setting</td>
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<tr>
<td>4. *Individualize the examination and evaluation for child, team, and family needs.</td>
<td>X</td>
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<tr>
<td>5. *Evaluate family strengths, resources, concerns, and priorities</td>
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Next Steps

• Further analyze the family interview transcripts - thematic analysis
• Compare the interview themes with EI Competencies
• Compare the interviews with the Family Focus Group transcriptions/themes
• Conduct a focus group or individual interviews with former students
• Finalize and publish the EI Competencies
In order to view the:

• Family Life Experience Project
• Presentation Overheads

Visit our web site

http://jeffline.tju.edu/cfsrp

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