

Family Support, Self-Determination and Disability

Table of Contents

Curriculum

Module I: Philosophy of Family Support

Class 1: Introduction, Family Systems Approach, Interdependence.....	9
Class 2: New Perspectives on Adjustment and Coping, Positive, Strengths-Based Approach.....	13
Class 3: Power, Control, and Self-Efficacy.....	16
Class 4: Redefining Professional Roles, Models of Decision-Making.....	23

Module II: Cultural Competence

Class 5: Exploring Individual Cultural Values, How Language Shapes Values.....	29
Class 6: Discovering Other Cultural Values.....	36

Module III: Strengths, Needs, and Supports

Class 7: Holistic Perspectives, Needs and Goals, Rationale for Assessment.....	44
Class 8: Formal and Informal Needs Assessments, Effective supports.....	50

Module IV: Identifying and Coordinating Resources

Class 9: Emerging Models of Family Support, The Role of the Family Support Facilitator.....	55
Class 10: Working in Teams, Promoting Interagency Collaboration, Identifying Regional Resources.....	61
Class 11: Information Systems and Interagency Collaboration, Person-Centered Futures Planning and the Family.....	66

Module V: Working Together with Families

- Class 12: Conflict Resolution69
- Class 13: Creative Problem Solving.....73

Module VI: Evaluating Family Support

- Class 14: Concepts of Quality Assurance,
Measuring Outcomes.....76
- Class 15: Complaint Analysis for Continuous Quality Improvement,
Evaluation and Governance.....80

Evaluation84

References.....86

A few words of introduction...

Welcome to the **Family Support, Self-Determination and Disability** course. We are looking forward to the ideas and experiences you bring to this class, because we know we will learn from you as you learn from the materials, the teachers, and each other.

This course was developed by family members with a grant from the U.S. Administration on Developmental Disabilities. For this reason, a particular focus of the cases and examples is on families with members with developmental disabilities, including emotional and behavioral challenges. The disability field is proud to have led in the development of strong Family Support practices in this country.

The theory of resiliency and other related theories on which this course is based, developed in the broader arena and apply to all families. We hope you will generalize beyond the specific examples to consider how these theories and practices apply in your own work with families, regardless of how they may be described.

We believe that **all** families experience stress at some time or another, and benefit from respectful, responsive support. At times, circumstances and the amount of stress may make the task of providing support seem overwhelming and what we have to offer seem puny. Nevertheless, we are committed to the human act of believing in a family, asking **them** what would help, and doing our best to make it happen. Over time, we believe that stressed families can get their feet under them, see positive changes in their lives, celebrate their own capability and control, and, in turn, help other families.

This class is designed to be conducted as a series of related workshops, with the time spent on exercises and discussion. Lectures are kept to a minimum. For this reason, the readings are hefty. We have chosen the best and most recent we could find in our field, regardless of the length. There will be times you will struggle to finish the readings for one class, only to find little assigned for the next. Try to pace yourselves. We will seldom have time to discuss the readings in class, and we won't quiz you on them. They make the difference, however, between an introduction to the concepts of family support and a deeper knowledge and understanding. The readings are especially important for graduate credit.

We hope you enjoy this course and your classmates as much as we have enjoyed the classes that have come before you!

THE DEVELOPMENT OF THIS MANUAL WAS SUPPORTED BY GRANT NO. 90DD0306 OF THE ADMINISTRATION FOR CHILDREN AND FAMILIES OF THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES. HOWEVER, THE OPINIONS EXPRESSED IN THIS MANUAL DO NOT NECESSARILY REFLECT THE POSITION OF THE U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES AND NO OFFICIAL ENDORSEMENT BY THEM SHOULD BE INFERRED

Family Support, Self-Determination and Disability Course Description

Module 1 Philosophy of Family Support

This four-chapter module defines the values base for the curriculum, a family-centered approach which views individuals and family members as interdependent parts of a family system. Emphasis is placed on strengths and resources which assist families in coping and adjustment, as well as positive contributions of people with disabilities to their families. Programs and service providers are viewed as effective to the extent that they enable families to exercise power and control over the supports they receive and ultimately over their own family lives. Competency areas covered include:

- * redefining professional roles
- * understanding the family systems approach
- * delivering family-centered services
- * building interdependence, reciprocity
- * using a positive, strengths-based approach
- * changing perspectives on adjustment and coping
- * changing models of decision-making in family supports
- * analyzing power
- * empowering families; family-driven approach
 - locus of control
 - self-efficacy perception

Module 2 Cultural Competence

This two-chapter module develops awareness in participants of the cultural basis for their own value systems, viewing cultural values as relative rather than absolute. Special attention is paid to attitudes which might lead to judging the choices and actions of families from other cultural backgrounds. In the area of family and disability issues, participants explore the values of at least one other culture in order to strengthen respect for diverse perspectives. The implications of cultural attitudes are considered in relation to communication and program planning. Competency areas covered include:

- * exploring individual cultural values
 - toward family
 - toward child-raising
 - toward disability
- * understanding how language shapes values
- * discovering other cultural values
- * uncovering cultural assumptions in program planning
- * identifying implications of cultural practices in communication
- * building culturally respectful family support

Module 3 Assessing Needs and Determining Supports

This two-chapter module considers the difference between planning for supports based on the limitations of existing services and on more flexible, open-ended reliance on resources. On the principle that families are able to identify their own needs and most appropriate supports, participants explore ways to help families with this process. Criteria are developed for what is appropriate to ask a family; these criteria are then applied to existing assessment tools and interview protocols to develop a familiarity and a situational and critical awareness of what is available and useful. Innovative program options are introduced, along with literature on their effectiveness. The possibility of replacing disability-related supports with natural supports is discussed. The concept, "whatever it takes" is debated as the ultimate support option. Competency areas include:

- * taking holistic perspectives on assessment of needs
- * understanding the difference between judgment and assessment
- * considering criteria for appropriateness of questions
- * identifying strengths and needs
 - reviewing available tools and protocols
 - discussing guidelines for respectful use of assessments
- * identifying and reviewing options for support
 - "generic" supports
 - disability-related family supports
 - replacing disability-related supports with natural supports

Module 4 Identifying and Coordinating Resources

This three-chapter module considers the evolving role of the professional in connecting and coordinating supports for families, moving from "gatekeeper" to "agent" for the family. The dynamics of team decision-making are explored to identify the extent to which they support or hinder families from determining their own choices. Duplication in processes and paperwork are examined, with a view to improving coordination among interagency services and personnel supporting families. Participants identify and learn about other regional services supporting families and practice facilitating planning processes with families and individuals in the context of their families. Competency areas covered include:

- * defining the evolving role of the family support facilitator
- * working in teams in the context of self-determination
- * promoting interagency collaboration for family support
- * identifying regional resources for families
- * planning across the lifespan
 - MAPS
 - PATHS
 - Circles of Support
- * identifying issues in information management
- * identifying issues of accountability in financial assistance

Module 5 Skills for Working Together with Families

This two-chapter module hones essential skills in more complex communication situations with families. Participants identify their own "natural" conflict mode or style and learn when it is most likely to help them and when it may cause more problems, according to the situation. Practice in negotiation skills is governed by the value of subordinating these skills to the self-determined choices of the individual and family. Participants have the opportunity to apply the full range of creative problem solving processes to specific situations they identify. Competency areas covered include:

- * identifying conflict style
- * evaluating the effectiveness of conflict styles in a situational model
- * identifying positions, interests and underlying interests
- * negotiating acceptable resolutions
- * creative problem solving

Module 6 Evaluating Family Support

This two-chapter module examines the role of evaluation as a vehicle for the empowerment of families over the quality of supports they receive. Participants discuss various methods of ensuring quality, including monitoring and quality assurance review, complaint analysis, and current practices of total quality management and continuous quality improvement. Current directions in outcomes-based services and outcomes-based budgeting are discussed in the light of family-identified outcomes. Families' perceptions of their own ability and effectiveness are examined as a measure of program success. Quantitative, qualitative and participatory approaches to evaluation are briefly considered in the light of family empowerment. Quality is considered in evolving models of service delivery--monopolistic, competitive, and managed care approaches.

Competency areas covered include:

- * empowering families through the evaluation process
- * understanding different aspects of "quality"
- * identifying and measuring outcomes and indicators
- * using complaint analysis in quality improvement
- * measuring family empowerment
- * ensuring participatory program evaluation
- * identifying issues of quality in different models of service delivery
 - monopolies
 - competition
 - managed care

SYLLABUS AND SUGGESTED READINGS

MODULE I: PHILOSOPHY OF FAMILY SUPPORT

Class 1 Introduction, Family Systems Approach, Interdependence

Turnbull, A.P., Turbiville, V., & Turnbull, H.R. (2000). Evolution of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In Shonkoff, J.P. & Meisels, S.J. Handbook of early childhood intervention (2nd Ed.), Cambridge, Cambridge University Press, pp. 630-650.

Class 2 New Perspectives on Adjustment and Coping, Positive, Strengths-based Approach

Singer, G. H. S. & Powers, L. E. (1993). Contributing to resilience in families: An overview, in Singer & Powers, Families, disability, and empowerment. Baltimore: Brookes, pp. 1-25.

Kingsley, E.P. (1987). Welcome to Holland. In Heartline.

Class 3 Power, Control, and Self-efficacy

Powers, L. E. (1996). Family and consumer activism in disability policy. In Singer, Powers & Olson, Redefining Family Support. Baltimore: Brookes, 413-433.

Center on Human Policy, Syracuse University. (2000). The Community Imperative: A statement against institutionalizing any person because of a disability. Syracuse: Syracuse University.

The Seattle 2000 declaration on self-determination & individualized funding. <http://members.home.net/directfunding>.

Silverstein, R. (2000). An overview of the emerging disability policy framework: A guidepost for analyzing public policy. (Appendices). Iowa Law Review, Vol. 85:5.

Class 4 Redefining Professional Roles, Models of Decision-making

Principles of Federal Family Support Bill, (Part I, IDEA). (Note: These are of historical value only, as they were not included in S.1809).

S.1809. Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title II—Family Support.

HSRI, Expecting Excellence in Family Support. (1993) (National Quality Indicators);

MODULE II: CULTURAL COMPETENCE

Class 5 Exploring Individual Cultural Values, How Language Shapes Values

Lynch, E. W. & Hanson, M. J. (1996). Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families, 2nd Ed. Baltimore: Brookes. Chapters 1-3 required reading; additional chapters for specific cultures.

Association for Cerebral Palsy, Vt. Developmental Disabilities Council. (1992). Choosing words with dignity. Waterbury, VT: author.

Class 6 Exploring Individual Cultural Values, How Language Shapes Values, Discovering Other Cultural Values

Lynch, E. W. & Hanson, M. J. (1996). Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families, 2nd Ed. Baltimore: Brookes.

McAdoo, H.P. (1999). Family Ethnicity (2nd Ed.). Thousand Oaks, CA: Sage Publications. (Note: Both of these books include chapters on specific ethnic groups. Please choose from either source or any other authentic writing representative of the culture you choose to study).

MODULE III: STRENGTHS, NEEDS AND SUPPORTS

Class 7 Holistic Perspectives, Family-driven Approach, Rationale for Assessment

Class 8 Formal and Informal Needs Assessment, Effective Supports

Agosta, J. (1999). Family needs: Summary results from ten years of research. Family Support Policy Brief #2. Salem, Oregon: National Center for Family Support @ HSRI.

Friedrich, W. N., Greenberg, M. T., & Crnic, K. A. (1983). A short form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 88, 47-48.

Scheier, M. & Carver, C. (1994). Life Orientation Test. American Psychological Association.

Snyder, C. R., Harris, C., et al. (1991). The will and the ways: Development and validation of an individual differences measure of hope. Journal of Personality and Social Psychology, 60, 585. (The Hope Scale).

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Appendices in Enabling and Empowering Families. Cambridge, MA: Brookline Books.

Turnbull, A. P. & Turnbull, H. R. (1990). Appendix B: Guide for Gathering Family Information through Discussion. in Families, Professionals and Exceptionality, (2nd Ed.). Columbus, OH: Merrill Publishing Co., 435-440.

MODULE IV: IDENTIFYING AND COORDINATING RESOURCES

Class 9 Emerging Models of Family Support, the Role of the Family Support Facilitator

Agosta, J. & Melda, K. (1995b). Supplemental security income for children with disabilities. Salem, OR: Human Services Research Institute.

Bergman, A. & Singer, G. H. S. (1996). The thinking behind new public policy. In Singer, G. H. S., Powers, L. & Olsen, A. Redefining Family Support. Baltimore: Brookes, pp. 435-463.

Dunst, C. & Trivette, C. (1994) What is effective helping? In Dunst, Trivette & Deal, (Eds.). Supporting and strengthening families. Cambridge, MA: Brookline Books, pp. 162-170.

Turnbull, A.P., Blue-Banning, M., Turbiville, V., & Park, J. (1999). From parent education to partnership education: A call for a transformed focus. Topics in early childhood special education 19:3.

Class 10 Working in Teams, Promoting Interagency Collaboration, Identifying Regional Resources

Anderson, B. & Hogan, C. (1994). Education -- Human Services View: A Continuum of Systemic Change. Oxford, OH: Danforth Foundation.

Gardner, S. L. (1993). The ethics of collaboration. Georgia Academy Journal, Summer, 220-222.

Class 11 Information Systems and Interagency Collaboration, Person-centered Futures Planning and the Family

Falvey, M. A., Forest, M., Pearpoint, J., & Rosenberg, R. L. (1994). Building connections. In Thousand, J. S., Villa, R. A., & Nevin, A. I.. Creativity and collaborative learning. Baltimore: Brookes Publishing Co., 347-368.

MODULE V: WORKING TOGETHER WITH FAMILIES

Class 12 Conflict Resolution

Johnson, D. W. (1990). Reaching out: interpersonal effectiveness and self-actualization (4th ed.) Englewood Cliffs, NJ: Prentice-Hall, Inc., 222-228.

Class 13 Creative Problem Solving

Cloninger, C. (1991). Problem Solving Processes, Strategies, Ideas, and Resources. Burlington, VT: The UAP of Vermont.

MODULE VI: EVALUATING FAMILY SUPPORT

Class 14 Concepts of Quality Assurance, Measuring Outcomes, Managed Care

Bradley, V. J. (1990). Conceptual issues in quality assurance. In Bradley, V. J. & Bersani, H. A. Quality assurance for individuals with developmental disabilities. Baltimore: Brookes, 3-15.

Advisory Council, New Approaches to Family Support Training Initiative Project, University Affiliated Program of Vermont. (1993). Outcomes for Impact of NAFS Training for Service Providers. Burlington, VT: University Affiliated Program of Vermont.

Center on Human Policy et al. (1996). A position statement on managed care and long-term supports. Syracuse, NY: Syracuse University.

Nerney, T. & Shumway, D. (1996). Beyond managed care. Concord, NH: Robert Wood Johnson Foundation.

Nerney, T. (1998). The poverty of human services. Concord, NH: Robert Wood Johnson Foundation.

Moseley, C. & Nerney, T. (2000). Emerging best practices in self-determination. AAMR News & Notes, Vol. 13, No. 6, pp. 1-5.

Class 15 Complaint Analysis for Continuous Quality Improvement, Evaluation and Governance, Measuring It All

Cochran, M. Parent empowerment: Developing a conceptual framework, Family Science Review, Vol. 5, No. 1 & 2, Feb. & May 1992, pp. 3-21.

Koren, P. & DeChillo, N. (1993). Measuring empowerment in families whose children have emotional disabilities. Portland, Oregon: Research & Training Center on Family Support and Children's Mental Health, Portland State University.

Module I

Philosophy of Family Support

Class 1 in the Certificate Program

Introduction

Family Systems Approach

Interdependence

HOUSEKEEPING

Activities

- Registration
- Scheduling
- Telephone tree, refreshment sign-up schedule
- Identify hopes and expectations of participants
- Generate class norms, expectations

Suggested guidelines for successful completion of the course: missing no more than 3 class periods, making up missed assignments or identifying additional homework to cover missed classes. The suggested grading scale is a generous one for students taking the course for credit: Active participation plus successful completion of all assignments, with no more than 3 missed classes, qualify the student for an A. Half a grade will be deducted for each missing assignment. Considerable flexibility may be given in accepting late work, but all assignments must be in by Class 14, in order for instructors to complete grades on time.

INTRODUCTION EXERCISE

Objectives

- To introduce class members and begin class networking
- To practice listening skills
- To practice non-verbal encouragement
- To build awareness of individual perspectives

Instructions

1) In pairs, one person listens silently, responding only non-verbally while the other talks for 2 minutes about him/herself. Try to do this without taking notes. Then the two reverse for the next 2 minutes.

