

## ***Supporting Involvement of Families and Individuals with Disabilities in Preservice Preparation: An Overview of Options***

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### **Objectives:**

- Establish the importance of involvement of families and individuals with disabilities in preservice training
- Exchange information and resources about options and models for implementation
- Identify various roles of families and individuals with disabilities in preservice training
- Identify and share a variety of supports for family, individuals with disabilities, faculty and students when families and individuals with disabilities participate in preservice preparation
- Discuss strategies and issues related to sustaining and institutionalizing this approach

### **Outline:**

#### **I. Why! The importance of involvement of families and individuals with disabilities in preservice preparation**

- A. Reauthorization of IDEA and other legislative initiatives continue to set the conceptual framework for working with families in innovative ways

*"Part C of LDEA mandates a statewide system that shall provide at a minimum, for each infant or toddler with a disability to receive "a family-directed assessment" of the resources, priorities and concerns of the family and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the infant or toddler." (P.L. 105-17 Title I Amendment to IDEA, Sec. 636, 1997)*

*In addition, IDEA states that the LEA shall ensure that the parents of children with disabilities are involved in the design, evaluation, and if appropriate, implementation of school-based improvement plans*

- B. IDEA also provides the conceptual framework for involving individuals with disabilities in decision-making roles.

*Generally, a child with a disability should attend the IEP meeting if the parent decides that it is appropriate for the child to do so. If possible, the agency and parents should discuss the appropriateness of the child's participation before a decision is made, in order to help the parents determine whether or not the child's attendance would be (1) helpful in developing the IEP or (2) directly beneficial to the child or both. The agency should inform the parents before each IEP meeting—as part of notification under §300.345(a)(1)—that they may invite their child to participate.*

- C. “Key elements of family-centered care” (Shelton & Stepanek, 1994) offer guidelines for collaboration and parent leadership initiatives

- D. Benefits to involvement of families and individuals with disabilities in preservice training: Reflections from students.

*“Hearing from families was one of the most meaningful, touching, and best learning experiences I’ve ever had. I learned so much about how families cope from these real stories.”*

Graduate student at UNC-CH, 1997

*“The family partnership project gave me an incredible “real world experience.” Hearing about the informational needs of 23 different families and how broad and diverse they were opened my eyes to the need for me to know about many resources.”*

Graduate student at UNC-CH, 1998

*“I was able to see the life of a child with a disability from another view. Some things I do in the clinical setting that I thought were good, may not be perceived as so by the family. I was able to realize the hurtful things I may say or do without even knowing. This experience forced me to think differently and to be more compassionate.”*

Graduate student in North Dakota, 2002

*“Parent co-instructor gave me the ability to see the disability from a family perspective; seeing how busy parents are and how educated parents are about their child's disability.”*

Graduate student in North Dakota, 2002

## **II. Possibilities!! Options & models for involvement of families and individuals with disabilities in preservice preparation**

- A. Options and Models:

- Family/Consumer presentations and panels (*Family Stories*)
- Parents and individuals with disabilities taking the lead to educate others
- Parent-faculty co-instruction
- Participation in program admissions process
- Develop curricula, courses and syllabi
- Participation in class assignments and projects/activities
- Family mentor or practica programs –

- Planning, monitoring and evaluating programs
- Families as mentors to other families
- Participation in personnel preparation grant applications

### III. Reflection and application to practice

#### Small Group Brainstorm and Information Sharing

##### Part I

- Think about and identify one way you are currently involving families and/or individuals with disabilities in personnel preparation or staff development activities.
- Participants will be grouped around individuals who are currently trying some of the options

##### Part II

- Identify one idea you want to try
- Please write down the idea you want to try on the “Back Home Plan” **[Attached]**
- Re-group yourself so that members of state teams are sitting together
- Share your idea with your small group in a round robin fashion
- Identify the resources that you need to accomplish your idea and share those with the small group
- As a group identify two “burning questions” related to resources and supports for implementing the ideas generated in the group.
- Write down the “burning questions” on a post-it note. One question for each post-it note.

### IV. The “How To’s”

#### A. Key considerations

- How do you recruit, prepare and support families and individuals with disabilities for these experiences?
- How do you prepare and support students for these experiences?
- How do you support and prepare faculty for these experiences?
- What are strategies for evaluating these experiences in terms of impact on students? On individuals with disabilities and families? On faculty? Other evaluation considerations?
- How do you sustain this approach over time?
- Others?

