Enhancing Family Involvement in Policy Level Activities

2005 OSEP National Early Childhood Conference
Marriott Wardman Park Hotel
Monday, February 7, 2005
4:00 P.M. – 5:30 P.M.
Purpose

- To highlight examples of family leadership projects, sharing ideas and strategies related to:
  - Types of leadership projects and outcomes.
  - Outreach, recruitment/selection, involving culturally and linguistically diverse families, funding, curricula, support, personnel, accomplishments, etc.
Agenda

- Welcome and Introductions
- Overview of Session
  - Purpose
  - Agenda Review
    - Q & A
  - Housekeeping
- Panel Discussion
- Question and Answer Session
- Recap and Close
Parents As Presenters: Infusing Family Stories into Preservice and Inservice

Lisa Sharp, Early ACCESS Parent Consultant
Mary Schertz
Bureau of Children, Family and Community Services
Iowa Department of Education
Overview

Parents of children with disabilities play a critical role in preparing new professionals. The Iowa Department of Education in collaboration with the PTI Center of Iowa and Iowa State University has developed a proven model for engaging, training, and supporting parents as instructional (pre-service and in-service) resources and partners.
Overview

This model – “Parents as Presenters” – uses a two prong approach:
1) Training for parents in how to “tell their story;” and,
2) The development of a manual for college and university faculty as well as early childhood trainers addressing the use of parents in pre-service and in-service activities.
Training

- Parents of children with disabilities – birth to adulthood – apply for the forty slots available each year for the training.
- The two-day training addresses: 1) accepting the invitation, 2) presentation strategies, and 3) the continuum of involvement for parents. Parents have ample time to practice telling their stories before small and large groups.
- A resource manual has been developed to assist parents.
A manual, which includes a directory, has also been developed for college/university faculty and early childhood trainers within our state.

This document addresses: 1) finding families, 2) continuum of roles for family involvement, and 3) compensation for families.

The directory is distributed to all college and university faculty within the state as well as early childhood trainers and is up-dated annually.
Infusing Family-Centered Principles into Preservice

- Family-centered principles in the curriculum
- Family-Centered Principles
  www.state.ia.us/earlyaccess/doc/fcs04.pdf
- Parents as instructional partners
Parents As Presenters Model

- Description and process of the model
- Resources for families and faculty
- Parents as Presenters Manual and Directory
  [www.state.ia.us/earlyaccess/doc/fapm04.pdf](http://www.state.ia.us/earlyaccess/doc/fapm04.pdf)
- Parents as Presenters Workshop Participant Guide
  [www.state.ia.us/earlyaccess/doc/fap04.pdf](http://www.state.ia.us/earlyaccess/doc/fap04.pdf)
Outcomes

- Outcomes of infusing family-centered principles and Parent’s As Presenters
  - Outcomes for students in preservice
  - Outcomes for families involved
Roles for Family Partnerships in Preservice Training (a)

<table>
<thead>
<tr>
<th>Panel Presentation</th>
<th>Parents (usually 2-3) share together their personal experiences usually following similar themes or questions (e.g. what is your experience with inclusion?). Students can submit questions in advance.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sharing “Telling My Story”</td>
<td>Parents share their own personal family experiences to help students to understand unique family characteristics, strengths, needs, coping strategies, and successes.</td>
</tr>
</tbody>
</table>
## Roles for Family Partnerships in Preservice Training (b)

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Mentor for Students</td>
<td>Parents provide an opportunity for students to visit their home and spend time with their family in their routines and activities. Students learn first hand about family experiences raising a child with disabilities.</td>
</tr>
<tr>
<td>Parent Mentor for other Parents</td>
<td>Parents who are experienced in being an instructional partner with professionals can help new parents with needed emotional and logistical support. A parent may want to debrief after sharing personal information.</td>
</tr>
</tbody>
</table>
Roles for Family Partnerships in Preservice Training (c)

<table>
<thead>
<tr>
<th>Initial/Targeted Presentations of Course Content</th>
<th>Parents provide content to students in areas or course content: developing IEPs or IFSPs, communicating with professionals, cultural sensitivity from professionals, or experiences with child assessment.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Use of Family Scenario Method of Instruction</td>
<td>Parents take an active role in discussion of family scenarios to help students apply family-centered principles and generate possible solutions to needs. They can use an experience from their own family or others.</td>
</tr>
</tbody>
</table>
## Roles for Family Partnerships in Preservice Training (d)