2) Each partner introduces the other to the group, and singles out the most important fact about that person from the point of view of the listener. The person being introduced is then asked to fill in gaps, and to single out the most important fact from her own point of view. Continue until all are introduced.

3) As a group, process the exercise, answering the following:

- a) What did it feel like not being able to speak? As the listener? As the speaker?

- b) What did the listener do non-verbally to help the speaker?
- c) How accurate was your memory without notes?
- d) Did the two of you identify the same fact as the most important?
- e) Did each introduction take the full two minutes? Why?
- f) When would you use "silent listening" in your work?

COURSE OVERVIEW - CONTENT

Objectives

- To outline the scope of the course subject matter
- To match student expectations with course intent

Areas for discussion

- Syllabus
- Competency areas
- Questions and answers

EXERCISE: FAMILY-CENTERED PLANNING

Objectives

- To introduce the concept of family systems
- To build awareness and sensitivity to differing perspectives within a family system
- To include the individual within the context of the family
- To differentiate between child and family-centered planning
- To determine when person-centered or family-centered planning would be appropriate
- To heighten sensitivity to the voice of the individual in planning

Instructions

- 1) Divide into small groups of 5 or 6. Choose a recorder.
- 2) From the hat, draw a situation card describing a family with a member with a disability, and three proposed "interventions".
- 3) Draw family roles. At the beginning, identify a member of the group who will take the role of the member with a disability.
- 4) For each intervention proposed for the member with a disability, each other family member and the "target person" describes the potential impact on him/herself within the family. Record on the flipchart.
- 5) Evaluate whether you think the impact of the intervention on the whole family is positive or negative. Remember that the member with a

disability is part of the whole family. Suggest ways to improve the impact on the family (family-centered interventions).

6) Groups report back to the whole class.

Additional discussion: Approaches to planning

We have just experienced an exercise in family-centered planning. What other approaches to planning can you think of?

Later in the course, we are going to learn two techniques in person-centered planning--MAPS and PATHS. How would you decide which approach to use--family-centered or person-centered?

Do you think these approaches are opposed to each other?

Give some examples from your experience of service or system-centered planning.

MINILECTURE AND DISCUSSION ON FAMILY SYSTEMS APPROACH

Objectives

- To demonstrate interconnections of members in a family system
- To create awareness of the impact of a crisis on balances in a family system
- To create awareness of the lasting impact of a crisis on reestablished balances within the family system

READING

Turnbull, A.P., Turbiville, V., & Turnbull, H.R. (2000). Evolution of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In Shonkoff, J.P. & Meisels, S.J. Handbook of early childhood intervention (2nd Ed.), Cambridge, Cambridge University Press, pp. 630-650.

HOMEWORK ASSIGNMENT

Objectives

- To personalize the concepts of independence, dependence and interdependence
- To reflect on the nature of reciprocity in relationships
- To consider the impact of payment on the nature of relationships and reciprocity
- To identify barriers to interdependence and how they might be overcome

Instructions

- Create a Relationship Map with yourself in the center of a piece of paper. Around you, write the names of the key people in your life with

whom you are interdependent. Draw arrows between you, going both ways. Think about the nature of your interdependence with one another.

- Then put in the key people with whom you have relationships in which either you are dependent or the other person is dependent on you, without a two-way return. Put your arrows pointing in only one direction.
- Examine your map, noticing paid and unpaid relationships. Are your one-way relationships paid or unpaid? How would the map look for the family of a person receiving public sector services? For the person himself/herself?
- In what ways could interdependence (two-way relationships) be encouraged? What are the problems or barriers to interdependence?
- One of the ways to think about interdependence is to consider the concept of reciprocity. What are some of the ways people give back to one another? Can you think of examples where people don't necessarily give back to the person they received from, but instead give to others, in a kind of "flow" of help? What do you think the process of reciprocity does for the person who receives help? Can you give examples?
- How does the concept of independence fit into your picture? Write your ideas in response to these questions briefly and attach them to your map.

Module I

Philosophy of Family Support

Class 2 in the Certificate Program

New Perspectives on Adjustment and Coping

Positive, Strengths-based Approach

HOMEWORK DISCUSSION

Objectives

- To personalize the concepts of independence, dependence and interdependence
- To reflect on the nature of reciprocity in relationships
- To consider the impact of payment on the nature of relationships and reciprocity
- To identify barriers to interdependence and how they might be overcome

PRESENTATION BY THREE FAMILIES

Topic: "How has the experience of having a family member with challenges changed your family?"

Objectives

- To build understanding of the family experience
- To build awareness of the changing nature of the experience over time
- To create sensitivity to the impact of professionals on the family
- To practice identifying family strengths and needs

Instructions: Listen to the three presentations with the following questions in mind. The answers to these will form the basis of the homework assignment for today.

- 1) How did the experience of having a family member with challenges change over time?
- 2) What adjustments did the family make to accommodate for the changing situation?
- 3) How did the balances in the family change?
- 4) What roles did professionals play?
- 5) What attitudes towards professional involvement has the family formed from their experiences?
- 6) What strengths have helped this family?
- 7) What unmet or ongoing needs do you hear?

Opportunity for questions and answers.

MINI LECTURE AND DISCUSSION ON THE DOMINANT MODEL OF ADJUSTMENT AND COPING

Objectives

- To draw out from participants their awareness and understanding of the model which has dominated popular understanding of the experience of families with members with disabilities
- To recognize the contributions of that model
- To identify the problems and misfit with experience of this model
- To identify the characteristics and contributions of models to understanding
- To experience the need for models to change and grow as our understanding and experience changes

EXERCISE: ADJUSTMENT AND COPING

Objectives

- To construct a model of experience
- To build confidence of participants to conceptualize theory
- To build empathy with families

Instructions

Divide into small groups. Choose a recorder. Based on your personal and professional experience, as well as the stories you have heard today, come up with a different model of coping and adjustment. Record on flipchart paper and share models with the class.

MINI LECTURE AND DISCUSSION ON HILL (1949), MCCUBBIN & PATTERSON (1983) ABCX MODELS, WIKLER'S (1986) WORK ON TIMES OF STRESS IN THE FAMILY LIFECYCLE, HILTON'S (1989) MODEL.

Objectives

- To build familiarity with the model currently dominating research on family adjustment and coping (ABCX)
- To identify the times of greatest stress for families
- To understand the cyclical or recurring nature of emotion for families

Instructions

- In large group, present the models listed above, drawing parallels with the models constructed by the students in the previous exercise whenever possible. Use the overheads in the additional materials.
- Ask students what they think are the times of greatest stress for families. Follow with the ideas of Wikler.
- Discuss the question: How do "models" affect our work with families?

READINGS

Singer, G. H. S. & Powers, L. E. (1993). Contributing to resilience in families: An overview, in Singer & Powers, Families, disability, and empowerment. Baltimore: Brookes, pp. 1-25.

Kingsley, E.P. (1987). Welcome to Holland. In Heartline.

HOMEWORK ASSIGNMENT

Objectives

- As listed for the Presentation, and,
- To practice listening for meaning

Instructions

- How well did I hear? Write up your answers for the questions listed at the beginning of today's class for one of the families that spoke.
- Reflect.

Module I

Philosophy of Family Support

Class 3 in the Certificate Program Power, Control, and Self-Efficacy

Today we're exploring concepts and terminology of power, that have been used by the professional community in viewing families caring for members with disabilities or other challenges. These concepts can be complex and sometimes misunderstood and misused. For this reason, we'll consider them in some detail.

EXERCISE: POWER ANALYSIS

Objectives

- To identify areas of actual and potential control for families in services
- To create awareness of factors that limit and enhance control
- To analyze the operation of these factors in specific services
- To evaluate the responsiveness of services to family and individual choices

Instructions: Working in pairs or small groups of people who are part of the same program, analyze the amount of power of individuals and families served by that program in decision-making. Don't get sidetracked into debates over the appropriateness of the power; stick to questions like:

- 1) What choices are available to individuals and families?
- 2) How do program values limit or enhance their choices?
- 3) How does funding limit or enhance their choices?
- 4) How do administrative practices limit or enhance their choices?
- 5) How do decision-making processes limit or enhance their choices?
- 6) How does availability of information limit or enhance their choices?
- 7) When choices are expressed, to what extent are they respected?

Be as objective as possible, mutually respecting confidentiality.

EXERCISE AND DISCUSSION: LOCUS OF CONTROL

Objectives

- To introduce the concept of locus of control
- To identify this concept as a factor in perception for families and individuals
- To personalize the concept of individual locus of control
- To analyze the impact of locus of control on family adjustment

Instructions

How much control do you believe you have over your own life? One way psychologists have measured this is the Rotter Locus of Control test. For your own knowledge of how you fit into this concept, take and score the Rotter Locus of Control test (at the end of materials for this class), following the printed instructions.

Internal control can be defined as a belief that you control life events or their outcomes yourself; external control can be defined as a belief that life events or their outcomes are controlled by forces outside yourself.

As a class, discuss the following:

- 1) What is the impact of a sense of internal or external control on the experience of having a family member with a disability?
- 2) What is the impact of having a family member with a disability on a person's sense of internal or external control?
- 3) In the Hill (1949), McCubbin & Patterson (1983) models of coping and adjustment, how does locus of control fit into the picture?

DISCUSSION: DEPENDENCY; LEARNED HELPLESSNESS

Objectives

- To define, clarify, and correct misuses of terms
- To create awareness of practices that strengthen and weaken family and individual power

Instructions

In large group, discuss, recording important points on the flipchart:

- 1) How would you define dependency?
- 2) Give examples of practices that build dependency in families.
- 3) How do you decide how much help is necessary and how much will build dependency? Who decides?
- 4) What is learned helplessness? What causes it?
- 5) How is this different from dependency?
- 6) What does the presence of learned helplessness reveal about the service system?

MINILECTURE AND DISCUSSION: SELF-EFFICACY PERCEPTION

Objectives

- To define and clarify the term self-efficacy perception

- To distinguish the situational nature of this concept from more permanent traits of personality
- To understand the impact of self-efficacy on the adjustment process for families with children with disabilities
- To identify ways to build self-efficacy perception

Instructions

- 1) Define perceived self-efficacy. How is it different from locus of control?
- 2) Give examples of a time when you thought that you could not do something, but in the end you actually did it.
- 3) How did you overcome that belief?

In either large or small groups, brainstorm the question, "How can an individual or family build a sense of self-efficacy?" Give both general strategies and specific examples. Share with the large group. Discuss and fill in gaps with minilecture.

EXERCISE: EMPOWERING AND DISEMPOWERING PRACTICES

Objectives

- To build awareness of the impact of service practices on families
- To identify positive practices to replace disempowering ones

Instructions

- 1) In small groups, list as many practices as you can that disempower families.
- 2) For each disempowering practice, counter with an empowering version to address the same issue or need.

MINILECTURE AND DISCUSSION: HISTORY OF THE CHANGING PERCEPTION AND ROLE OF FAMILIES AND PEOPLE WITH DISABILITIES

Objectives:

- To build awareness of the history of devaluing and blame for families with members with disabilities in this century in America
- To identify milestones in national family and disability advocacy
- To identify major initiatives in state family support and disability advocacy

Instructions

- In large group discussion, share previous knowledge of historical attitudes toward people with disabilities and their families in America in this century
- Identify major national and state initiatives that have changed attitudes and practices
- Identify current issues in disability and family advocacy

READINGS

Powers, L. E. (1996). Family and consumer activism in disability policy. In Singer, Powers & Olson, Redefining Family Support. Baltimore: Brookes, 413-433.

Center on Human Policy, Syracuse University. (2000). The Community Imperative: A statement against institutionalizing any person because of a disability. Syracuse: Syracuse University.

The Seattle 2000 declaration on self-determination & individualized funding.
<http://members.home.net/directfunding>.

Silverstein, R. (2000). An overview of the emerging disability policy framework: A guidepost for analyzing public policy. (Appendices). Iowa Law Review, Vol. 85:5.

HOMEWORK ASSIGNMENT

Objectives

- To personalize the power assessment
- To build empathy between service providers and families

Instructions

- Complete the power analysis if you didn't have time to finish it in class
- Submit the analysis as a group effort if possible
- Optional variation: Do the same power analysis for yourself as an employee.
- Consider the parallels between your experience and that of the families served
- If you are familiar with the concepts of Total Quality Management and Continuous Quality Improvement, consider their relationship to the power of an employee or a family served by a program

ADDITIONAL MATERIALS Locus of control test and scoring information.

**APPENDIX VII: THE ROTTER
INTERNAL-EXTERNAL LOCUS OF CONTROL**
(Lefcourt, 1982)

The Rotter internal-external locus of control scale is a 23-item forced choice questionnaire with 6 filler items adapted from the 60-item James scale. It is scored in the external direction, that is, the higher the score the more external the individual.

Social Reaction Inventory: This is a questionnaire to find out the way in which certain important events in our society affect different people. Each item consists of a pair of alternatives lettered *a* or *b*. Please select the one statement of each pair (and only one) which you more strongly *believe* to be the case as far as you're concerned. Be sure to select the one you actually believe to be more true rather than the one you think you should choose or the one you would like to be true. This is a measure of personal belief; obviously there are no right or wrong answers.

Your answer, either *a* or *b* to each question on this inventory, is to be reported beside the question. Print your name and any other information requested by the examiner on the bottom of page 4, then finish reading these directions. Do not begin until you are told to do so.

Please answer these items *carefully* but do not spend too much time on any one item. Be sure to find an answer for every choice. For each numbered question make an X on the line beside either the *a* or *b*, whichever you choose as the statement most true.

In some instances you may discover that you believe both statements or neither one. In such cases, be sure to select the one you more strongly believe to be the case as far as you're concerned. Also try to respond to each item independently when making your choice; do not be influenced by your previous choices.

Remember

Select that alternative which you *personally believe to be more true*.

I more strongly believe that:

1. ___ a. Children get into trouble because their parents punish them too much.
 ___ b. The trouble with most children nowadays is that their parents are too easy with them.

2. ___ a. Many of the unhappy things in people's lives are partly due to bad luck.
 ___ b. People's misfortunes result from the mistakes they make.

3. ___ a. One of the major reasons why we have wars is because people don't take enough interest in politics.
 ___ b. There will always be wars, no matter how hard people try to prevent them.

4. ___ a. In the long run people get the respect they deserve in this world.
 ___ b. Unfortunately, an individual's worth often passes unrecognized no matter how hard he tries.

5. a. The idea that teachers are unfair to students is nonsense.
 b. Most students don't realize the extent to which their grades are influenced by accidental happenings.
6. a. Without the right breaks one cannot be an effective leader.
 b. Capable people who fail to become leaders have not taken advantage of their opportunities.
7. a. No matter how hard you try some people just don't like you.
 b. People who can't get others to like them don't understand how to get along with others.
8. a. Heredity plays the major role in determining one's personality.
 b. It is one's experiences in life which determine what they're like.
9. a. I have often found that what is going to happen will happen.
 b. Trusting to fate has never turned out as well for me as making a decision to take a definite course of action.
10. a. In the case of the well prepared student there is rarely if ever such a thing as an unfair test.
 b. Many times exam questions tend to be so unrelated to course work that studying is really useless.
11. a. Becoming a success is a matter of hard work, luck has little or nothing to do with it.
 b. Getting a good job depends mainly on being in the right place at the right time.
12. a. The average citizen can have an influence in government decisions.
 b. This world is run by the few people in power, and there is not much the little guy can do about it.
13. a. When I make plans, I am almost certain that I can make them work.
 b. It is not always wise to plan too far ahead because many things turn out to be a matter of good or bad fortune anyhow.
14. a. There are certain people who are just no good.
 b. There is some good in everybody.
15. a. In my case getting what I want has little or nothing to do with luck.
 b. Many times we might just as well decide what to do by flipping a coin.
16. a. Who gets to be the boss often depends on who was lucky enough to be in the right place first.
 b. Getting people to do the right thing depends upon ability; luck has little or nothing to do with it.
17. a. As far as world affairs are concerned, most of us are the victims of forces we can neither understand, nor control.
 b. By taking an active part in political and social affairs the people can control world events.
18. a. Most people can't realize the extent to which their lives are controlled by accidental happenings.
 b. There really is no such thing as "luck."