#### B. Resources and Ideas to Help Implement your Plan

1. Support for families and individuals with disabilities
  - a. Financial support (e.g., salary, stipend, child care & travel coverage)

- b. Emotional, support (e.g., regular communication, awareness of challenges in sharing highly personal information with strangers)
  - c. Preparations, practice and support in building expertise:  
*Telling Your Family Story, Parents as Presenters* (Wisconsin)  
 Moss, J. *Telling Your Story* (UAP, Oklahoma)  
 Wesley, P. et al. *Families as Presenters* (North Carolina)  
 Colwell, R. *Opportunities for Parent Leadership in North Carolina*
  - d. Access (facilities, room arrangement, interpreters, AV support, etc.)  
 “Planning for Accessible Meetings & General Guidelines When Serving Anyone with Special Needs”—web site created by the DisAbled Women’s Network / DAWN Ontario:  
[http://dawn.thot.net/accessible\\_meetings.html](http://dawn.thot.net/accessible_meetings.html)
2. Support for faculty:
- a. Funding from federal (US Dept of Ed and others) and state (Part C and others) agencies
  - b. Other grants (PA example)
  - c. Collaboration with an advocacy organization (e.g., the ARC, Family Voices, local or state ICC, and others)
  - d. Material support  
*Parent Consultant Directory* (Wisconsin) or *Early Connections* (NC)  
*Essential Allies* and *Families as Advisors* (IFCC)
3. Student Support:
- a. Informational support
    - Make sure students understand why families are being included
    - Introduce students to “People First” language (see handout based on the Disability is Natural web site:  
<http://www.disabilityisnatural.com/peoplefirstlanguage.htm>)
  - b. Emotional support (e.g., create an open and safe environment where it is "okay" to talk about all aspects of working with families)

### Resources

Barrick, M. & Cusick, E. (1999). Family partnerships. *All Together Now*, 4(3), 12-13.

Butera, G., Matuga, K., & Riley, S. (1999). Doing as we do: Guiding student development in family focused intervention using family stories and parent co-instruction. *Infant Toddler Intervention: The Transdisciplinary Journal*, 9(2), 107-121.

Bricker, D. & Widerstrom, A. (1996). *Preparing personnel to work with infants and young children and their families: A team approach*. Baltimore, MD: Paul Brookes.

- Brinker, R.P. (1992). Family involvement in early intervention: Accepting the unchangeable, changing the changeable, and knowing the difference. *Topics in Early Childhood Special Education, 12*(3), 307-332.
- Bromwich, R. (1997). *Working with families and their infants at risk: A perspective after 20 years experience*. Austin, TX: Pro-Ed.
- Capone, A.M., & DiVenere, N. (1996). The evolution of a personnel preparation program: Preparation of family-centered practitioners. *Journal of Early Intervention, 20*(3), 222-231.
- Coleman, M., & Wallinga, C. (2000). Teacher training and family involvement. *Childhood Education, Winter*, 76-81.
- Colwell, R. (2002). *Opportunities for parent leadership in North Carolina: A resource guide for parents of children with special needs*. Raleigh, NC: Infant-Toddler Program, NC Early Intervention Services.
- Diamond, K., & Innes, F. K. (2000). The origins of young children's attitudes toward peers with disabilities. In M.J. Guralnick (Ed.), *Early childhood inclusion: Focus on change* (pp. 159-177). Baltimore, MD: Brookes.
- Early Childhood Report (2002). Even kindergartners can participate in IEP meetings. *12* (9), 1,5
- Edelman, L. (1991). *Getting on board: Training activities to promote practice of family centered care*. Association for the Care of Children's Health: Bethesda, MD.
- Eggbeer, L., Fenichel, E., Pawl, J.H., Shanok, R.S., & Williamson, G.G. (1994). Training the trainers: Innovative strategies for teaching relationship concepts and skills to infant/family professionals. *Infants and Young Children, 7*(2), 53-61.
- Gilkerson, L. (1994). Supporting parents in leadership roles. *Zero to Three, 14*(4), 23-24.
- Hains, A.H., & Whitehead, A. (1994, July). *The role of families in the field/clinical experience*. Paper presented at the 1994 Ohio Early Childhood Special Education/ Higher Education Consortium Summer Institute, Oregon, OH.
- Hanson, M.J. & Lynch, E.W. (1992). Family diversity: Implications for policy and practice. *Topics in Early Childhood Special Education, 12*(3), 283-306.
- Harry, B. (1992). Developing cultural self-awareness: The first step in values clarification for early interventionists. *Topics in Early Childhood Special Education, 12*(3), 333-350.
- Harry, B., Torguson, C. Katkavich, J., & Guerrero, M. (1993). Crossing social class and cultural barriers in working with families: Implications for teacher training. *Teaching Exceptional Children, 26*(1), 48-51.
- Iowa Department of Education. (no date). *Parents as presenters workshop*. Des Moines, Iowa: author.
- Jeppson, E.S., Thomas, J. (1997). *Families as advisors: A training guide for collaboration*. Bethesda, MD: Institute for Family-Centered Care.
- Jeppson, E.S., & Thomas, J. (1995). *Essential allies: Families as advisors*. Bethesda, MD: Institute for Family-Centered Care.
- King, S. (1994). *Telling your family story... Parents as presenters*. Madison, WI: Parent Projects, Wisconsin Personnel Development Project, Waisman Center, University of Wisconsin-Madison.