<table>
<thead>
<tr>
<th>Shared Curriculum Organization and Course Evaluation</th>
<th>Parents take an active role in organizing the agenda, and readings for a class. Parents can participate in grading assignments and giving students feedback on coursework from a family member perspective.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shared Co-instruction of Course Content</td>
<td>Parents take an equal role in planning and delivering course content and participate in the role of co-instructor. They are identified as instructional faculty.</td>
</tr>
</tbody>
</table>
## Roles for Family Partnerships in Preservice Training (e)

<table>
<thead>
<tr>
<th>Program and Curriculum Evaluation</th>
<th>Parents take a leading role in helping teacher-training programs to evaluate their curriculum and make recommendations for family-centered changes or revisions.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training for Faculty on Co-Instruction and involving Families</td>
<td>Parents take a leading role in planning and delivering training to faculty to assist them in including parents in a variety of preservice roles.</td>
</tr>
</tbody>
</table>
Variables to Consider in Engaging Family Partners

Context

- Where does the experience fit into the educational program? Part of a course? Practicum? Seminar? Required? Optional?
- What is the purpose? Anticipated outcomes? Nature of the experience?
- Duration of the experience? One visit? Multiple visits?
- What kinds of resources (fiscal and human) will support the experience?
Families

- Number involved
- Characteristics (Age of children? Types of disabilities? Cultural and linguistic diversity? Representing which communities?)
- Finding and recruiting families
- A range of supports for family participation (e.g., child care, travel reimbursement, honorarium)
- Family expectations
- Preparation for experience (Materials? Curriculum? Methods?)
- Ongoing, structured support
Faculty

- Preparation and support with concept and logistics
Students

- Number involved
- Characteristics (Graduate? Undergraduate? Disciplines? Level of previous experience with families?)
- Preparation for experience (Materials? Curriculum? Methods?) Should students have supervised contact with families before having unsupervised contact?
- Student expectations
- Ongoing, structured support (Small group brainstorming? Individual consultation? Feedback on reflections?)
- Strategies for individualizing the experience based on students’ needs, background or discipline
Evaluation

- Family opportunities to provide feedback on the experience? On the students?
- Impact on students? Families? Other impact?
- Strengths and weaknesses of the experience? Priority for repeating the experience?
- Advice or “lessons learned”
- Capacity to sustain effort over time
Contact:

Lisa Sharp
Early ACCESS Parent Consultant
Iowa Department of Education
Phone # 515-281-5751
Email: Lisa.Sharp@iowa.gov

Mary Schertz
Bureau of Children, Family and Community Services
Iowa Department of Education
Phone # 515-281-5433
Email: Mary.Schertz@iowa.gov
Family Initiatives/Early Intervention Parent Leadership Project

Suzanne Gottlieb
Massachusetts Department of Public Health, Bureau of Family and Community Health
Target Audience

- Families of children receiving EI services, families of children with special health care needs.
Purpose and Anticipated Outcomes

- Development of an informed family constituency to partner in policy development, program planning, implementation and evaluation.
- Promotion of lifetime advocacy and leadership skills.
- Support the Massachusetts Early Intervention system to become increasingly family-centered.
Timeline/Location/Funding

- Training, mentoring and participation opportunities identified on an on-going basis in response to family and system needs and interests.
- Activities occur statewide.
- Funding: federal and state
Outreach

- Outreach to Early Intervention programs, statewide newsletter, regional parent meetings, community based meetings.
Participant Selection

- Opportunities available to any interested family member.
Involving Culturally and Linguistically Diverse Families

Outreach materials available in multiple languages, connections made with community based organizations serving ethnically, linguistically and culturally diverse constituencies.
Special Accommodations and Supports

- Interpreters as needed, materials available in multiple languages, scheduling to accommodate family identified needs.
Opportunities for Family Involvement

- System wide commitment to culturally competent, collaborative training - family members supported to take on co-training roles.
- All training is designed to accommodate a variety of learning styles.
Family Support

- All family members receive stipends to cover travel, childcare, etc.
- Co-trainers are compensated for their time.
Challenges

- Personal circumstances that deter attendance at training or in participating in partnering opportunities.
- Getting beyond "token parent" situations.
Efforts to Measure Outcomes

- Participants and presenters evaluate all training.
- Follow up with all family members taking part in policy, planning evaluation activities.
- Survey administered to parent participants to determine long-term efficacy of training.
Leadership Opportunities for Graduates