19. ___ a. One should always be willing to admit his mistakes.
___ b. It is usually best to cover up one's mistakes.
20. ___ a. It is hard to know whether or not a person really likes you.
___ b. How many friends you have depends upon how nice a person you are.
21. ___ a. In the long run the bad things that happen to us are balanced by the good ones.
___ b. Most misfortunes are the result of lack of ability, ignorance, laziness, or all three.
22. ___ a. With enough effort we can wipe out political corruption.
___ b. It is difficult for people to have much control over the things politicians do in office.
23. ___ a. Sometimes I can't understand how teachers arrive at the grades they give.
___ b. There is a direct connection between how hard I study and the grades I get.
24. ___ a. A good leader expects people to decide for themselves what they should do.
___ b. A good leader makes it clear to everybody what their jobs are.
25. ___ a. Many times I feel that I have little influence over the things that happen to me.
___ b. It is impossible for me to believe that chance or luck plays an important role in my life.
26. ___ a. People are lonely because they don't try to be friendly.
___ b. There's not much use in trying too hard to please people, if they like you, they like you.
27. ___ a. There is too much emphasis on athletics in high school.
___ b. Team sports are an excellent way to build character.
28. ___ a. What happens to me is my own doing.
___ b. Sometimes I feel that I don't have enough control over the direction my life is taking.
29. ___ a. Most of the time I can't understand why politicians behave the way they do.
___ b. In the long run the people are responsible for bad government on a national as well as on a local level.

Module I

Philosophy of Family Support

Class 4 in the Certificate Program **Redefining professional roles** **Models of decision-making**

SMALL GROUP DISCUSSION: ASSUMPTIONS AND VALUES

Objectives

- To introduce most recent statements of national principles of family support and self-determination
- To introduce national quality indicators for family support
- To introduce state principles, outcomes and indicators and other relevant documents for family support and self-determination
- To begin initial standards-based evaluation of specific programs

Instructions

- In mixed small groups, read and discuss the national quality indicators for family support (Expecting Excellence in Family Support, HSRI, 1992), principles from national and state family support bills, and other values-based documents from your state.
- Begin the process of thinking about your own programs in relation to these guidelines. What are the strongest areas for your programs in relation to these values?
- Share your observations and reactions with the larger group.

EXERCISE: REDEFINING PROFESSIONAL ROLES

Objectives

- To identify ideal characteristics of effective family support workers
- To build group solidarity and common vision

Instructions

- In small groups, brainstorm a list of adjectives to describe the "ideal" family support worker.
- Draw a picture to illustrate your list.
- Share pictures with the class.

"WE ARE ALL RESOURCES"--A NETWORKING EXERCISE

Objectives

- To begin networking within the group
- To identify existing resources within the group
- To anticipate future discussion of strengths-based assessment by offering personal experience with this process

Instructions

- Within 5 minutes, see how many "resources" you can identify among your fellow classmates. Ask each person if he/she is a particular "resource" rather than just asking that person to sign your list.
- If this exercise is being used as a scavenger hunt (as an ice-breaker), a prize should be given for the person who identified the most resources.
- Using posted flipchart papers with most important categories listed, participants should sign their names and give phone numbers or e-mail addresses by the areas where they are willing to serve as resources to the rest of the class (or use Post-Its, address labels or taped business cards)
- Instructors will summarize resource lists and disseminate to class members in following class

EXERCISE: MODELS OF DECISION MAKING FOR SERVICES AND SUPPORTS

Objectives

- To build awareness of different models of decision-making in service coordination currently in use
- To identify strengths and weakness of each model

Instructions

- Divide into three small groups, each assigned one of the following models of making decisions about services and supports: traditional case-management, interdisciplinary team, self-determination or family driven approach. (Fairly rigid, distinct definitions of these are included in the pages at the end of this class).
- Recording on flipcharts, identify the strengths and weakness of the approach assigned to each group.
- Share results with the large group.

EXERCISE: CHANGING MODELS OF DECISION-MAKING

Objectives

- To explore strategies for organizational change toward family-driven or self-determination model
- To identify barriers to this change
- To identify strategies to overcome these barriers
- To identify strategies to build participation and commitment to the family-driven or self-determination model
- To identify strategies to overcome weaknesses in family-driven or self-determination model

Instructions

- In the same small groups, take the model you worked on and brainstorm how to move from that model into a family-driven or self-determination model.

- In the group working with the family-driven or self-determination model, problem-solve how to build a level of participation and commitment to the process, and how to overcome the weaknesses of the model. Report your results to the large group.

READINGS

Principles of Federal Family Support Bill, (Part I, IDEA). (Note: These are of historical value only, as they were not included in S.1809).

S.1809. Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title II—Family Support.

HSRI, Expecting Excellence in Family Support. (1993) (National Quality Indicators)

HOMEWORK ASSIGNMENT

Objective

- To compare organizational and program values statements with national and state documents reflecting values and standards for family support and self-determination

Instructions

- Find any vision or mission or values statements from your organization or program.
- Compare these with the documents presented today. How compatible are the underlying values and philosophical assumptions of your organization and program with the values we have been discussing?
- Write your reflections in a paragraph or two.

ADDITIONAL MATERIALS "We are all resources;" Woodruff & Hanson (1987). Three Models of Early Intervention. Brighton, MA: Project KAI.

WE ARE ALL RESOURCES--A Networking Exercise

Please check all the resources that apply to you (no modesty, please):

I am connected to the Internet.

I know how to make a web page.

I am a member of an interagency team (check all that apply).

individual

local

regional

state

I am a member of an advocacy organization (please specify).

I am involved with a support group (please specify).

I have a disability or have someone in my family who requires support.

I have good friends in high places (please specify if you are comfortable).

I am a member of a board, advisory council, planning council or task force whose work affects people with disabilities or their families (please specify).

I have experience doing needs assessment with individuals or families.

I have experience evaluating programs (of any sort, but especially those for people with disabilities or their families).

I have helped form or been a part of a "circle of support."

I have taken part in a MAPS or other person-centered planning process.

I have been trained in conflict resolution or as a mediator.

I have been trained in collaborative teaming.

I have been a citizen advocate.

I have been a child advocate.

I have testified in the legislature.

I'm good at graphics.

I'm a good writer.

I've got a great collection of cartoons.

I'm good as a public speaker and can talk about (please specify):

I've got a joke for any occasion.

- I speak another language (please specify).
- I've lived in another country or culture (please specify where and how long).
- I'm familiar with other cultures (please specify).
- I know sign language.
- I have a collection of ice breakers, team builders, or other exercises.
- I know a lot about Medicaid waivers.
- I know a lot about SSI.
- I know a lot about transportation in my area of the state.
- I know a lot about housing.
- I know a lot about assistive technology, how to get it, and how to fund it.
- I have experience with family/school partnerships.
- I have great ideas for celebrations.
- I know how to organize a conference.
- I'm good at organizing volunteers.
- I know how to operate all kinds of audio-visual equipment--nothing scares me.
- I have the names and phone numbers of all the different supports for individuals and their families in my area.
- I know a lot about laws, rules and regulations.
- I have a good collection of books and articles on (please specify):
- I have access to videos for people with disabilities and their families.
- I make great food (please specify!).
- Other (as many as you need).

Models of Service Coordination and Decision-Making

Expand on the following brief descriptions from your own experience with these models. Identify the strengths and weaknesses of each.

Traditional case-management: The service coordinator assesses the needs of the individual or family, identifies resources to meet the needs (in some cases presenting options for choice), and arranges for services.

Team (Multidisciplinary, Interdisciplinary, or Transdisciplinary [see additional materials]): a group of people with different areas of expertise who work together to assess needs, plan and develop services. Ideally, individuals and family members are members of the team with equal voice in the process.

Self-determination or family-driven: The individual or the family determines the needs they have for services and the manner in which those services should be delivered. Service coordinators and other team members act as resources and facilitators of the process.

Three Models for Early Intervention

	Multidisciplinary	Interdisciplinary	Transdisciplinary
Assessment	Separate assessments by team members	Separate assessments by team members	Team members and family conduct a comprehensive developmental assessment together
Parent Participation	Parents meets with individual team members	Parents meet with team or team representative	Parents are full, active and participating members of the team
Service Plan Development	Team members develop separate plans for their discipline	Team members share their separate plans with one another	Team members and the parents develop a service plan based upon family priorities, needs and resources
Service Plan Responsibility	Team members are responsible for implementing their section of the plan	Team members are responsible for sharing information with one another as well as for implementing their sections of the plan	Team members are responsible and accountable for how the primary service provider implements the plan
Service Plan Implementation	Team members implement the part of the service plan related to their discipline	Team members implement their section of the plan and incorporate other sections where possible	A primary service provider is assigned to implement the plan with the family
Lines of Communication	Informal lines	Periodic case-specific meetings	Regular team meeting where continuous transfer of information, knowledge and skills are shared among team members
Guiding Philosophy	Team members recognize the importance of contributions from other disciplines	Team members are willing and able to develop, share and be responsible for providing services that are a part of the total service plan	Team members make a commitment to teach, learn and work together across discipline boundaries to implement unified service plan
Staff Development	Independent and within their discipline	Independent within as well as outside of their discipline	An Integral component of team meetings for learning across disciplines and team building

Source: Woodruff, G. & Henson, C. (1987). *Project KAI, 77B Warren Street, Brighton, MA 02135. Funded by U.S. Dept. of Special Education Programs, Handicapped Children's Early Education Program*

Module II Cultural Competence

Class 5 in the Certificate Program Exploring Individual Cultural Values How Language Shapes Values

VALUES EXERCISE--FAMILY

Objectives

- To identify individual family history of values
- To identify current individual values
- To identify cultural factors forming values
- To examine the nature and causes of change in values over time
- To build awareness and acceptance of difference in values in different people
- To build awareness of how our values influence our work with families

Instructions

Arrange the following list of nouns in order of greatest importance for your own family of origin, starting with #1 as the most important, going down to #10 as least important. Then rank them on the right hand side for yourself, now.

___tradition, ritual___

___hierarchy___

___equality___

___religion___

___independence___

___work___

___education___

___money___

___love___

___food___

___other (list)_____

Cards with these words are placed around the edge of the room. Go and stand on the #1 value for your family of origin. Look at the others who share your first choice. See what values were more important to others in the class. Rotate to your second choice, and notice who is with you and who has different values. (This will be important in a later lesson). Go to your third choice and look around

you. Then go to the choice that is lowest on your list and see where you are in relation to your classmates. Repeat for your own values now.

VARIATION: SELF-DETERMINATION AND FAMILIES

If you are a parent, how do you think your children would rank these values, both for you (as their family of origin) and for themselves? Take the questionnaire home and see how accurate you were in your predictions of their choices and how accurate they are in their identification of your values. If your children are willing, discuss with them how they formed their choices and where each of you was accurate or mistaken about the other.

PAIRED DISCUSSION: CULTURAL IDENTITY

Objectives

- To identify cultural background of participants
- To sort out multiple influences and their importance
- To determine how participants choose to identify themselves
- To determine the importance to participants of cultural identity in the choice of life-partners
- To introduce the concept of culture in child-raising practices
- To personalize the experience of misunderstanding or disagreement in child-raising practices to sensitize participants to projected judgments

Instructions: In pairs, discuss the following questions:

- 1) What is the cultural/ethnic/linguistic origin of your parents?
- 2) Your grandparents?
- 3) If each of your parents came from a different group, did one predominate in your family experience?
- 4) How do you identify yourself?
- 5) If you have chosen a life-partner, is this person from the same background as yourself? Is this important to you?
- 6) If you have children, how have your cultural backgrounds influenced the ways you are raising them? (We will explore this in greater depth in the next lesson).
- 7) Think of examples of child-raising practices you use that might be misunderstood by people from a different generation or culture.

EXERCISE: CULTURAL ATTITUDES TOWARD DISABILITY

Objectives

- To identify and examine the cultural basis of attitudes toward disability
- To identify ways to change attitudes
- To debate the rights of one group to change the attitudes of another

Instructions: Divide into three small groups, and choose a recorder. Draw a "situation" from the hat. Discuss the following questions in relation to your group's situation:

- 1) Describe the underlying attitude in the situation.
- 2) Where does this attitude come from? How is it formed?
- 3) To what extent is this attitude "cultural"?
- 4) How would you go about changing it?
- 5) Do you have the right to try to change it?

Report your group's ideas to the large group.

EXERCISE: HOW LANGUAGE SHAPES VALUES

Time limit 15 minutes

Objectives

- To build awareness of connotations of disability-related words
- To identify and encourage the use of neutral or positive, respectful terminology
- To practice the use of person-first language

Instructions

As a class, examine the language in the following sentences, all of which were actually heard at one time or another. Discuss the impact of the language on attitudes and values. Improve the sentences, using words with different connotations. Feel free to get in a debate about politically correct language if you want to; the important thing is awareness of the power of words. Move quickly through these.

- 1) She suffers from multiple sclerosis.
- 2) They adopted two Down's kids.
- 3) "Mom" says we can't get the blood sample that way.
- 4) Though wheelchair-bound, John has been heroic in overcoming obstacles.
5. Handicapped parking is to the left.
6. The number of welfare families is putting increasing pressure on state budgets.
7. Gloria is not only non-compliant; she's a runner.
8. We give special consideration to the disabled.

9. Dysfunctional families like this have trouble producing normal children.

10. Autistics often appear deaf and dumb.

Brainstorm other "loaded" words and phrases you have heard in your work or life experience. What is the worst real example you can come up with?

DISCUSSION: ACRONYMS AND JARGON

Objectives

- To build awareness of the "in-group" nature of the use of acronyms and jargon
- To build sensitivity to families' feelings about the use of acronyms and jargon

Instructions: As a whole class, discuss the reasons people use acronyms (initials, words made out of initials) and jargon to refer to people, programs and organizations? Give some examples. Discuss the impact on families.

DISCUSSION: CLASS LANGUAGE NORMS

As a group meeting together in class, how do we want to respond to non-person-first, or "undignified" language? How can we raise our own awareness and still feel comfortable about how we do it?

READING

Lynch, E. W. & Hanson, M. J. (1996). Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families, 2nd Ed. Baltimore: Brookes. Chapters 1-3 required reading; additional chapters for specific cultures.

Association for Cerebral Palsy, Vt. Developmental Disabilities Council. (1992). Choosing words with dignity. Waterbury, VT: author.

HOMEWORK ASSIGNMENT

Objectives

- To increase exposure to at least one other culture's attitudes and practices around family and disability
- To prepare to represent, as accurately as possible, another culture's attitudes and practices as they relate to planning processes (IFSP's, IEP's, IPP's, Person-centered planning, etc.)

Instructions

Choose another culture with which you are familiar or interested; find out as much as possible in the time you have about their attitudes toward family and disability. This information can come from books, films, interviews with families or individuals, or anything else you can document as being rooted in that culture, not just in mainstream American views or stereotypes of that culture. Choose the

appropriate chapter from Lynch and Hanson (teachers will have copies) to strengthen your knowledge about that culture, so that you can be a resource for the class in further discussion.

ADDITIONAL MATERIALS: Values cards, Cases, Cultural attitudes, cultural chapters from Lynch and Hanson.

Cases--Cultural Attitudes

At the Balloon Festival a few years ago, a young woman with cerebral palsy was not allowed to ride in a balloon. The Human Rights Commission ruled she had experienced discrimination.

At a Developmental Services annual conference, the keynote speaker was a leading prevention psychologist. The audience included state people, providers, families and self-advocates. The speaker advocated for amniocentesis and abortion of fetuses with identifiable conditions like Down Syndrome. People were outraged.

At an IEP meeting for a girl with behavioral problems, a psychologist reported that the children in the family had different fathers. A special educator referred to the mother as a "multi-partner parent."

In the current tight labor market, it has been very hard to hire and keep good direct support workers. Service coordinators, families and individuals can spend weeks recruiting, interviewing and training people. A mother has turned down several qualified workers, saying, "I don't want gays or lesbians working with my son."

Module II Cultural Competence

Class 6 in the Certificate Program Exploring Individual Cultural Values How Language Shapes Values Discovering Other Cultural Values

EXERCISE: FOLK MEDICINE -- ONE EXAMPLE OF CULTURE IN OUR LIVES

Objectives

- To identify culturally specific practices and beliefs
- To examine, from personal experience, the belief that cultural wisdom is accurate for each person

Instructions

In either large or small groups, for the following "ailments," identify all the "folk remedies" that have come down from your families. On flipchart paper or the blackboard, record the ailment, the remedies, a guess at the culture the remedy came from, and your own personal judgment of whether or not the remedy works.

Ailment	Remedy	Culture	Effectiveness
1) colicky baby			
2) hiccups			
3) warts			
4) cramps			
5) head cold			
6) cough			
7) high fever			
8) muscle aches			
9) impotence			
10) upset stomach			

Every culture has evolved health remedies from generations of experimentation, observation, and interpretation. What has remained over time are the things that, in the belief of that culture, have worked. The same is true of all the other aspects of a culture, from family structure to politics to beliefs and practices around birth and death.

To disagree with the practices and beliefs of a culture is to challenge the collective experience of generations whose care and love made possible the people of the present. In some cultures, to challenge the ways of the ancestors is the boldest form of disrespect, ingratitude and arrogance.

