

Parents Learning to Lead

Kathleen McNamara Miller, MSW
Institute on Disabilities
Temple University

Matthew Tincani, Ph. D., BCBA-D
Temple University

Parents Learning to Lead

- ▶ Overview of our Family Leadership Development Training Program
- ▶ Preview a Sample of the Training Participants Receive

Competence and Confidence: Partners in Policymaking for Families of Children in Early Intervention (C2P2/EI)



Leadership Development Training Series for family members of young children with developmental delays and disabilities

C2P2/EI

- ▶ 13th Program Year
- ▶ Lancaster
- ▶ Four 2-day sessions, starting in October



C2P2/EI



- ▶ No Cost to attend Training
 - Meals provided
 - Lodging provided
- ▶ Reimbursement provided for:
 - Childcare
 - Travel expenses

Sampling of Topics

Legislation and Advocacy	Creating a Vision	Inclusive Education
Communication Skills	Resources and Networking	PA Early Intervention Systems
Assistive Technology	Early Intervention Best Practices	Positive Behavioral Supports

Competency #1



Family members will be able to communicate their child's needs and become confident in identifying the necessary supports and services for their child.

Competency #2

- ▶ Family members will be able to identify inclusive education practices and outline strategies to achieve quality education.



Competency #3



▶ Family members will be able to describe state-of-the-art technologies for children with disabilities.

Competency #4

Family members will be able to define a vision for the future for their child that is family driven.



Competency #5



▶ Family members will be able to identify Community Resources.

Competency #6

▶ Family members will be able to describe critical state and federal issues.



Competency #7



Family members will be able to describe the Early Intervention System in Pennsylvania.

Competency #8

Family members will be able to identify best practices in Early Intervention.



A Training Preview

Family Involvement, Positive Behavior Support, and Young Children with Autism

Matt Tincani, Ph.D., BCBA-D
Temple University

What families had to say:

I have been more active with support groups and advocating for other children in my area	I met and networked with other parents that I continued to be in contact with today	I am on the board of our local grass roots parent organization.- Autism Spectrum Connections. I am also a rep. of our local United Way
I didn't feel "alone" anymore. I knew there were resources available when/if needed	Started attending LICC (local interagency coordinating councils) and SICC (State ICC) meetings	I have participated in Right to Ed Task Force, started a non-profit to help others and I am newly appointed board member to PA families
I started a path that led me to federal training in special education. I am helping many families because of my C2P2 start	I am now a mentor for our local Early Intervention parent connection program	I acquired the knowledge and tools/connections to take control of my daughter's education and therapies

C2P2/EI

- Lancaster Location: Homestead Suites Hotel

- Four two-day sessions
 - October 23 & 24, 2009
 - December 4 & 5, 2009
 - February 5 & 6, 2010
 - April 16 & 17, 2010

Family Involvement, Positive Behavior Support, and Young Children with Autism

Matt Tincani, Ph.D., BCBA-D
Temple University



Overview

- Elements of Family-Centered Intervention
 - Strength-based Assessment
- Family-Focused Positive Behavior Support
- Lessons Learned



Elements of a Family-Centered Approach to Intervention

- Strength-based assessment of children and families
 - Requires a paradigm shift from the deficit-based understanding of autism
 - What are the child's preferences, emerging communication abilities, and other skills?
 - How can these be utilized to develop interventions?



Activity

- Deficit-based perspective: "Sara displays inflexibility with routines and is prone to tantrums if her activities are interrupted."
- Strength-based perspective: "Sara enjoys consistency in her routines and is good at following a schedule."



Activity

- Describe a communication, social interaction, or repetitive / stereotyped behavior deficit of a child with autism
- Rephrase the deficit as a preference or skill



Elements of a Family-Centered Approach to Intervention

"In the vast majority of cases, families are the most committed, enduring, and knowledgeable source of personal support available for their children." (Dunlap, Newton, Fox, Benito, & Vaughn, 2001, p. 215)



Elements of a Family-Centered Approach: Guiding Questions

- Considering buy-in and contextual fit
- What are the family's goals, both short- and long-term, for intervention?
- Examples
 - Meaningful relationships with siblings and friends
 - Attending church
 - More time in the community



Elements of a Family-Centered Approach: Guiding Questions

- What routines are important to the family?
- Examples
 - Visiting the grocery store
 - Eating dinner as a family
 - Going to the park



Elements of a Family-Centered Approach: Guiding Questions

- What are the elements of the family system that support interventions?
 - Extended family members
 - Siblings



Family-Focused Positive Behavior Support

- Step 1: Identifying Goals
- Step 2: Gathering Information
- Step 3: Developing Hypotheses
- Step 4: Designing Support Plans
- Step 5: Implement & Monitor the Plan



Step 1: Identifying Goals

- Bring together a team of critical stakeholders
- Conduct person centered planning to identify desired outcomes
- Refocus efforts from the challenging behavior itself to how it serves as a barrier to important life goals



Step 2: Gathering Information

- Identify the person's strengths, skills, and preferences
- Analyze the environment to determine events that make the problem behavior occur
 - FBA
- Collect data



Step 3: Developing Hypotheses

- Develop hypotheses about why the behavior is occurring
 - Motivating operations (setting events)
 - Triggering antecedents
 - Maintaining consequences



Step 4: Designing Support Plans

- Use the competing behaviors analysis to develop intervention strategies



Step 5: Implement & Monitor the Plan

- Team members decide, collectively, which elements of the plan they are responsible for
- Use data to evaluate if the plan is working
- Revisit and modify the plan as needed



Lessons Learned

- Sometimes it is hard to break parents' and professionals' patterns of negative thinking
 - Keep the focus positive and concentrate on what you can change!
- The transition from Part C to Part B services can be confusing
 - Provide information and support



Lessons Learned

- Parents receive A LOT of contradictory “expert” information from professionals
 - It’s important to develop interventions that have contextual fit with the child and family, as opposed to what we, the professionals, think is best for them



Lessons Learned

- Encourage parents to be leaders and advocates for their child
 - But acknowledge that parents have differing capacities to support intervention



Questions?