- Variety of partnering opportunities within the Early Intervention system, Title V programs and other education and health care settings.
Contact:

Suzanne Gottlieb, MA
Director, Family Initiatives
MA Dept of Public Health
250 Washington St
Boston, MA 02108
Phone: (617) 624-5979
Email: Suzanne.Gottlieb@state.ma.us
Early Intervention Partners Training Project

Margaret Sampson
Family Initiative Coordinator
Just Kids Early Childhood Learning Center
Sponsors

Sponsored by The NYS Department of Health Early Intervention Program and the Family Initiative Project at Just Kids.
Target audience

- Parents of children in the Early Intervention Program
- Parent Members of Local Early Intervention Coordinating Councils (LEICCs)
- Parent Members of the Early Intervention Coordinating Council (EICC)
Purpose

To nurture and develop the leadership abilities of parents of children with disabilities receiving early intervention services, and parent members of Local Early Intervention Coordinating Councils by enhancing their knowledge of the Early Intervention Program.
Anticipated Outcomes (a)

Participants will:

- Become informed decision makers on behalf of their own children with disabilities.
- Remain active and involved in early intervention program and policy activities, such as:
  - The Local Early Intervention Coordinating Council (LEICC).
  - State Early Intervention Coordinating Council (EICC) subcommittees, workgroups, or task forces.
  - NYS Department of Health, early intervention program committees, workgroups, task forces, and related activities.
Anticipated Outcomes (b)

- The participants will have access to the information and support they require to become “equal” partners in the process.
- The participants will become part of a larger network of families who they can turn to for feedback, information and support.
Guiding Principles

- To promote collaboration in all activities.
- To provide supports to aid family participation in the program.
- To respect the diversity of all participants.
- To incorporate principles of adult learning theory into all training activities.
- To encourage and nurture parent leadership in the Early Intervention Program.
Timeline/Location/Funding

- The project is held twice a year, in the Fall and Spring. Approximately 70 families complete the training annually.
- The state is divided into six training regions and the project targets two regions per year.
- Funding is provided by the NYS Department of Health Early Intervention Program through a contract with the Family Initiative Project at Just Kids.
Outreach/Recruitment

- Mailing directly to families in the targeted region by the NYS DOH EIP.
- Mailing to EICC Members and municipal Early Intervention Officials.
- Outreach to graduates and parent organizations.
Participant Selection

- Steering Committee reviews and rates applications on a scale of 1-3.
- Selection criteria:
  - Reviewers look for leadership indicators, statements that tell us that the parent wishes to become involved and/or use the information to benefit children and families in the Early Intervention Program. This helps to include parents with low literacy levels and has proved to be a successful strategy.
  - Applications are reviewed to ensure that the participants are representative of the region: geographic, ethnic, cultural, linguistic, religious, age groups birth to three, and disabilities.
Involving Culturally and Linguistically Diverse Families

- Successful approaches:
  - Use of AT&T Language Line for telephone communication with non-English speaking families.
  - Individual contact prior to the first session to welcome the participant, answer questions and build a relationship.
Special Accommodations and Supports

- Use of translation equipment and professional interpreters. This enables the parent to be fully involved in group activities and discussions.

- Working on an individual basis to meet the religious dietary needs of participants. Arrangements have been made to provide for Halal, Glatt Kosher, Kosher, Vegan, Vegetarian, etc. meals.

- The session format alternates yearly from a Friday/Saturday to a Sunday/Monday to enable the participation of families who worship on Friday/Saturday.
Issues and/or Challenges

- Childcare issues and accommodating children at the sessions, while at the same time maintaining family-centered practices.
- Attrition
Core Curriculum

- Each session has a specific theme and learning objectives. Materials are continuously updated and revised to respond to the needs of the group.
- Session I: History of the Parent Movement, Advocacy and Laws/Regulations
- Session II: Public Policy
- Session III: Parent Involvement
Leadership Goal

- Each participant is asked to identify a leadership goal.
- Participants work on their goal across all sessions.
- During Session III, participants are asked to form small groups and to design a website, incorporating all of their leadership goals.
Opportunities for Family Involvement

- Graduates of the Early Intervention Partners project have returned as trainers/presenters; served as members of the Steering Committee; and have provided support to other parents as liaisons at the sessions.