In America, history is short, and old ways are not often revered. In other cultures, it is best to ask questions to understand how a practice has come about rather than to directly challenge it with new ways.

DISCUSSION: THE WAY WE SPEAK IS THE WAY WE THINK

Objectives

- To introduce the concept that language influences thinking
- To build awareness that speakers of a different language may have differences in perception from native English speakers.
- To examine some of these differences, such as perception of detail, locus of control, emphasis on time, etc.

Instructions

When possible, this exercise and discussion should be introduced by a presentation from a representative of the deaf community, addressing the question, "What influence does the use of sign language have on cultural differences between the deaf and hearing communities?"

Language is the most intimate expression of a culture. When a child is raised in a culture, exposed to a language from birth, the view of the world is shaped by that language (Sapir-Whorf hypothesis, linguistic relativity--a controversial concept, developed by anthropologists and linguists, currently experiencing a revival [Gerrig, R. & Banaji, M., 1994; Kay, P. & Kempton, W., 1984]. It contends that the patterns of the language we learn as little children shape the way we think and see reality. Usually we believe the way we think forms the way we speak; this concept reverses the process). This concept is appreciated by people from the deaf community, whose use of sign language, facial expressions and non-verbal communication creates a rich style of communication and an important sense of identity.

For each of the following statements about a language, answer two questions:

- a) What does it reveal about the way the people who use that language may see reality?
 - b) What are the implications of this for the work we do?
- 1) Chinese has specific names and forms of address for every relative you could ever have.
 - 2) Spanish is full of reflexive verbs that create a separation of the self from the action, such as caerse--to fall (oneself) down, levantarse--to get (oneself) up.
 - 3) Passamaquoddy (native American tribe in northern Maine) structures its grammar around "things that pierce and things that yield."
 - 4) French, Spanish and German all have a familiar "thee" (tu, du), and a formal "you".
 - 5) Chinese verbs don't have tenses.
 - 6) Are there linguistic structures in any other language you are familiar with that may reflect a different way of seeing the world? Give examples for class discussion.

PAIRED DISCUSSION: BASIC CULTURAL ASSUMPTIONS UNDERLYING FAMILY SUPPORT

Objectives

- To identify child-raising practices from different family cultures
- To develop understanding and acceptance of different practices
- To practice interviewing skills
- To develop awareness of invasiveness in a protocol
- To balance invasiveness against information gained
- To determine individually how to modify an interview to fit the comfort level of the person being interviewed

Instructions

- Pair with someone who is as different from you as you can find (remember the values exercise--find someone who was consistently on different values from yourself, if possible).

- Using Lynch's Guidelines for the home visitor, (additional materials) interview one another. This should take about 30 minutes each. Since this interview protocol was developed for families with young children, make any adaptations you feel are necessary to fit the person you are interviewing. If the person doesn't have children, he or she can answer the questions referring to his or her family of origin.

- Practice good listening skills, and take notes.

DISCUSSION: APPLYING CULTURAL ADAPTATIONS TO THE PLANNING PROCESS

Objectives

- To identify different factors involved in planning for disability-related services and supports
- To increase awareness of the extent to which these processes are rooted in the mainstream Anglo-American culture
- To identify culturally-specific adaptations to make planning more comfortable and respectful to families from different cultures
- To share information about different cultures
- To become aware of the danger of overgeneralization about other cultures

Using the following list of cultural factors as a guide, generate examples of adaptations which might make the process of program planning more comfortable for families from other cultures. Refer to your experience or background reading for this class, contributing as much expertise as you can about another culture.

Factors in Planning with Families

- sense and importance of time
- space or physical distancing
- eye contact
- timing, pacing

- numbers of people involved
- who should be involved?
- what roles do they play?
- patterns of courtesy and address
- amount of directness in communication
- handling disagreement
- use of interpreters
- sense of fate vs. free will
- language
- talkativeness or quietness
- maintaining appearances or "face"
- degree of formality

HOMEWORK ASSIGNMENT

Objective

- To translate information learned from an interview into individualized, culturally-sensitive practices in service delivery

Instructions

On the basis of your interview with your classmate, make recommendations for "fine-tuning" culturally responsive family support for this family. If you were offering your services to this family, what modifications would you make to adapt to their cultural background, defining culture broadly?

READING

Lynch, E. W. & Hanson, M. J. (1996). Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families, 2nd Ed. Baltimore: Brookes.

McAdoo, H.P. (1999). Family Ethnicity (2nd Ed.). Thousand Oaks, CA: Sage Publications. (Note: Both of these books include chapters on specific ethnic groups. Please choose from either source or any other authentic writing representative of the culture you choose to study).

ADDITIONAL MATERIALS: Lynch & Hanson Interview Protocol; Althen (1988). Characteristics of American Culture.

GUIDELINES FOR THE HOME VISITOR

Part I--Family structure and child-rearing practices

- Family structure
 - Family composition
 - Who are the members of the family system?
 - Who are the key decision makers?
 - Is decision making related to specific situations?
 - Is decision making individual or group oriented?
 - Do family members all live in the same household?
 - What is the relationship of friends to the family system?
 - What is the hierarchy within the family? Is status related to gender or age?
 - Primary caregiver(s)
 - Who is the primary caregiver?
 - Who else participates in the caregiving?
 - What is the amount of care given by mother versus others?
 - How much time does the infant spend away from the primary caregiver?
 - Is there conflict between caregivers regarding appropriate practices?
 - What ecological/environmental issues impinge upon general caregiving (i.e., housing, jobs, etc.)?
- Child-rearing practices
 - Family feeding practices
 - What are the family feeding practices?
 - What are the mealtime rules?
 - What types of foods are eaten?
 - What are the beliefs regarding breastfeeding and weaning?
 - What are the beliefs regarding bottle feeding?
 - What are the family practices regarding transitioning to solid food?
 - Which family members prepare food?
 - Is food purchased or homemade?
 - Are there any taboos related to food preparation or handling?
 - Which family members feed the child?
 - What is the configuration of the family mealtime?
 - What are the family's views on independent feeding?
 - Is there a discrepancy among family members regarding the beliefs and practices related to feeding an infant/toddler?
 - Family sleeping patterns
 - Does the infant sleep in the same room/bed as the parents?
 - At what age is the infant moved away from close proximity to the mother?
 - Is there an established bedtime?
 - What is the family response to an infant when he or she awakes at night?
 - What practices surround daytime napping?
 - Family's response to disobedience and aggression
 - What are the parameters of acceptable child behavior?
 - What form does the discipline take?
 - Who metes out the disciplinary action?

Family's response to a crying infant

Temporal qualities--How long before the caregiver picks up a crying infant?

How does the caregiver calm an upset infant?

Part II--Family perceptions and attitudes

- Family perception of child's disability
 - Are there cultural or religious factors that would shape family perceptions?
 - To what/where/whom does the family assign responsibility for their child's disability?
 - How does the family view the role of fate in their lives?
 - How does the family view their role in intervening with their child? Do they feel they can make a difference or do they consider it hopeless?

- Family's perception of health and healing
 - What is the family's approach to medical needs?
 - Do they rely solely on Western medical services?
 - Do they rely solely on holistic approaches?
 - Do they utilize a combination of these approaches?
 - Who is the primary medical provider or conveyer of medical information?
 - Family members? Elders? Friends? Folk healers? Family doctor?
 - Medical specialists?
 - Do all members of the family agree on approaches to medical needs?

- Family's perception of help-seeking and intervention
 - From whom does the family seek help--family members or outside agencies/individuals?
 - Does the family seek help directly or indirectly?
 - What are the general feelings of the family when seeking assistance--ashamed, angry, demand as a right, view as unnecessary?
 - With what community systems does the family interact (educational/medical/social)?
 - How are these interactions completed (face-to-face, telephone, letter)?
 - Which family member interacts with other systems?
 - Does that family member feel comfortable when interacting with other systems?

Part III--Language and communication styles

- Language
 - To what degree:
 - Is the home visitor proficient in the family's native language?
 - Is the family proficient in English?

 - If an interpreter is used:
 - With which culture is the interpreter primarily affiliated?
 - Is the interpreter familiar with the colloquialisms of the family members' country or region or origin?
 - Is the family member comfortable with the interpreter? Would the family member feel more comfortable with an interpreter of the same sex?
 - If written materials are used, are they in the family's native language?

- Interaction styles

- Does the family communicate with each other in a direct or indirect style?

- Does the family tend to interact in a quiet manner or a loud manner?

- Do family members share feelings when discussing emotional issues?

- Does the family ask you direct questions?

- Does the family value a lengthy social time at each home visit unrelated to the early childhood services program goals?

- Is it important for the family to know about the home visitor's extended family? Is the home visitor comfortable sharing that information?

From Wayman, K.I., Lynch, E.W., & Hanson, M.J. (1990). Home-based early childhood services: Cultural sensitivity in a family systems approach. Topics in Early Childhood Special Education, 10, 65-66.

- 1. Importance of individualism and privacy**
- 2. Belief in the equality of all individuals**
- 3. Informality in interactions with others**
- 4. Emphasis on the future, change, and progress**
- 5. Belief in the general goodness of humanity**
- 6. Emphasis on the importance of time and punctuality**
- 7. High regard for achievement, action, work, and materialism**
- 8. Pride in interactional styles that are direct and assertive**

Althen (1988)

**Module III
Strengths, Needs, and Supports**

**Class 7 in the Certificate Program
Holistic perspectives
Needs and goals
Rationale for assessment**

DISCUSSION: FAMILY RESILIENCY--REVIEW OF THE ABCX MODEL

Objectives

- To introduce the concept of resiliency
- To link resiliency to strengths-based approaches
- To consider the role of strengths in coping and adjustment

Instructions

Ask participants to define "resiliency." Explore the concept by inviting suggestion of words that mean the opposite. Ask why they think one person would be "resilient" and another not.

Discuss the assessment of family strengths in relation to the ABCX model of family coping and adjustment. Where do strengths come in, in that model? Give some examples of strengths in both the resources and perception parts of the model.

- A = stressor**
- B = resources and supports (internal or external)**
- C = perception or interpretation**
- X = outcome**

EXERCISE: ASSESSMENT--THE ZOOM LENS; FOCUSING ON YOURSELF

Objectives

- To experience two methods of self-assessment: free, using self-generated criteria and using reference to criteria generated by someone else
- To explore the feelings generated by the experience of self-assessment
- To compare the experience of strengths-based assessment with the assessment of needs

Instructions

- 1) For 5 minutes, brainstorm "for your eyes only" all the strengths you bring to the field of family support. Give yourself credit for things you are good at naturally, as well as things you have learned.
- 2) Taking the list of "Competency Areas" in Family Support (Class 1), match your strengths with that list. The list may act as a prompt to help

you remember things you know and skills you have. Refer back to "We are All Resources" (in Class 4) to help you be as comprehensive as possible in your assessment of your strengths.

3) In the large group, describe how it felt doing self-assessment of competencies. Record on flipchart paper or the blackboard, with positive impressions on one side and negative on the other. Discuss, answering the following questions, and others you may think of:

- * What are the factors that influenced how you felt?
- * Why do some people have positive feelings and others negative?
- * Does assessing strengths always feel better than assessing needs?
- * Are there ways to make self-assessment of strengths a positive experience? Share and record.

EXERCISE: BEING FOCUSED ON BY OTHERS

Time limit 15 minutes

Objectives

- To contrast assessment and judgment
- To explore "subjectivity" and "objectivity" in relation to these two terms
- To sensitize participants to the tendency to judge and its impact
- To identify the short and long-term emotional impact of judgment
- To explore the role of information in preventing or correcting misjudgment

Instructions

- With the whole class, discuss the difference between assessment and judgment.
- Divide into pairs, and describe to each other a time when you felt you were being judged.
- Who was judging you?
- Why were they judging you?
- How did it feel?
- How did you handle it?
- What short-term impact did it have on you?
- Long-term impact?
- What information could prevent or correct the judgment?
- What prevented you from giving that information?

- Share your most important reflections with the whole class.

HOLISTIC PERSPECTIVES ON ASSESSING FAMILY STRENGTHS AND NEEDS

Objectives

- To raise awareness of the number of assessments to which a family may be subjected
- To differentiate between family assessments and assessments of individual family members
- To identify assessments that address the family as a holistic system
- To consider the relationship between individual strengths and needs and family strengths and needs

Instructions

- In the same small groups you were in during the exercise on the family-centered approach (first class), draw the family on flipchart paper, leaving space in the center.
- Identify things that might possibly be assessed, measured, or otherwise considered in relation to serving that family.
- Where something relates to the family as a whole, write it in the center.
- Where something relates only to a certain member, write it next to that member.
- Where something relates to connections between members, draw arrows between the term and the members concerned.
- Which things reflect a more holistic approach to the family system?
- What is the relationship of the strengths and needs of specific members to the strengths and needs of the family as a whole?

NEEDS AND GOALS -- MASLOW'S HIERARCHY- CLASS DISCUSSION

Objectives

- To review the model of a hierarchy of needs
- To examine this contributions of this model to the understanding of family needs
- To identify areas where this model can be overgeneralized

Instructions

- Draw a pyramid or triangle on flipchart paper, dividing it into 5 levels.
- From the collective memory (or common sense) of the group, try to reconstruct Maslow's model of the hierarchy of needs.
- Discuss the nature of movement through the levels.

- Is the process linear (a steady progress up through the levels)?
- Can you be on more than one level at a time? Skip levels?
- Once you reach the top, is it easier to get back there?
- Any other thoughts?

EXERCISE: DEVELOPING A RATIONALE AND CRITERIA FOR ASSESSMENT

Objectives

- To identify the purpose of assessment
- To develop awareness of the invasiveness of assessment
- To raise awareness of issues of confidentiality
- To develop a critical judgment of assessments
- To develop justifiable criteria for the inclusion of questions in an assessment

Instructions

In small groups, discuss the rationale for assessment and criteria for judging what is appropriate to ask members of a family. Consider questions like:

- * How do we decide what it's "our business" to know?
- * Who decides?
- * Why are we asking?
- * Who is doing the asking?
- * How does the purpose of the questions determine the content?
- * Do the ends justify the means--in other words, does the purpose justify the questions we ask?
- * Who is going to see the results of the assessment?
- * What about privacy?
- * What about confidentiality
- * any other questions you consider important

Remember, you are not deciding on specific questions that are appropriate yet; you are deciding how to judge those questions. Compile a list of criteria or guidelines.

Share with the large group. Merge the lists, working toward consensus. Compare with ideas from other sources. When you are satisfied with your criteria, this will become your guide for examining different surveys and interviews.

HOMEWORK: MASLOW'S HIERARCHY - SELF-REFLECTION

Objectives

- To personalize knowledge of this model
- To apply this model critically
- To heighten awareness of the experience of self-assessment
- To increase self-knowledge
- To build empathy with families

Instructions

- Take a few minutes quietly and consider your own life in relation to Maslow's hierarchy of needs.
- Where are you now?
- What factors in life lead you to that conclusion?
- Thinking back to 3 or 4 different points in the past, where were you?
- Why?
- Where do your goals for the future fit on the model?
- Are there events that need to happen first to reach a particular goal, (e.g. "when I get my motorcycle, then I can travel across the country")?
- How "realistic" are your goals?
- What is the relation of your locus of control to your goal-setting?
- Supports? Perceptions? (Tie into ABCX model).

ADDITIONAL MATERIALS: Maslow's Hierarchy of Needs.