- Lynch, E.W., & Hanson, M.J. (1992). *Developing cross-cultural competence: A guide for working with young children and their families*. Baltimore: Paul Brookes.
- Miller, P., Niemeyer, J., and Brotherson, M (2003). Family participation in personnel preparation, (pp 11-36). In V. Stayton et al. (Eds.) *DEC Personnel Preparation in Early Childhood Special Education*. Missoula, MT: DEC.
- McBride, S.L., Sharp, L., Hains, A.H., & Whitehead, A. (1995). Parents as co-instructors in pre-service training: A pathway to family-centered practice. *Journal of Early Intervention, 19*(4), 343-355.
- Moss, J. (1997). *Telling your story*. University Affiliated Program of Oklahoma, College of Medicine, University of Oklahoma Health Sciences Center. Publication No. CA398.jm.
- Poyadue, F.S. (1988). Parents as teachers of health care professionals. In *Children's Health Care* (pp. 43-45). Bethesda, MD: The Association for the Care of Children's Health.
- Rosin, P., Whitehead, A.D., Tuichman, L., Jesien, G.S., Begun, A.L., & Irwin, L. (1996). *Partnerships in family-centered care: A guide to collaborative early intervention*. Baltimore: Paul Brookes.
- Shelton, T.L., & Stepanek, J.S. (1994). *Family-centered care for children needing specialized health and developmental services*. Bethesda, MD: Association for the Care of Children's Health.
- Telling Your Family Story. (1994). Parent Projects. Madison, WI: Waisman Center, University of Wisconsin at Madison.
- Wells, H.G. (1997). *The country of the blind*. Gardner Press.
- Whitehead, A., & Sontag, J.C. (1993). *Co-instruction: A case study*. Madison, WI: Wisconsin Personnel Development Project, Waisman Center-UAP, University of Wisconsin-Madison.
- Whitehead, A. (Ed.). (1994). *The parent perspective: A parent consultant directory* (2nd Ed.). Madison., WI: Wisconsin Personnel Development Project, Waisman Center, University of Wisconsin-Madison.
- Whitehead, A. (1996). *The benefits of parents speaking to classes: The student perspective*. Paper presented at International parent to Parent Conference, New Mexico.
- Whitehead, A., Jesien, G., & Ulanski, B.K. (1998). Weaving parents into the fabric of early intervention interdisciplinary training: How to integrate and support family involvement in training. *Infants and Young Children, 10*(3), 44-53.
- Winton, P.J. (1991). *Working with families in early intervention: An interdisciplinary preservice curriculum*. Chapel Hill, NC: Frank Porter Graham Child Development Center.
- Winton, P.J., & DiVenere, N. (1995). Family-professional partnerships in early intervention: Guidelines and strategies. *Topics in Early Childhood Special Education, 15*(3), 296-313.
- Wong-Fillmore, L. (1991). When learning a second language means losing the first. *Early Childhood Research Quarterly, 6*(3), 323-347.