- Participants are recruited to lead group activities, role plays, etc.
Family Support

- Funding support is available for childcare reimbursement and travel expenses.
- Project staff is committed to working individually with families to meet their needs and to enable their participation in the sessions.
Challenges

Our biggest challenge has been meeting the needs of very diverse adult learners.
Outcomes

- Participants complete an evaluation form at the end of each session.
- No formal measures have been implemented to collect outcome data.
Accomplishments

- Our graduates have:
  - Gone on to serve on the Federal and State ICC.
  - Served on committees and task forces at the state and local level,
  - Become involved with their LEICCs.
  - Been responsible for promoting change within their communities in libraries, playgrounds, schools, religious affiliations.
  - Started a national disability magazine and radio talk show.
Contact:

Margaret Sampson
FICSP/Just Kids
P.O. Box 12, Longwood Road
Middle Island, NY 11953
Phone: (631) 924-0008 x270
Email: margaret.sampson@att.net
Family Leadership Opportunities

Roxanne Romanick
BECEP
North Dakota
Background

Over the past 5 years, there have been some significant changes in North Dakota, which have pushed family leadership and involvement in policy level activities to the forefront.
Highlights of Changes (a)

- The development of 8 Regional Interagency Coordinating Committees.
  - Requires 30% participation by parents of children who are under 12 and have received Part C services.

- A federal HHS grant focusing on family support awarded to the North Dakota Center for Persons with Disabilities (NDCPD) at Minot State University.
  - A state-wide Family Support Advisory Board was established, involving families in policy and program decision-making.
Highlights of Changes (b)

- The designation of discretionary Part C dollars to support hiring parent mentors or experienced parent specialists in all 8 of North Dakota’s human service regions.
- The establishment of parents as co-teachers programs in several of North Dakota colleges and universities’ service-oriented educational programs.
- The growth and maturity of our state-wide Family Voices chapter and Family-To-Family Network.
Increase in Opportunities for Families

Important activities are those which:

- Promoted collaboration amongst service providers.
- Assisted in the dissemination of information to families in a useful manner.
- Demonstrated unique strategies to promote family involvement.
Survey

“A Survey of North Dakota Families Raising Children with Special Needs and What They Have to Say about Attending Education and Training Opportunities

- Conducted as a collaborative effort between family support providers in the state.
- Results compiled into a design checklist for use by individuals and/or agencies that are coordinating family training opportunities.
- Widely distributed to family support partners and is universally used as a reminder in designing training.
Family Leadership Training Opportunities

Compilation of Family Leadership Training Opportunities

- A compilation of the family leadership opportunities available to families in North Dakota.
- All training opportunities are gathered and packaged in a way that is useful and helpful for families.
A product of the family support grant has been the creation of a collaborative conference.

Collaboration refers to both bringing family support partners together to share an annual conference and to create a learning environment where both parents and professionals are honored together.
Highlights of the Conference

- 40% of the attendees were registered as a parent.
- 6 key state policy makers and 7 parents facilitated round table discussions with families and professionals.
  - Discussions have resulted in observable action steps in several key state departments.
- 72% of the participants completing evaluations reported that they were leaving the conference with useful strategies to use when returning home.
- Families were supported financially to attend.
- Family connections with parents of children of similar age were supported by organized meeting times.
Common Ground Training

- Acknowledges the importance of people being able to work together.
- The workshop provides information and skill-building activities to help parents feel confident in working with others and advocating for children.
- The workshop covers information about different types of conflicts and how to resolve problems by working together.
Navigating the System

- This training offers families an overview of the educational, finance, health care, recreation, mental health and social service programs available in ND.
Veteran Family Training

- This training teaches veteran families to mentor other families whose children have similar disabilities.
- Many parents who have completed the training said that the program has been very instrumental in reducing their own isolation and helping them come to terms with issues related to parenting a child with special needs.
Partners in Policymaking

This intensive leadership training program assists people with disabilities and parents of children with disabilities in developing advocacy skills. The program analyzes disability issues and builds skills that participants use to influence legislation, create systems change, and obtain appropriate supports and services for themselves, family members, and other North Dakotans.
Collaborative Family Training

- This training is conducted by the regional director of special education or coordinators and provides families with basic information about the special education law and process.

- The training helps to establish positive relationships with new families and give participants insight into how families can participate as an equal partner in the planning process.