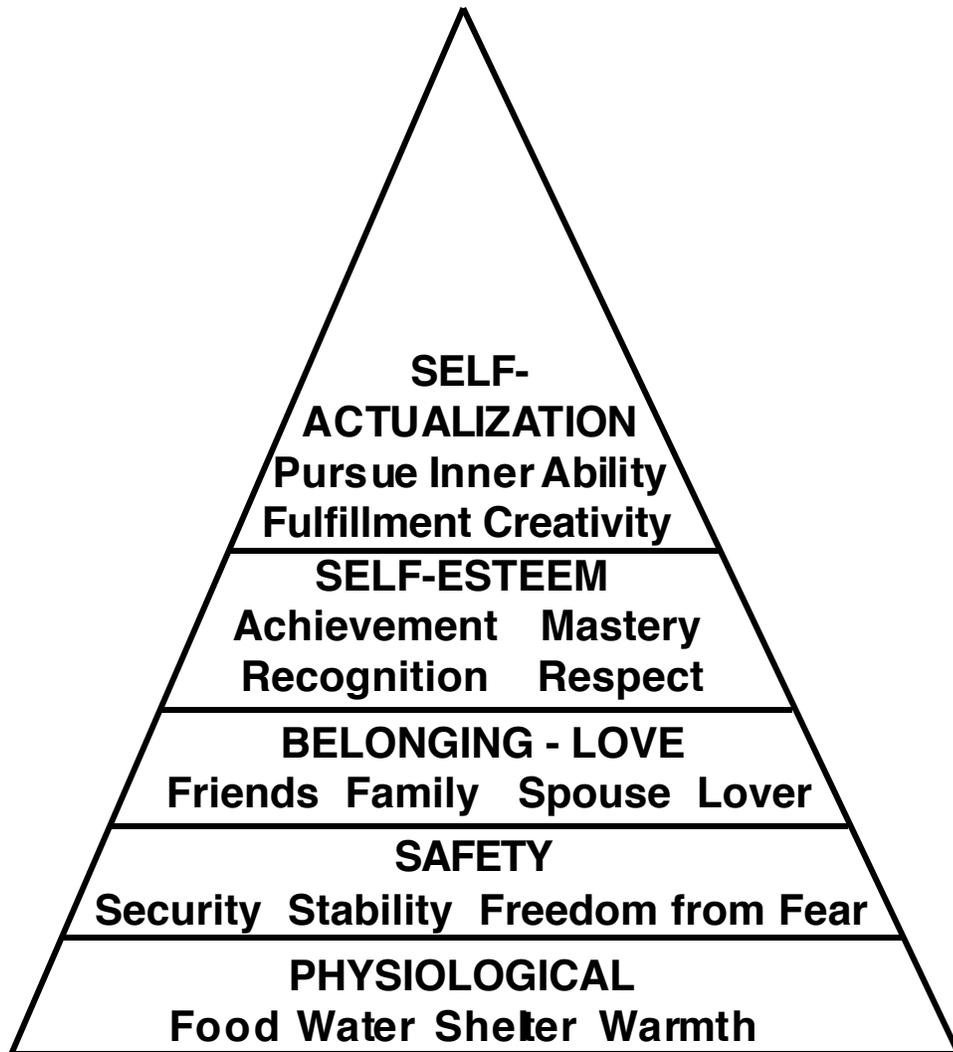


Figure 1: Maslow's hierarchy of human needs. (From Maslow, A. (1970). *Motivation & personality* (2nd ed.). New York: Harper & Row; reprinted by permission of Harper Collins Publishers.)

**Module III
Strengths, Needs, and Supports**

**Class 8 in the Certificate Program
Formal and informal needs assessments
Effective supports**

SMALL GROUP DISCUSSION: EVALUATING DIFFERENT FORMAL QUESTIONNAIRES AND INTERVIEW STRUCTURES

Objectives

- To become familiar with frequently used tools and inventories in family support
- To evaluate these instruments against specific criteria
- To assess the usefulness of these instruments in real work situations

Instructions

In the same small groups as the previous lesson, choose a questionnaire from the samples in the readings. Working individually, complete that questionnaire for yourselves and your own family lives. Then working together, discuss your evaluation of the questionnaire against the criteria your group established, making notes about the particular "instrument" or

Choose an interview protocol or set of guidelines. Read through the set of interview questions, imagining using the questions with the families you serve. Afterward, discuss your evaluation of the interview protocol against the criteria your group established, making notes about the particular "protocol".

Would the questionnaire or interview protocol be useful in your work? If not, why not? If so, what does it accomplish that fits your goals?

Continue with other questionnaires or protocols, as long as you have time, evaluating and making notes.

LARGE GROUP DISCUSSION: SHARING INFORMATION ON INSTRUMENTS AND PROTOCOLS

Objectives

- Same as previous exercise

Instructions

Through your group's "reporter," present the questionnaires or interview protocols that your group reviewed. Discuss their strengths and weaknesses, guided by your experience using them and your criteria. Take turns until all groups have presented.

BRIEF DISCUSSION: FAMILY-FOCUSED, FAMILY-CENTERED, OR FAMILY-DRIVEN OR SELF-DETERMINED SUPPORTS

Objective

- To differentiate among the assumptions underlying different terminology in support approaches

Instructions

The first two terms are both used to describe service approaches for families. What is the difference? Give examples. What is different about the third approach?

How does this parallel the difference between traditional supports for individuals and self-determination?

SMALL GROUP DISCUSSION: CHANGE OVER TIME; FLEXIBILITY OF SUPPORTS

Objectives

- To raise awareness of family change
- To examine the responsiveness of services and supports to changing needs

Instructions

In small groups, consider families you have known or worked with over time (or your own family if you don't have experience working with others). Discuss:

- How have you seen their needs change?
- How relevant were supports or services to their needs at different points?
- How have the supports or services changed in response to their changing needs?
- Share dramatic examples with the class.

SMALL GROUP DISCUSSION: BUILDING FLEXIBILITY INTO PROGRAMS

Objectives

- To raise awareness of creativity and flexibility in different programs
- To examine underlying causes of variations in flexibility from program to program

Instructions

Working in small groups, preferably of people who work together or in similar programs, share your thoughts on designing flexibility into the supports and services you provide.

- How much leeway do you have?
- What are the barriers?
- How could you overcome them?
- Consider this in the light of the model of decision-making that prevails in your workplace.
- How could increasing flexibility move the prevailing model toward a family or consumer-driven approach?
- Share with the larger group.

LARGE GROUP DISCUSSION: FAMILY SUPPORT--WHAT IS IT?

Objectives

- To identify the range of supports needed by families
- To identify supports specific to families with members with disabilities
- To raise awareness that families whose members with disabilities are living outside the family home may still have needs for support
- To examine the extent to which natural supports or generic supports can replace the need for specialized supports

Instructions

As a large group, brainstorm first all the generic supports that might be needed by any family. List on flipchart paper or blackboard.

Then, brainstorm all the specialized supports that might be needed by a family caring for a member with disabilities at home. List.

What supports might be needed by a family whose member is living outside the family home? List.

Consider the two lists for families with a member with a disability. How many of the specific supports could be effectively provided by generic or natural supports? How many do you think would need specialized services?

LARGE GROUP DISCUSSION: CATEGORIZING FAMILY SUPPORT

Objective

- To raise awareness of different ways of grouping family supports, and the way these are driven by existing services and practices

Instructions

Group the supports from all three lists into categories that make sense to you. You are creating a taxonomy of family support (like a biologist creates a taxonomy of organisms, classifying them into a system). Compare with Karp and Bradley's taxonomy (1992) (*additional materials*).

Discuss the extent to which your categories are driven by existing services and practices. Are there other ways to group these supports?

READINGS:

Agosta, J. (1999). Family needs: Summary results from ten years of research. Family Support Policy Brief #2. Salem, Oregon: National Center for Family Support @ HSRI.

Friedrich, W. N., Greenberg, M. T., & Crnic, K. A. (1983). A short form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 88, 47-48.

Scheier, M. & Carver, C. (1994). Life Orientation Test. American Psychological Association.

Snyder, C. R., Harris, C., et al. (1991). The will and the ways: Development and validation of an individual differences measure of hope. Journal of Personality and Social Psychology, 60, 585. (The Hope Scale).

Dunst, C. J., Trivette, C. M., & Deal, A. G. (1988). Appendices in Enabling and Empowering Families. Cambridge, MA: Brookline Books.

Turnbull, A. P. & Turnbull, H. R. (1990). Appendix B: Guide for Gathering Family Information through Discussion. in Families, Professionals and Exceptionality, (2nd Ed.). Columbus, OH: Merrill Publishing Co., 435-440.

HOMEWORK

Objectives

- To examine current practices in needs assessment
- To consider the applicability of selected instruments and protocols in practical working situations

Instructions

Describe how families' needs are assessed in your current work. Are you pleased with the results? Are the families served pleased with the results? What are the strengths of your current method? The weaknesses? Would any of the sample formal assessments or interview protocols be useful to you in your work? If "no", why not? If "yes", which would you prefer to use? Why?

ADDITIONAL MATERIALS: Karp and Bradley (1992), Taxonomy of Family Support.

Taxonomy of Family Support

Service

√ **CORE SERVICES**

Respite & Child Care

Respite
Child Care
Sitter Services

In-Home Assistance

Homemaker
Attendant Care
Home Health Care
Chores

Environmental Adaptations

Adaptive Equipment
Home Modification

Recreation

Recreation
Camp

Supportive

Family Counseling
Family Support
Groups

Extra-Ordinary/ Ordinary Needs

Transportation
Vehicle Modification
Special Diet
Special Clothing
Utilities
Health Insurance
Home Repairs
Rent Assistance

Training

Parent Training

Systematic Assistance

Information & Referral
Advocacy

√ **TRADITIONAL DEVELOPMENTAL SERVICES**

Behavior Management
Speech Therapy
Occupational Therapy
Physical Therapy
Individual Counseling
Medical/Dental
Skill Training
Evaluation Assessment
Nursing

CASE MANAGEMENT/SERVICE COORDINATION

FINANCIAL ASSISTANCE

Discretionary cash subsidy
Allowances
Vouchers
Reimbursement
Line of credit

Source: *Family Support Services in the United States: An End of Decade Status Report*, HSRI.

Module IV
Identifying and Coordinating Resources

Class 9 in the Certificate Program
Emerging Models of Family Support
The Role of the Family Support Facilitator

LARGE GROUP DISCUSSION: EMERGING MODELS OF FAMILY SUPPORT

Objectives

- To identify and describe a variety of family supports
- To analyze the amount of control each support offers families
- To identify issues in the delivery of support

Instructions

Discuss as a class the following types of "state-of-the-art" family support, giving examples of programs and reports of your own experience. Consider the following questions and others you may think of:

- What families would find this support most useful?
- How much control is in the hands of the family with this support?
- What are the problems that might arise in offering this support?

Support groups--

Who should lead--parents or professionals?

What kind of support? Stress management? Talking about emotions? Informational? Celebration? Other?

One-to-one support

Parent to parent (peer support, mentoring)
Professional to parent
Counseling

Service coordination (more later this lesson)

Families as case managers or service coordinators
for themselves
for other families

The gift of time

Respite

Financing
Finding workers
Training workers
Respite barterers

Generic child-care and the child with a disability
After-school programs
Extended school-year programs

Adult programs
Day programs
Supported employment
Site-based
Community-based

In-home support
Plans for children living at home
Short-term therapeutic in-home support
Live-in workers
Workers coming into the home

Financial assistance

Flexible funding
Cash Subsidies
Vouchers
Reimbursements
Loan Funds
Lines of credit

SMALL GROUP DISCUSSION: THE EVOLVING ROLE OF THE FAMILY SUPPORT FACILITATOR

Objectives

- To raise awareness of subtle distinctions between job descriptions and expectations for different professional titles
- To examine underlying assumptions for the different terminology

Instructions

Families may encounter professionals with different titles, different perceptions of the nature of their role, and different helping styles.

In small groups, try your hand at defining the different titles, showing the philosophical differences between them in your definitions. How would the job descriptions for these positions differ? (If you have different terms evolving in your state, substitute the appropriate words).

case manager

service coordinator

service broker

support facilitator

Share your definitions with the larger group, and discuss any differences in your group's perceptions of the roles.

EXERCISE: HELPING STYLES

Objectives

- To identify and raise awareness of different styles of helping, and their underlying assumptions, beliefs and practices

Instructions

A recent study (Dunst et al., 1993), identified 5 different styles of helping, based on the following defining characteristics of beliefs and practices of case managers:

- 1) Adherence to family support principles;
- 2) Enabling and empowering philosophy, including
 - a) treating families as capable, and able to become more competent;
 - b) positive and proactive in the way they talked about and interacted with families;
 - c) using strengths-based rather than deficit-oriented approaches;
 - d) creating opportunities for families to participate in family-centered interventions";
- 3) Resource-based approaches to intervention
 - a) using existing resources flexibly instead of existing services rigidly to meet the needs of families
 - b) using informal as well as formal supports
 - c) responding rather than prescribing;
- 4) Consumer-driven approaches to intervention as opposed to professional-centered or paternalistic approaches
- 5) Family-centered intervention practices
 - going beyond saying to doing--practicing what they preach

The five styles that emerged were:

Helping Style A: all the above, and applying the philosophy equally to all the different families;

Helping Style B: most of the above, with the exception of using professional and service-based solutions;

Helping Style C: belief-system mostly deficit-oriented; professional perspective; service-based solutions; emphasizing correcting dysfunction; sees some families as capable but others as not;

Helping Style D: moderate to strong agreement with family support principles, but lack of behavioral adherence to the principles--saying but not doing; expecting gratitude from families; paternalistic; no shared responsibility or collaboration;

Helping Style E: belief system inconsistent with family support principles; strong paternalistic viewpoint; deficit-oriented with belief that families generally incompetent; professional-driven and service-based approaches; imposing values on families; lack of consumer-driven and needs-based practices.

Granted that there is overlap between the styles, that the differences may be a matter of degree, and that these quotes are taken out of context, try to match the following real quotes, taken from the study, to the helping styles. Page references refer to the article. Discuss differences of opinion.

1. "The parent knows where to come if she has a problem. The mother knows we have all the answers."(p. 171)_____
2. "The mother decided if she wanted the nutritionist to continue to make home visits. She decided it wasn't very helpful, so we discontinued this service."(p. 167)_____
3. "We have an honest and up-front relationship. We both feel we have a good partnership. After the family decides what they need, we sit down together and come up with a plan to access the needed resources."(p. 166)_____
4. "We allow the child to remain in the care of the parents. We know that if we didn't provide them our services, the parents couldn't take care of the child."(p. 170)_____
5. "We put (the person with a disability) in a job coaching program (because) he needs to learn to work independently some day."(p. 171)_____
6. "It's a friendly relationship, but there is not much exchange of information."(p. 170)_____
7. "The family has total control over whether their daughter participates in our program."(p. 168)_____
8. "If my beliefs run counter to those of the family, I don't bother trying to change their mind because it's not worth the time and effort."(p. 169)_____
9. "The mother knows much better what her daughter's needs are and decides what services she gets from our program and when we provide the services."(p. 167)_____
10. "The family knows it has a lot of control and choices about what we do and when we do it. We also build on family strengths. During our interventions, we always try to build on the things families already do well."(p. 166)_____
11. "I let the (caregiver) pick out clothes to buy for (the person with a disability)."(p. 171)_____

12. "We encourage use of the same physicians and dentists, and encourage the use of the same playgrounds and restaurants, as other people in the community."(p. 166)_____

13. "Our staff decides what services the family needs. We explain to the family what our plans are."(p. 169)_____

14. "We tell the parents once a year what we are doing with their son."(p. 171)_____

15. "We never push our beliefs on the family. We respect their decisions and maintain confidentiality about what the family shares with us."(p. 166)_____

If time remains, come up with statements from your own experience to add to the list above, and to classify for helping style.

SMALL GROUP EXERCISE: CONTRIBUTIONS OF THE FAMILY TO THE TEAM

Objectives

- To raise awareness of importance of family contributions to the team

Instructions

Working in small groups, brainstorm the contributions and special expertise the family can bring to the team. In the large group, share and combine lists, giving specific examples from your experience to illustrate the contributions, especially where the information significantly changed the picture the team had of an individual or situation.

READINGS

Agosta, J. & Melda, K. (1995b). Supplemental security income for children with disabilities. Salem, OR: Human Services Research Institute.

Bergman, A. & Singer, G. H. S. (1996). The thinking behind new public policy. In Singer, G. H. S., Powers, L. & Olsen, A. Redefining Family Support. Baltimore: Brookes, pp. 435-463.

Dunst, C. & Trivette, C. (1994) What is effective helping? In Dunst, Trivette & Deal, (Eds.). Supporting and strengthening families. Cambridge, MA: Brookline Books, pp. 162-170.

Turnbull, A.P., Blue-Banning, M., Turbiville, V., & Park, J. (1999). From parent education to partnership education: A call for a transformed focus. Topics in early childhood special education 19:3.

HOMEWORK

Objectives

- To identify different methods of assuring accountability for funding
- To consider arguments for or against the different methods identified

Instructions

Imagine that you have been asked to share your ideas with the Secretary of your state's Agency of Human Services, on accountability in proposed financial assistance programs for families with members with disabilities. What do you think about it? Should there be prior approval on expenditures? Vouchers? Receipts? Make an argument for whatever position you take.

Module IV
Identifying and Coordinating Resources

Class 10 in the Certificate Program
Working in Teams
Promoting Interagency Collaboration
Identifying Regional Resources

LARGE GROUP BRAINSTORMING: THE CHALLENGES OF SELF-DETERMINATION IN THE TEAM CONTEXT

Objectives

- To raise awareness of ways in which team process can inhibit self-determination
- To suggest strategies to minimize this inhibition and promote self-determination while taking advantage of the strengths of team process

Instructions

As a large group, identify the challenges involved for a family and/or an individual attempting to exercise self-determination within a team context. Suggest strategies for overcoming those challenges and maximizing the "voice" of the family and/or individual in team decision-making.