## The Key Elements of Family-Centered Care

- Incorporating into policy and practice the recognition that the *family is the constant* in a child's life, while the service systems and support personnel within those systems fluctuate.
- Facilitating *family/professional collaboration* at all levels of hospital, home, and community care:
  - care of an individual child;
  - program development, implementation, evaluation, and evolution; and,
  - policy formation
- *Exchanging complete and unbiased information* between families and professionals in a supportive manner at all times.
- Incorporating into policy and practice the recognition and *honoring of cultural diversity*, strengths, and individuality within and across all families, including *ethnic, racial, spiritual, social, economic, educational, and geographic diversity*.
- Recognizing and respecting *different methods of coping* and implementing comprehensive policies and programs that provide *developmental, educational, emotional, environmental, and financial supports* to meet the diverse needs of families.
- Encouraging and facilitating *family-to-family support* and networking.
- Ensuring that *hospital, home, and community service and support systems* for children needing specialized health and developmental care and their families are *flexible, accessible, and comprehensive* in responding to diverse family-identified needs.
- *Appreciating families as families* and children as children, recognizing that they possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and developmental services and support.

Shelton, T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services. Association for the Care of Children's Health. 7910 Woodmont Avenue, Suite 300, Bethesda, Maryland 20814, 301/654-6549.



Name \_\_\_\_\_

State \_\_\_\_\_

Date \_\_\_\_\_

### MY PLAN FOR BACK HOME\*

*INSTRUCTIONS: In the spaces provided, develop a plan of action for yourself. Please make your plan of action something that you will implement. Write goals that are clear, specific and "do-able" for you. Next, think of the steps involved in accomplishing these goals. Then, think of people and resources that might help you overcome any difficulties in reaching these goals.*

Goal I want to achieve: \_\_\_\_\_  
\_\_\_\_\_

Date by which I want to achieve this goal: \_\_\_\_\_

**Steps to take**

**Resources and people who could help me accomplish this step**

- |          |       |
|----------|-------|
| 1. _____ | _____ |
| 2. _____ | _____ |
| 3. _____ | _____ |

Goal I want to achieve: \_\_\_\_\_  
\_\_\_\_\_

Date by which I want to achieve this goal: \_\_\_\_\_

**Steps to take**

**Resources and people who could help me accomplish this step**

- |          |       |
|----------|-------|
| 1. _____ | _____ |
| 2. _____ | _____ |
| 3. _____ | _____ |

*\*Adapted from the Special Needs Adoption Curriculum, published by Group Child Care Consulting Services, School of Social Work, University of North Carolina, Chapel Hill, North Carolina, 1982.*

Goal I want to achieve: \_\_\_\_\_  
\_\_\_\_\_

Date by which I want to achieve this goal: \_\_\_\_\_

**Steps to take**

**Resources and people who  
could help me accomplish this  
step**

- |          |       |
|----------|-------|
| 1. _____ | _____ |
| 2. _____ | _____ |
| 3. _____ | _____ |

Goal I want to achieve: \_\_\_\_\_  
\_\_\_\_\_

Date by which I want to achieve this goal: \_\_\_\_\_

**Steps to take**

**Resources and people who  
could help me accomplish this  
step**

- |          |       |
|----------|-------|
| 1. _____ | _____ |
| 2. _____ | _____ |
| 3. _____ | _____ |

Goal I want to achieve: \_\_\_\_\_  
\_\_\_\_\_

Date by which I want to achieve this goal: \_\_\_\_\_

## Examples of People First Language

<http://www.diversityisnatural.com/peoplefirstlanguage.htm>

<b>Say</b>	<b>Instead of</b>
people with disabilities	the handicapped or disabled
he has a cognitive disability	he's mentally retarded
she has autism	she's autistic
he has Down syndrome	he's Downs
she has a learning disability	she's learning disabled
he has a physical disability	he's a quadriplegic/crippled
she's of short stature	she's a dwarf (or midget)
he has an emotional disability	he's emotionally disturbed
she uses a wheelchair or mobility chair	she's wheelchair bound she's confined to a wheelchair
he receives special ed services	he's in special ed
typical kids kids without disabilities	normal or healthy kids
congenital disability	birth defect
brain injury	brain damaged
accessible parking	handicapped parking
she needs . . . or she uses . . .	she has a problem with . . .

***And no more "special needs"! A person's needs aren't special to him—they're normal and ordinary! Keep thinking—there are many descriptors we need to change. Practice new ways of thinking!***