- The training program was developed through the ND State Improvement Grant.
Parents as Teachers

- Parents receive personalized home visits by certified parent educators, trained in child development.
  - Visitors help parents understand what to expect in each stage of their child’s development.
  - They also offer practical tips on ways to encourage learning, manage challenging behavior, and promote strong parent-child relationships.

- Group meetings: Parents get together to gain new insight and to share their experiences, common concerns and success. Group meetings also provide families with opportunities to participate in parent-child activities.
Parent-School-Community Partnerships

- This two-hour workshop provides a system for enhancing parent/family involvement in the school environment.
- It is designed for parents, school officials and community members.
- A second workshop, approximately one-and-a-half hours in length, involves the training consultant working with a small group of parents, school officials and community members as they write goals, objectives and action plans regarding the partnership ideas generated during the initial workshop.
NDCPD CD CASTS

- Three hour online workshops sponsored by the North Dakota Center for Persons with Disabilities at Minot State University help families access the latest research.

- Participants receive a CD in the mail with a power point presentation and handouts.

- At the scheduled time, parents who register may call the number provided and listen to a state or national presenter review the slides and discuss the topics.

- Topics have included alternate assessment, sexuality, family involvement and behavior intervention.
NDCPD Community Training Modules

- Parents who wish to earn a degree (non teaching) in Developmental Disabilities can take courses online for credit through Minot State University leading to an associate’s degree in Developmental Disability.

- Over 14 modules covering seizures, job development, sexuality, and a variety of other topics are available.
Contact:

Roxanne Romanick
BECEP
806 N Washington
Bismark, ND 58501
Phone: (701) 527-4645
Email: romanick@bis.midco.net
Vermont Community Leadership Training Curriculum

Ginger Potwin
Vermont
Target Audience

- Parents, and community members
Purpose and Anticipated Outcomes

- The purpose of the curriculum is about building community.
- Each participant enters the class with his or her own set of unique strengths, abilities, and areas of growth.
- The diversity of individuals, as well as the diversity of their strengths, builds a strong group—a community within a community.
- The anticipated outcome of the curriculum is to strengthen communities.
Timeline

The curriculum is implemented across the state five or six times a year.
Location

Each curriculum is located throughout the state of Vermont, and the training sessions are community based.
Funding

Funding comes from a number of sources. Some of the sources include: Federal grants, the Children’s Trust Fund, Community Foundation’s, local organizations, and communities.
Outreach/Recruitment

Some examples of outreach and recruitment of parents and families include:

- **Word of mouth**—from community member to community member;
- **Advertising**—press releases to local newspapers, brochures, mass mailing, and letters; and,
- **E-mails** listing the curriculum information to other organizations.
Participant Selection

- The facilitators’ set-up an interview with the participants.
- The interview is used as a means of screening the interested participant’s ability to commit to the curriculum.
- The facilitator and the interested participant decide whether or not he or she is able to commit to the curriculum at the time of the interview.
Involving Culturally and Linguistically Diverse Families

- The curriculum will be focusing on adjusting the curriculum to the needs of culturally and linguistically diverse families.
Successful Approaches

- The curriculum is successful in the recruitment of diverse members.
- The sessions are adult learning based.
- The activities are hands on.
- Participants are encouraged to find their voices.
- The curriculum also focuses on personal development.
Special Accommodations and Supports

- The facilitators are receptive to the needs of the participants, and do what they can to provide the special accommodations that are requested.
- Meals are provided during the training sessions.
- Dietary needs are met.
Issues and/or Challenges

- The ongoing funding of the curriculum remains a problem.
- The Vermont Children’s Forum is currently trying to resolve funding issues.
- The lack of funding affects the availability of the curriculum, as well as the ability to train the facilitators.
Opportunities for Family Involvement

Community members, parents, and prior graduates of the curriculum are encouraged to become trained as facilitators.
Family Support

- Transportation is provided if it is needed.
- Childcare costs are reimbursed in some communities.
Challenges

- Participants’ may find a 20 week period a challenge.
Efforts to Measure Outcomes

- Follow up on projects and evaluations.
Leadership Opportunities

- Some include organizing community forums, public education, council or board membership, and starting workshops and/or support groups.
Contact:

**Ginger Potwin**
87 Radio Drive
Randolph, VT 05060
Phone: (802) 728-6216
Email: gpotwin@innevi.com

**Carlen Finn**
The Vermont Children’s Forum
Phone: (802) 229-6377