SMALL GROUP EXERCISE: INTERAGENCY COLLABORATION

Objectives

- To build empathy for the roles and restrictions of representatives of different agencies in interagency teams
- To practice interagency collaboration around support for a family

Instructions

- 1) Form groups of five to seven participants representing as many different agencies or organizations in each group as possible.
- 2) Very quickly, create a hypothetical/real family who could be using the services of all your agencies.
- 3) Into this scenario inject the problem of the primary caregiver being hospitalized for three weeks. You are collectively trying to minimize the impact of this on family functioning.
- 4) Share with one another your real job title and agency affiliation. Then pass your job position and role to the person on your right in the group. That person must then "walk in your shoes." Speaking from the perspective of your new role, spend five minutes brainstorming how you each will collaborate in addressing the family's situation.
- 5) At the end of the discussion, share
 - a) How it felt to be in their role and
 - b) How it felt to listen to someone else represent your role.

LARGE GROUP DISCUSSION: ISSUES IN INTERAGENCY COLLABORATION

Objectives

- To identify issues and barriers to interagency collaboration not related to funding
- To consider strategies to overcome these barriers
- To build understanding, empathy and collaboration between representatives of various agencies

Instructions

As a large group, identify the primary issues, problems or barriers you have encountered in your experience in interagency collaboration. Target one or two (not related to budgeting) for discussion on how these were overcome or suggestions for how to overcome them.

SMALL GROUP EXERCISE: ISSUES OF BUDGETING AND PRIORITIES IN BLOCK GRANTS

Objectives

- To identify issues in group decision-making involving turf and money
- To identify procedures for making group financial decisions

Instructions

In small groups representing as many programs and agencies as possible, consider how you would proceed if you just found out that your budgets were all lumped into one block grant and cut by 5%. If you were the interagency steering committee responsible for developing procedures for setting budgets and priorities, how would you proceed? Come up with an action plan to get beyond what your programs now consider to be an “untenable situation.” Share your plans with the class. Or...

Consider a situation in which your programs and agencies must respond collaboratively for a large grant application for family support. How would you decide to divide the benefits and responsibilities?

Do you have a regional planning group in your area to help with coordination of supports and prevention activities? Who is on it? Who are the contact people? How representative is it of families who could be served?

LARGE GROUP EXERCISE: IDENTIFYING REGIONAL RESOURCES FOR FAMILIES

Objectives

- To identify and share information about regional resources
- To identify gaps in information and seek to fill those gaps
- To produce a regional resource guide
- To annotate an existing resource guide

Instructions

For each question or situation listed below, give the appropriate resource or reference, including contact person and telephone number, where possible. Work together to identify as many resources as possible in the remaining class time. In each situation, consider the information you collectively gather, asking the following questions as you go:

- * Do families have a choice of where to get help in your region?
- * Is there more than one source of help?
- * Is the resource a generic or specialized resource?
- * Are there ways to accommodate cultural or individual preferences?
- * Is this support resource-based or service-based? (Resource-based--funding is available to support what the individual or family identifies as necessary; service-based--services are available if the needs fit what is offered.)
- * What are the reasons for the nature of the supports in your area?
 - Underlying assumptions and attitudes?
 - Limitations on funding?
 - Scarcity of personnel?
 - Issues of training?
 - Issues of leadership?
 - Other reasons?
- * If interagency teams were to be built around the needs of each family in the exercise above, which agencies would be represented?
- * What is the role of the family in determining who would be on the team?
- * Could a family change the composition of the team? "Fire" someone?
- * Would this make a difference in the family's ability to get the necessary supports?

Situations

1) A family with a teen-aged son covered by Medicaid under SSI, has to travel long distances for medical care. They have heard that medically related transportation expenses might be covered under Medicaid. Find out if this is true, and the appropriate process they need to go through in your area of the state.

2) The father of this family was in a motorcycle accident 2 years ago, and experienced traumatic brain injury. He is being cared for at home by his wife and

teenaged daughter. Can they get respite? Is it available in your area? In-home or out? Trained or untrained workers? How do they get it?

3) A family has a 4-year old son with emotional and behavioral challenges. They want information about both respite services and play therapy. Can you connect them?

4) A mother is separated from her husband, and is trying desperately to please her husband so they can get back together. At the moment, he is not providing any child support payments and the family is under the poverty level. She needs to get as many services for her children and herself as possible, but doesn't want to give the state information they would need to collect child support, because it might make her husband angrier. What can she get? Where and how can she get it?

5) A family with a 9-year old daughter who can only walk short distances without tiring, wants to buy a big umbrella stroller, but they can only afford \$100. Help them find out the supplier, the cost, and potential sources of help with funding.

6) The mother in a family has died, leaving the father and his 13-year old son, who has limited communication skills. The father would like some grief counseling for his son. Is there anyone willing or able to provide such counseling in your area?

7) The same father needs to arrange after-school activities for his son. The son will need a support person, but the father wants his son to be doing something with his own peers, if possible. What resources are there for the support person? What activities are available?

8) A family which recently immigrated from Vietnam has a premature baby in the neonatal intensive care unit. Who is available to support them? Who can help with language and cultural communication?

9) A young woman with autism in her late 20's needs a gynecological exam, but is extremely anxious and fearful. Her family needs to find someone to help her become more comfortable with the process. Is there anyone around who can help?

10) A family has a son who is in his last year of high school. They have recently learned about Facilitated Communication, and would like the opportunity for their son to try it. Who should they contact? How will this carry over into his life after graduation?

Please list any other resources you consider important in your region.

READINGS

Anderson, B. & Hogan, C. (1994). Education -- Human Services View: A Continuum of Systemic Change. Oxford, OH: Danforth Foundation.

Gardner, S. L. (1993). The ethics of collaboration. Georgia Academy Journal, Summer, 220-222.

HOMEWORK

Finish collecting the information above on Post-Its or 3x5 cards. We will finish discussing the questions about the nature of the services at the beginning of the next class.

**Module IV
Implementing and Coordinating Resources**

**Class 11 in the Certificate Program
Information Systems and Interagency Collaboration
Person-centered futures planning and the family**

SMALL GROUP DISCUSSION: INFORMATION SYSTEMS

Objectives

- To identify positive contributions of information management in human services
- To strategize how to protect privacy and confidentiality within information management systems
- To address issues and identify best practices in informed consent in information sharing

Instructions

Computerized information storage and retrieval systems have been around for three decades now. As early as 1964, programmers were designing systems that could "draw inferences," making connections among separate pieces of information.

In small groups, discuss and record your ideas on the following:

- 1) What are the potential positive outcomes of a centralized computer file connecting all human service agencies and providers?
- 2) How do you balance the benefits of efficient service coordination and the right to privacy?
- 3) Accepting the fact that these systems are here to stay, what protections would you try to "design in" to a system to ensure the rights of families and individuals?
- 4) What guidelines would you set forth for maintaining confidentiality for families?
- 5) What would you put on a consent form for families for sharing information?
- 6) Do you have any other recommendations for states as they struggle with this process of designing an information system for provision of human services?

Share your ideas with the rest of the class.

LARGE GROUP DISCUSSION: PERSON-CENTERED FUTURES PLANNING (MAPS) AND FAMILY PARTICIPATION IN PLANNING

Objectives

- To learn and practice facilitating a model of person-centered planning
- To practice graphic recording, especially for participants with difficulty reading
- To clarify family and individual roles in person-centered planning

Instructions

Choose a facilitator, recorder and timekeeper for the first of the 5 steps in the MAPS process.

The facilitator will lead the class in the process of real person-centered futures planning for the class member who volunteered last week. Usually, this process takes considerably longer than an hour, but take a minute to plan, as a class, how much time to devote to each section in order to finish, this time, within an hour. The timekeeper will be important to keep us moving.

For each new step in the process, quickly choose new facilitators, recorders and timekeepers, to give everyone in the class some experience.

Recorders should attempt to represent the ideas in pictures, wherever possible. The idea is to make the MAP as accessible to the person as possible, regardless of level of literacy.

Remember to keep the information positive and strengths-based, unless you are doing the section on fears.

At the end of the hour, discuss the process, considering some of the following questions:

- * What did it feel like to have a MAP done for you?
- * What parts were most comfortable? Most uncomfortable?
- * How could the process be improved?
- * How did it feel from the perspective of the other people involved? (If anyone has experienced the process in other situations, what was it like?)
 - As a parent?
 - As a brother or sister?
 - As a friend?
 - As a teacher?
 - As a service coordinator?
 - As a facilitator of the MAP?
- * What is the role of the family in the MAP for a person living at home?
- * Whose MAP is it--the individual's or the family's? Explore arguments on both sides of this question.

* Besides planning for a person with disabilities, how else could the MAP process be used?

If you would like more information and an example of conducting this process, a video developed to complement the reading material is available from the UAP of Vermont..

READINGS

Falvey, M. A., Forest, M., Pearpoint, J., & Rosenberg, R. L. (1994). Building Connections. In Thousand, J. S., Villa, R. A., & Nevin, A. I.. Creativity and Collaborative Learning. Baltimore: Brookes Publishing Co., 347-368.

HOMEWORK

If the small groups did not have time to finish thinking through the process of protecting confidentiality in an information system, then give your ideas individually.

Module V
Working Together with Families

Class 12 in the Certificate Program
Conflict Resolution

A question arises here. Which should come first--creative problem-solving or conflict resolution? We have decided to explore conflict resolution first, as a short term solution, and end the module with creative problem-solving, which we find more useful in the long term.

SELF-ASSESSMENT AND DISCUSSION: WHAT'S YOUR STYLE?

Objectives

- To identify your own personal style of handling conflict
- To locate your personal style in a model based on assertiveness and cooperation
- To consider the appropriateness or inappropriateness of each style in a situational framework

Instructions

Consider situations in which you find your wishes differing from those of another person. How do you usually respond to such situations? Come up with one or two examples to describe to the class, sharing your scenarios. List a number of these situations on the flipchart.

Using the Thomas-Kilmann Conflict Mode Instrument (1974), or How I act in conflicts?, from Johnson, D. W. (1990). Reaching out: interpersonal effectiveness and self-actualization (4th ed.) Englewood Cliffs, NJ: Prentice-Hall, Inc., 222-228, explore your natural style for handling those difficult situations you wish wouldn't come up!

Discussion:

Total up your scores, and see where you fall on the dimensions of cooperation and assertiveness. Is your natural style competing, collaborating, compromising, avoiding, or accommodating?

Many people believe that they have one style out in the working world, and a different style in their personal relationships. Why would that be? Can anyone share examples? On the other hand, your style may actually be more consistent than you may think.

- Why is it important to know your individual style?
- How would it help if you knew the natural style of the other people you work with?
- How would it help if you knew the natural style of the people with whom you are in conflict?

When you know your own style, you can also find out when it may be most effective, and when it is likely to get you in trouble. Read and discuss the uses and warnings about the different styles, and consider how this would apply in your work situation.

LARGE GROUP EXERCISE: WHICH STYLE WOULD WORK BEST HERE?

Objective

- To analyze situations to determine the most appropriate style for successful resolution

Instructions

1. Taking the real conflict situations you described at the beginning of the class, consider which conflict resolution style would work best to resolve the situation. Was it the one you used? How do you think a different style would have changed the situation?

2. Consider the following situations and decide what style would help you resolve the situation best:

a. A mother whose adult son is moving into his own apartment arrives and starts to put up pink ruffled curtains on all the windows. You ask the son what he wants and he won't answer. He just seems to want to avoid the whole situation. What do you want to accomplish? Is there any common ground you can find? What style might help you most here?

b. The respite budget is almost empty, and there are three months to go. You are meeting with the families to tell them they can't use any more respite. What do you want to accomplish? Is there any common ground you can find? What style might help you most here?

c. The local day program for elders has told you they can't accommodate the woman with Alzheimer's Disease you are trying to get into their program. The family has chosen this as the most appropriate activity; plus, they desperately need to have their grandmother busy and happy during at least part of the day. You support them. What do you want to accomplish? Is there any common ground you can find? What style might help you most here?

d. A family lives seventeen miles from town. They need daily after-school attendant care for their teenage daughter. The respite worker wants to start charging time from the moment he leaves town to the moment he arrives back home. The family doesn't want to spend their respite money on travel time, and says they are willing to have respite pay only from the time their daughter is picked up until they arrive home in the evening. You are trying to resolve the situation with both the family and the respite worker. What do you want to accomplish? Is there any common ground you can find? What style will help you most? Try taking all three perspectives--your own, the family's, and the worker's. What styles would help each here?

e. You are the parent of a little girl who is in kindergarten. She loves her hat and mittens, and insists on wearing them home from school, even though spring is arriving. The kindergarten teacher says it is inappropriate, and doesn't want to allow her to wear them now that the warmer weather is here. You think it is a "tempest in a teapot" and that it really doesn't make all that much difference to give in to your daughter on this point, and you want the teacher to lay off. Is there any common ground you can find? What style would help you most here?

Generate additional examples, especially for styles that didn't fit the situations you have already discussed.

SMALL GROUP EXERCISE: COMING TO AGREEMENT (loosely based on Getting to Yes, and a workshop on Negotiation by Jolie Bains Pillsbury)

Objectives

- To differentiate between positions and interests
- To practice identifying underlying interests
- To generate criteria for judging successful solutions

Instructions

- In pairs, one at a time describe a conflict or disagreement you have recently experienced or are experiencing which needs resolution
- Helping one another with probing questions, first identify the positions of each party to the conflict--what each person is asking for or demanding
- Probing further, identify the interests driving each person in the situation
- Next, identify the underlying interest at the emotional level which may be affecting the response to the situation at the deepest level
- Finally, generate a list of criteria which would need to be met by any proposed solution that would satisfy the interests and underlying interests of both parties
- Repeat the process for the second person
- Process and share observations with the class

For example, a mental health agency disagreed with the parents of a young man who had been in a residential program out of state. Treatment at the residential program had been successful, and the position of the agency was that the young man should return home. Their interest was to serve him at lower cost. Their underlying interest was to be able to serve others who were in crisis. The position of the parents was that he should continue treatment where he was. Their interest was that he should continue to experience success, as it had been a long time since anything had "worked." Their underlying interest was to keep him from going into state's custody. They feared that if he returned home and his behavior deteriorated, they would lose their rights as his parents.

In order to reach an acceptable consensus, it became clear that the criteria would need to provide adequate supports to prevent the situation deteriorating. To satisfy the underlying interest of the agency, these supports would need to cost less than the residential program.

READING

Johnson, D. W. (1990). Reaching out: interpersonal effectiveness and self-actualization (4th ed.) Englewood Cliffs, NJ: Prentice-Hall, Inc., 222-228.

ADDITIONAL RECOMMENDED READINGS

Fisher, R., Ury, W., and Patton, B. (1991). Getting to yes: negotiating agreement without giving in, 2nd ed. New York: Penguin.

Ury, W. (1993). Getting past no: negotiating your way from confrontation to cooperation, Revised edition. New York: Bantam Books.

ADDITIONAL MATERIALS: Thomas-Kilmann Conflict Mode Inventory

MODULE V
Working Together with Families

Class 13 in the Certificate Program
Creative Problem Solving

LARGE GROUP DISCUSSION: EXPLORING MODELS OF PROBLEM-SOLVING

Objectives

- To raise awareness of the process of problem-solving from past experience of participants
- To identify problems that can arise during problem-solving

Instructions

As a class, identify the steps you usually go through in solving a problem. Are there any particular models that people in the group have used? Was there anything about those models that made them unique or particularly successful? What are the problems that can arise during problem-solving?

LARGE GROUP EXERCISE: CONVERGENT AND DIVERGENT THINKING

Objectives

- To define and differentiate convergent and divergent thinking
- To identify the purpose of each type of thinking
- To apply this knowledge selecting the appropriate type to fit the situation

Instructions

Discuss: What is the difference between these two terms? What are some examples of the two? When would each process be more useful?

In the following situations, identify which kind of thinking process would serve the purpose best:

1. A teacher has carried out a day-long observation of a student in school, and has written a narrative description of what she has seen. The team is deciding what behavior to "target" to work on.
2. A family wants to get their child a computer to work on at home, but they don't have enough money available.
3. A teenager who has a strong fear of failure refuses to do any school work. The team is trying to figure out how to motivate him.
4. A family needs respite. A computerized information file has told them that 6 different respite programs exist in their area of the state.
5. A physician has observed a number of symptoms in a child's physical condition and is trying to diagnose the problem.

6. A family has just become eligible for a flexible-funding program that allows them use of \$1200 a year for "whatever it takes."
7. A new mother of twins can't figure out how to get them to go to sleep so she can get some rest.
8. The same exhausted mother is trying to keep up her previous standards of housekeeping and cooking, and is getting progressively more depressed.
9. A young woman with autism needs a job she can do with the help of a support person.
10. Legislators need evidence of a program's cost-effectiveness.

SMALL GROUP DISCUSSION: OVERCOMING BARRIERS TO CREATIVITY IN PROBLEM-SOLVING

Objectives

- To identify barriers to creativity in problem-solving, especially in organizations
- To identify techniques to encourage creativity

Instructions

In small groups, brainstorm "what clips our wings" in problem-solving? Record on flipchart paper. Thinking back to specific situations where problem-solving was difficult, list influences that limit our creativity. Include things that people say that can stifle or shut down the flow of ideas. After the brainstorming process, compare your list with "Mental Blocks--Excuses for a closed mind," in the reading for today.

Now list techniques participants have found that encourage or free-up the process of creativity. Include things that a group leader can say to open up the process. Share your "Techniques" with the whole class.

LARGE GROUP DISCUSSION: THE CREATIVE PROBLEM SOLVING PROCESS

Objective

- To create familiarity and experience with an extended model of problem-solving

Instructions

Review the steps in the Osborn-Parnes Creative Problem-Solving Process (Parnes, 1988), using the handout with the diamonds (Isakson & Treffinger, 1984). How is this process different from the other models of problem solving described at the beginning of class?

Recognizing that a process with this many steps will take more time, how would you decide when to use it? How would you encourage the commitment of time necessary for this process?

LARGE GROUP DISCUSSION: PRACTICE WITH THE PROCESS

Objective

- To increase familiarity and comfort with the extended process of creative problem-solving

Instructions

Choose a facilitator and a recorder. From the real experience of the class, possibly from their Conflict Resolution situations, identify a "mess" to work on, using the "Key Questions: Mess Finding." Continuing to use the materials as prompts and guides, carry out the entire creative problem-solving process.

Which parts felt most useful? Did anything feel like "overkill?" If you were tempted to skip steps, what would have been lost out of the process?

If possible, choose a very different mess and repeat as much of the process as time allows.

READING

Cloninger, C. (1991). Problem Solving Processes, Strategies, Ideas, and Resources. Burlington, VT: The UAP of Vermont.

Module VI Evaluating Family Support

Class 14 in the Certificate Program Concepts of Quality Assurance Measuring Outcomes

PAIRED EXERCISE: WHAT ARE WE LOOKING FOR IN AN EVALUATION OF FAMILY SUPPORT?

Objectives

- To identify the different constituencies interested in evaluation of family support
- To identify the type of information relevant for each constituency

Instructions

According to John Agosta of the Human Services Research Institute in a conversation in 1993, the answer depends on who is asking the questions and for what reasons. In an evaluation of a state's family support program, he described a situation in which he met with a diverse group of people, representing different interests. The psychologists wanted pre- and post- measures of depression, stress, and perception of the situation. The program administrators wanted cost-effectiveness measures in terms of out-of-home placements and more costly programs averted. Social workers wanted information on variations in reports of child abuse, and the divorce rate. Advocates wanted waiting lists and anticipated needs, as well as cost-effectiveness data that would catch the eyes of legislators. Families wanted a single question--"Did it help?"

Working in pairs, preferably of people working for the same program, identify all the "constituencies" that might have an interest in evaluating the program you represent. For each group, try to identify what they would be looking for in an evaluation, and what possible use they would make of the information. Share your information with the larger group.

PAIRED EXERCISE: DIMENSIONS OF SERVICE QUALITY

Objectives

- To identify the different methods used in participants' work to measure service quality
- To identify under- or over-utilized methods in participants' work

Instructions

Val Bradley (1990) has described four dimensions of service quality. Loosely quoted here, they are:

* Inputs--or "structural" measurements of the service system; the capacity that the provider brings to bear on the delivery of services. They include the physical facility, the nature and competency of the staff, and the regulatory framework in which the service is delivered, including emphasis on staffing ratios, staffing standards, etcetera.

* Process--reflects the interaction between the person receiving services and the organization providing the service; the "practices" of that organization. In many situations, this has deteriorated to just paperwork compliance.

* Outputs--synonymous with "product;" includes such things as numbers of clients served or the units of service delivered. This information often substitutes for true program results.

* Outcomes--a measurement of the effect or impact that the intervention actually has on the person receiving services. Outcomes reflect on the goals of the service and reveal whether the promise made to the person and his or her family has been kept. Problems can exist in establishing causality between a particular intervention and a specific result. (p. 9).

Working again in pairs or small groups, preferably representing the same or similar programs, identify how your program measures, or could measure the different dimensions of service quality. Does your program stress one of the dimensions over the others? Make sure, in this period of time when "outcomes" is the buzzword, that you pay enough attention to "process." Share your discussion results with the larger group.

SMALL GROUP EXERCISE: MAKING FAMILY-GENERATED OUTCOMES MEASURABLE

Objectives

- To reconsider human services' dependence on outcomes generated by professionals rather than recipients
- To identify creative ways to measure the outcomes considered important by the people served by the programs

Instructions

In human services and education today, there is increasing emphasis on measurable outcomes for programs. In small groups, consider the following broad list brainstormed by the Advisory Council for this training grant, of outcomes desired for family support services in Vermont (as a result of training from the grant). Obviously, this list is too long to use in its entirety. Your task is to narrow the list without losing too much of what the council considered important. In your process, consider the following: using the definitions of dimensions of quality given above, are these all "outcomes?" Break the list into four groups:

- * outcomes measurable by record or document review
- * outcomes measurable by surveys
- * outcomes measurable by interviews with families and service providers
- * outcomes that are unmeasurable

How do these outcomes differ from those written by people in professional positions? Could professionals ever become comfortable with

outcomes written like this, or do families need to shape their ideas into "more acceptable" form?

Share your edited lists and discussion points with the class.

Desired Outcomes of Advisory Council for Impact of Family Support, Self-Determination and Disability Training

- 1) Families are involved in design of services.
- 2) Families are involved in quality assurance of services.
- 3) Families are recognized as resources.
- 4) All families are recognized as competent.
- 5) Families are viewed as a whole, not as pieces or individuals.
- 6) Families are treated with respect.
- 7) Families are not judged.
- 8) Resources go to the families, not to the service providers.
- 9) Families are honored and celebrated.
- 10) Families receive action from service providers, not just empathy.
- 11) Service providers, along with families, keep things organized.
- 12) Empowered family members empower other family members.
- 13) Brothers and sisters receive support and opportunities to express their feelings.
- 14) The commonality of all families is recognized.
- 15) The privacy of families is respected.
- 16) The importance of emotional support is recognized.
- 17) Families have their choice of services.
- 18) Families are supported to hope.
- 19) Quality of life issues are balanced with safety/risk issues.
- 20) Differences in families are accepted.
- 21) Families are listened to.
- 22) Service providers advocate for families.
- 23) Families can refuse services.
- 24) Families are comfortable to speak up.
- 25) Families and service providers are informed about all available services.
- 26) Honesty and sharing guide communication with families.
- 27) Humor is encouraged as a coping strategy.
- 28) Fathers receive support and opportunities to express their feelings.
- 29) Families' schedules are respected.
- 30) Families' agendas are respected.
- 31) Families' ideas are respected.
- 32) Families' decisions are accepted.
- 33) Agencies collaborate with each other and families.
- 34) Emergency interventions with families take place in natural settings where the need occurs.
- 35) Suitable service options are developed where the need exists.
- 36) Respite is available for family members, not just for parents.
- 37) Services are not bound by medical models.
- 38) Peer support is available and encouraged for families.
- 39) Policies for family support encourage flexibility in eligibility and services.
- 40) Services support inclusionary models.
- 41) Financial assistance programs are implemented.
- 42) Family support is built on family, friends, and neighborhoods.

LARGE GROUP DISCUSSION: CHANGING MODELS OF SERVICE DELIVERY: MONOPOLIES, COMPETITION, AND MANAGED CARE

Objective

- To identify differences between quality assurance mechanisms in monopolies, free competition, and managed care models

Instructions

In large group discussion consider these questions:

- * What are some examples of the role of competition in assuring and improving quality in the business world.
- * What is the role of the customer in this process?
- * In monopolies, how has quality traditionally been insured?
- * What is the role of the customer in this process?
- * What is the role of other groups in insuring quality in monopolies?
- * Options and alternatives--what is their role in quality assurance in monopolies?
- * Is the notion of options and alternatives a contradiction in monopolies?
- * What would you see as the strengths and weaknesses of the three models: monopolies, competition, and managed care? List.

READINGS

Bradley, V. J. (1990). Conceptual issues in quality assurance. In Bradley, V. J. & Bersani, H. A. Quality assurance for individuals with developmental disabilities. Baltimore: Brookes, 3-15.

Advisory Council, New Approaches to Family Support Training Initiative Project, University Affiliated Program of Vermont. (1993). Outcomes for Impact of NAFS Training for Service Providers. Burlington, VT: University Affiliated Program of Vermont.

Center on Human Policy et al. (1996). A position statement on managed care and long-term supports. Syracuse, NY: Syracuse University.

Nerney, T. & Shumway, D. (1996). Beyond managed care. Concord, NH: Robert Wood Johnson Foundation.

Nerney, T. (1998). The poverty of human services. Concord, NH: Robert Wood Johnson Foundation.

Moseley, C. & Nerney, T. (2000). Emerging best practices in self-determination. AAMR News & Notes, Vol. 13, No. 6, pp. 1-5.

**Module VI
Evaluating Family Support**

**Class 15 in the Certificate Program
Complaint Analysis for Continuous Quality Improvement
Evaluation and Governance
Measuring It All: Instruments for Satisfaction, Cost Effectiveness,
Opportunity Cost, Empowerment, Self-Efficacy**

LARGE GROUP DISCUSSION: ASSURING QUALITY

Objective

- To identify and explore issues in peer monitoring

Instructions

In the reading for this module, three components of Quality Assurance are identified: setting standards, monitoring, and response mechanisms. Monitoring raises several questions. In large group, discuss:

- * Who should monitor programs? For individuals? For family support?
- * What issues are involved in having families monitor programs for individuals?
- * What issues are involved in having families monitor programs for families?
- * What issues are involved in having individuals monitor programs for each other?
- * What issues are involved in having citizens or community members monitor programs for individuals or families?
- * How independent should monitoring be from "the system?"
- * Who should choose the monitors?
- * Who should train the monitors?
- * What is the role of "boards of directors" in monitoring?
- * Are there other issues we haven't considered?

SMALL GROUP DISCUSSION: INVOLVING FAMILIES AND INDIVIDUALS IN MONITORING PROGRAMS; EVALUATION AND EMPOWERMENT

Objectives

- To expand options for families in monitoring program quality

Instructions

In small groups, brainstorm as many ways as you can to involve families and individuals in monitoring quality in programs. Let loose and be creative! Don't let the "issues" discussed above get in the way of the volume of creative ideas here.

Report back to the large group. Consider the question: How does involvement in evaluation lead to empowerment?

LARGE GROUP DISCUSSION: GETTING TO THE "ASSURANCE" PART OF QUALITY ASSURANCE: RESPONSE MECHANISMS

Objective

- To identify response mechanisms necessary to complete the process of quality assurance

Instructions

As a large group, discuss:

- * Once satisfaction surveys are in, monitoring visits are done and reports written, what happens to the information?
- * Who receives the reports?
- * What happens next?
- * If recommendations have been made, who carries them out?
- * How do "we" know they were carried out?
- * What "teeth" exist in the process of quality assurance?

SMALL GROUP DISCUSSION: COMPLAINT ANALYSIS FOR CONTINUOUS QUALITY IMPROVEMENT

Objectives

- To identify the role of complaints in quality improvement
- To identify procedures for complaint analysis

Instructions

Divide into small groups, preferably of people who work together. Describe what happens to complaints that come in to your program? Where are they recorded? What happens to them after they are "handled?"

In a business seminar on customer relations, a presenter once said, "If you hired a management consultant to come in and tell you where you needed to improve, you would gladly pay hundreds of dollars in fees for the information. Your customers give you the same information, for free." The difference is, a good consultant would organize the information for your use. How can you

organize complaint information about your program to make it as useful as possible for quality improvement?

LARGE GROUP DISCUSSION: OPPORTUNITY COSTS (Agosta, J. & Melda, K., 1995b)

Time limit 15 minutes

Objectives

- To define the concept of opportunity costs
- To identify the range of opportunity costs for families
- To explore ways to balance opportunity costs in family support policy

Instructions

When "systems" measure the cost effectiveness of family support programs, they usually look at such things as the savings involved in keeping individuals living at home with their families instead of in more expensive out-of-home placements. They look at program efficiency. They may recognize the difference in cost between prevention and crisis response. But there is another "systemic" as well as personal cost for families caring for members with special needs at home. There are choices that families make in accepting that responsibility.

- What do you think are the "opportunities" that families forego in caring for their member at home?
- Which opportunity costs affect the families?
- Which affect society as a whole?
- Do mothers and fathers experience different opportunity costs?
- How could changes in family support policy balance the opportunity costs experienced by families?

SMALL GROUP DISCUSSION: MEASURING IT ALL

Objective

- To gain familiarity with instruments for evaluating family support

Instructions

In small groups, choose among the sample of instruments currently in use in measuring the effect of family support programs in different states (*Readings*). Try them out, and discuss their potential usefulness in evaluating your own programs.

EVALUATING THIS PROGRAM

Please take a few minutes to give us feedback on this course and our teaching. People auditing need only complete the course form.

READINGS

Cochran, M. Parent empowerment: Developing a conceptual framework, Family Science Review, Vol. 5, No. 1 & 2, Feb. & May 1992, pp. 3-21.

Koren, P. & DeChillo, N. (1993). Measuring Empowerment in Families Whose Children Have Emotional Disabilities. Portland, Oregon: Research & Training Center on Family Support and Children's Mental Health, Portland State University.

ADDITIONAL MATERIALS

Course evaluation form, University or other program evaluation forms.

SOME THOUGHTS ON THIS COURSE...

1. Looking back over the different lessons, which class(es) do you consider the most important for yourself? Why?
2. Which class(es) were least important to you? Why?
3. Were there any exercises you particularly liked? Why?
4. Were there any exercises you particularly disliked? Why?
5. Do you intend to use any of the materials for your work? Which ones?
6. Are there any areas that need to be included or given more emphasis? Which?
7. Are there any areas that need to be deleted or given less emphasis? Which?

8. Would you recommend this course for others? Who do you think would benefit most from it?

9. Any other ideas?

Thank you!

References

- Abidin, R. R. (1990). Parenting Stress Index--Manual, 3rd Ed., Charlottesville, VA: Pediatric Psychology Press.
- Able-Boone, H. (1996). Ethics and early intervention: Toward more relationship-focused interventions. Inf. Young Children, 9(2), Aspen Publishers, Inc., 13-21.
- Advisory Council, New Approaches to Family Support Training Initiative Project, University Affiliated Program of Vermont. (1993). Outcomes for impact of NAFS training for service providers. Burlington, VT: University Affiliated Program of Vermont.
- Agosta, J. (1992). Evaluating Family Support Services: Two Quantitative Case Studies. In Bradley, V. J., Knoll, J. A. and Agosta, J. M. (Eds). Emerging Issues in Family Support. Washington, D.C.: AAMR Monographs, 18, AAMR, pp. 99-150.
- Agosta, J. (1999). Family needs: Summary results from ten years of research. Family Support Policy Brief #2. Salem, Oregon: National Center for Family Support @ HSRI.
- Agosta, J., Bradley, V. J. and Knoll, J. A. (1992). Toward Positive Family Policy: Components of a Comprehensive Family Support System. Cambridge, MA: Human Services Research Institute.
- Agosta, J., Karp, N., Melda, K., Faison, K., Smith, F. (1993). Quality Indicators for Family Support. Cambridge, MA: Human Services Research Institute.
- Agosta, J. & Melda, K. (1995). Results of a national survey of family support programs. Salem, OR: Human Services Research Institute.
- Agosta, J. & Melda, K. (1995b). Supplemental Security Income for Children with Disabilities: An Exploration of Child and Family Needs and the Relative Merits of the Cash Benefit Program. Washington, DC: The Joseph P. Kennedy Foundation.
- Alabama Family Support Program: Survey of Program Participants questionnaire. Cambridge, MA: Human Services Research Institute.
- Althen, G. (1988). American ways: A guide for foreigners in the United States. Yarmouth, ME: Intercultural Press, in Lynch, E. W. & Hanson, M. J. (1992). Developing cross-cultural competence, Baltimore: Brookes, p. 38.
- Anderson, B. & Hogan, C. (1994) Education--human services view: a continuum of systemic change. Oxford, OH: Danforth Foundation.
- Arnold, M. B. (Ed.) (1970). Feelings and emotions. New York: Academic Press.

- Association for Cerebral Palsy, Vt. Developmental Disabilities Council. (1992). Choosing words with dignity. Waterbury, VT: author.
- Attneave, C. (1982). American Indians and Alaska Native Families: Emigrants in their own Homeland. In M. McGoldrick, J. K. Pearce, & J. Giordano (Eds.), Ethnicity and Family Therapy (pp. 55-83). New York: The Guilford Press.
- Baker, B. L. (1989). Parent Training and Developmental Disabilities. Washington, D.C., AAMR Monographs, 13, AAMR.
- Bandura, A. (1986). Social foundations of thought and action: A social cognitive theory. Englewood Cliffs, N.J.: Prentice Hall.
- Banks, J. A. (1991). Teaching Strategies for Ethnic Studies, 5th Edition. Boston: Allyn and Bacon.
- Beck, A. T. (1972). Depression: Causes and Treatment. Philadelphia: University of Pennsylvania Press.
- Berard, G. (1993). Hearing equals behavior. New Canaan, CT: Keats Publishing.
- Bergman, A. & Singer, G. H. S. (1996). The thinking behind new public policy. In Singer, G. H. S., Powers, L. & Olsen, A. Redefining Family Support. Baltimore: Brookes, 435-463.
- Biklen, D. & Cardinal, D. (Eds.). (in press). Presuming Competence: Empirical Investigations of Facilitated Communication. New York: Teachers College Press.
- Blaney, B. (1992). Accomplishing Family Empowerment. Cambridge, MA: Human Services Research Institute.
- Borthwick-Duffy, S. A., Widaman, K. F., Little, T. D., & Eyman, R. K. (1992). Foster Family Care for Persons with Mental Retardation. Washington, DC: AAMR.
- Braddock, D., Hemp, R., Fujiura, G., Bachelder, L. & Mitchell, D. (1990). The State of the States in Developmental Disabilities. Baltimore: Paul H. Brookes Publishing Co.
- Bradley, V. J. (1992). Overview of the Family Support Movement. In Bradley, V. J., Knoll, J. A. and Agosta, J. M. (Eds). Emerging Issues in Family Support. Washington, D.C.: AAMR Monographs, 18, AAMR, pp. 1-8.
- Bradley, V.J., Ashbaugh, J. W., & Blaney, B.C. (1994). Creating Individual Supports for People with Developmental Disabilities. Baltimore: Brookes.
- Bradley, V. J. & Bersani, H. A. (1990). Quality Assurance for Individuals with Developmental Disabilities: It's Everybody's Business. Baltimore: Brookes, pp. 3-16.
- Bradley, V. J., Knoll, J. A. and Agosta, J. M. (Eds). (1992). Emerging Issues in Family Support. Washington, D.C.: AAMR Monographs, 18, AAMR.

- Bradley, W. (1991). S. 972, Family Caregiver Support Act. Congressional Record, Vol. 137, No. 62--Part II, April 25, 1991.
- Bromley, B., & Blacher, J. (1989). Factors delaying out-of-home placement of children with severe handicaps. American Journal on Mental Retardation, 94, (3), 284-291.
- Brownlee, A. T. (1978). Community, Culture, and Care: A Cross-Cultural Guide for Health Workers. Saint Louis: The C. V. Mosby Company.
- Callanan, C.R. (1990). Since Owen: A Parent-to-Parent Guide for Care of the Disabled Child. Baltimore: Johns Hopkins.
- Carney, I. H. (1987). Working with families. In I. F. Orlove & D. Sobsey (Eds.), Educating children with multiple disabilities: A transdisciplinary approach (pp. 15-338). Baltimore: Paul H. Brookes Publishing.
- Center on Human Policy et al. (1996). A position statement on managed care and long-term supports. Syracuse, NY: Syracuse University.
- Center on Human Policy, Syracuse University. (2000). The Community Imperative: A statement against institutionalizing any person because of a disability. Syracuse: author.
- Christie, C. (1989). (Aha) CPS process. Syracuse, NY: Challenge Institute.
- Clayton, J. M., Glidden, L. M., & Kiphart, M. J. (1994). The Questionnaires on Resources and Stress: What Do They Measure? American Journal on Mental Retardation, 99, (3), 313-315.
- Cloninger, C. (1992). Problem-solving processes, strategies, ideas, and resources. Workshop materials assembled from various sources including Doris Shallcross, and Ned Herman.
- Cobb, S. (1974). A model for life events and their consequences. In Dohrenwend, B. S. & Dohrenwend, B. P. (Eds.). Stressful life events (pp. 151-156). New York: Wiley.
- Cochran, M. Parent empowerment: Developing a conceptual framework, Family Science Review, Vol. 5, No. 1 & 2, Feb. & May 1992, pp. 3-21.
- Crossley, R., & McDonald, A. (1984). Annie's coming out. Middlesex, England: Penguin.
- Crnic, K., Frederick, W., & Greenberg, M. (1983). Adaptation of families with mentally retarded children: A model of stress, coping, and family ecology. American Journal of Mental Deficiency. 88, (2), 125-138.
- Devore, W., & Schlesinger, E. C. (1981). Ethnic-Sensitive Social Work Practice. St. Louis: The C. V. Mosby Company.
- Dohrenwend, B. S. & Dohrenwend, B. P. (Eds.). (1974). Stressful life events. New York: Wiley.

- Donnellan, A. & Leary, M. (1994). Movement Differences and Diversity in Persons with Autism and Mental Retardation. Madison, WI: DRI Press.
- Dunst, C. J., Trivette, C. M. & Deal, A. G. (1988). Enabling and Empowering Families: Principles and Guidelines for Practice. Cambridge, MA: Brookline Books.
- Dunst, C. J., Trivette, C. M. & Deal, A. G. (Eds.). (1994). Supporting and Strengthening Families. Cambridge, MA: Brookline Press.
- Dunst, C. & Trivette, C. (1989). An enablement and empowerment perspective of case management. In Families in special education: Topics in early childhood special education, 8, (4), (pp. 87-102). Austin, Texas: Pro-Ed.
- Dunst, C. & Trivette, C. (1994) What is effective helping? In Dunst, Trivette & Deal, (Eds.). Supporting and strengthening families. Cambridge, MA: Brookline Books, 162-170.
- Dunst, C., Trivette, C., Starnes, A. L., Hamby, D. W., & Gordon, N. J. (1993). Building and Evaluating Family Support Initiatives. Baltimore: Brookes.
- Dybwad, R. F. (1990). Perspectives on a parent movement: the revolt of parents of children with intellectual limitations. Cambridge, MA: Brookline Books.
- Falvey, M. A., Forest, M., Pearpoint, J., & Rosenberg, R. L. (1994). Building Connections. In Thousand, J. S., Villa, R. A., & Nevin, A. I. Creativity and Collaborative Learning. Baltimore: Brookes, 347-368.
- Families of Children with Disabilities Support Act of 1994, PL 103-382. (October 20, 1994). Title 20, U.S.C. 1491 et seq: U.S. Statutes at Large, 108, 3937.
- Featherstone, H. (1981). A Difference in the Family. New York: Penguin.
- Fewell, R. R., & Vadasy, P. F. (1986). Families of Handicapped Children: Needs and supports across the life span. Austin: Pro-Ed.
- Fisher, R., Ury, W. and Patton, B. (1991). Getting to yes: negotiating agreement without giving in, 2nd ed. New York: Penguin.
- Fisher, S. (1984). Stress and the perception of control. London: Lawrence Erlbaum Associates.
- Folkman, S., Schaefer, C. & Lazarus, R. (1979). Cognitive process as mediators of stress and coping. In Hamilton, J. and Warburton, D. (Eds.). Human stress and cognition (pp. 265-298). New York: Wiley.
- Forest, M. & Lusthaus, E. (1989). Promoting educational equality for all students: Circles and maps. In Stainback, S., Stainback, W., and Forest, M. (Eds), Educating all students in the mainstream of education. Baltimore: Brookes, 43-57.

- Forest, M. & Pearpoint, J. (1992). Putting all kids on the MAP. Educational Leadership, 50(2), 26-31.
- Frey, K., Greenberg, M., & Fewell, R. (1989). Stress and coping among parents of handicapped children: A multidimensional approach. American Journal on Mental Retardation, 94, (3), 240-249.
- Friedrich, W. N., Greenberg, M. T., & Crnic, K. A. (1983). A short form of the Questionnaire on Resources and Stress. American Journal of Mental Deficiency, 88, 41-48.
- Fujiura, G. T., Roccoforte, J. A., & Braddock, D. (1994). Costs of Family Care for Adults with Mental Retardation and Related Developmental Disabilities. American Journal on Mental Retardation, 99, (3), 250-261.
- Furney, K. S. (1993). Making dreams happen: How to facilitate the MAPS process. Burlington, VT: Vermont's Transition Systems Change Project, UAP of Vermont.
- Gallagher, J., & Vietze, P. (1986). Families of handicapped persons. Baltimore, MD: Brookes Publishing Co.
- Gardner, S. L. (1993). The ethics of collaboration. Georgia Academy Journal, Summer, 220-222.
- Gartner, A., Lipsky, D. K., & Turnbull, A. (1991). Supporting Families with a Child with a Disability. Baltimore, MD: Paul H. Brookes.
- Gerrig, R. J. & Banaji, M. R. (1994). Language and thought. In Sternberg, R. J. (Ed.), Thinking and problem solving. Handbook of perception and cognition, (2nd Ed.). San Diego, CA: Academic Press, Inc., pp. 233-261.
- Giangreco, M. F. Creative problem-solving: not just for adults. Burlington, VT: UAP of Vermont.
- Goldfarb, L. A., Brotherson, M. J., Summers, J. A., & Turnbull, A. P. (1986). Meeting the challenge of disability or chronic illness: A family guide. Baltimore: Paul H. Brookes.
- Gould, S. J. (1981). The mismeasure of man. New York: Penguin.
- Greenfield, J. (1975). A child called Noah. New York: Holt, Rinehart and Winston.
- Greenfield, J. (1978). A place for Noah. New York: Holt, Rinehart and Winston.
- Greenfield, J. (1986). A client called Noah. New York: Henry Holt & Company, Inc.
- Hamilton, V. & Warburton, D. (1979). Human stress and cognition: An information processing approach. New York: Wiley.

- Harry, B. (1992). Cultural Diversity, Families, and the Special Education System: Communication and Empowerment. New York: Teachers College Press, Columbia University.
- Hawkins, N., & Singer, G. (1989). A skills training approach for assisting parents to cope with stress. In Singer, G., & Irvin, L. (Eds.). Support for caregiving families (pp. 71-83). Baltimore: Brookes.
- Heller, T., Markwardt, R., Rowitz, L., & Farber, B. (1994). Adaptation of Hispanic Families to a Member with Mental Retardation. American Journal on Mental Retardation, 99, (3), 289-300.
- Hill, R. (1949). Families under stress. New York: Harper & Row.
- Hayden, M. F. (1992). Adults with mental retardation and other developmental disabilities waiting for community-based services in the U.S. Policy Research Brief, 4, (3), 1-16. Minneapolis: University of Minnesota, Center on Residential and Community Services, Institute on Community Integration.
- Hayden, M. F. & Abery, B. H. (1994). Challenges for a Service System in Transition: Ensuring Quality Community Experiences for Persons with Developmental Disabilities. Baltimore: Brookes.
- Herman, S. E. (1994). Cash Subsidy Program: Family Satisfaction and Need. Mental Retardation, 32, (6), 416-421.
- Hilton, A. (1989, December). Presentation at the meeting of the Association for Persons with Severe Handicaps, San Francisco, CA.
- Ho, M. K. (1987). Family Therapy with Ethnic Minorities. Newbury Park, CA: Sage Publications, Inc.
- Holroyd, J. (1987). Questionnaire on resources and stress for families with chronically ill or handicapped members. Brandon, VT: Clinical Psychology Publishing Co., Inc.
- Holt, J., Liles, C., & Swanson, M. (1992). Service Coordination Training: Targeted Case Management Little Rock, AR: University of Arkansas, University Affiliated Program.
- Hotaling, C. (1992). Workshop materials on auditory integration training, Shelburne, VT: Sounds of Success, p. 1.
- Hooper-Briar, K. & Lawson, H. (1994). Serving children, youth and families through interprofessional collaboration and service integration: a framework for action. Oxford, OH: Danforth Foundation.
- Hui, C. H., & Triandis, H. C. (1986). Individualism-Collectivism: A Study of Cross-Cultural Researchers. Journal of Cross-Cultural Psychology, 17(2), 225-248.
- Human Services Research Institute. (1992). Expecting excellence in family support. Salem, OR: Author.

- Isaksen, S. G. & Treffinger, D. J. (1984). Creative problem solving: the basic course. Buffalo, NY: Bearly Limited, pp. 169, 171, 173, 177, 183, 188.
- Jacobson, J., Mulick, J. & Schwartz, A. (1995). American Psychologist, 50(9), 750-765.
- Janko, S. (1994). Vulnerable Children, Vulnerable Families: the Social Construction of Child Abuse. New York: Teachers College Press, Columbia University.
- Johnson, D. W. (1990). Reaching out: interpersonal effectiveness and self-actualization (4th ed.) Englewood Cliffs, NJ: Prentice-Hall, Inc., 222-228.
- Journal of the Association for Persons with Severe Handicaps. Vol 19 (3), Fall 1994.
- Kagan, S. L., Powell, D. R., Weissbourd, B. & Zigler, E. F. (1987). America's Family Support Programs. New Haven: Yale University Press.
- Karp, N. & Bradley, V. J. (1990). Taxonomy of family support. Family support services in the United States: An end of decade status report. Cambridge, MA: Human Services Research Institute.
- Karp, N. & Bradley, V. (1992). Family Support: A State of the States. Children Today, Vol. 20, Number 2, pp. 28-31.
- Kaufman, N. (1976). Son-rise. New York: Warner Books.
- Kay, P. & Kempton, W. (1984). What is the Sapir-Whorf hypothesis? American Anthropologist, 86(1), 65-79.
- Kingsley, E.P. (1987). Welcome to Holland. In Heartline.
- Kluckhohn, C., & Others. (1951). Values and Value-Orientations in the Theory of Action: An Exploration in Definition and Classification. In T. Parsons, & E. A. Shils (Eds.), Toward a General Theory of Action (pp.388-433). Cambridge, MA: Harvard University Press.
- Kluckhohn, F. R. (1956). Dominant and Variant Value Orientations. In C. Kluckhohn & H. A. Murray (Eds.), Personality in Nature, Society and Culture (pp. 342-357), (2nd ed.). New York: Alfred A. Knopf. (Revised from Social Welfare Forum 1951, 97-113 and Dominant and Substitute Profiles of Cultural Orientation, in Social Forces, 1950, 28, 376-93.
- Kluckhohn, F. R., & Strodtbeck, F. L. (1961). Variations in Value Orientations. Evanston, IL: Row, Peterson and Co.
- Knoll, J. A. (1992). Being a Family: The Experience of Raising a Child with a Disability or Chronic Illness. In Bradley, V. J., Knoll, J. A., and Agosta, J. M. Emerging Issues in Family Support. Washington, D.C.: AAMR Monographs, No. 18, AAMR, pp. 9-56.

- Knoll, J. A. (1992, November). The Changing Paradigm in Human Services: What Does It Mean to Provide Support? Presentation at Annual Meeting of The Association of Persons with Severe Handicaps.
- Knoll, J. A., Covert, S., Osuch, R., O'Connor, S., Agosta, J., and Blaney, B. (1990). Family Support Services in the United States: An End of Decade Status Report. Cambridge, MA: Human Services Research Institute.
- Knoll, J. Covert, S., Osuch, R., O'Connor, S., Agosta, J. & Blaney, B. (1992). Support for Families: State Family Support Efforts. In Bradley, V. J., Knoll, J. A., & Agosta, J. M. (Eds.). Emerging Issues in Family Support. Washington, DC: AAMR, pp. 57-97.
- Knoll, J. A. and Racino, J. (in press). Field in Search of a Home: An Exploration of the Need for Support Personnel to Develop a Distinct Identity. In Bradley, V. J., Ashbaugh, J., & Blaney, B. (Eds). From Vision to Reality: Transforming Service Systems to Systems of Support for Persons with Developmental Disabilities. Baltimore, Brookes.
- Koppenhofer, J., Gilmer, D. and McElroy, M. (1993). Facilitated Communication: An Annotated Bibliography. Orono, MA: Center for Community Inclusion, University of Maine.
- Koren, P. & DeChillo, N. (1993). Measuring empowerment in families whose children have emotional disabilities. Portland, OR: Research and Training Center on Family Support and Children's Mental Health, Portland State University
- Kubler-Ross, E. (1969). On death and dying. New York: MacMillan.
- Kushner, H. S. (1981). When bad things happen to good people. New York: Avon Books.
- Lambert, W. E., Hamers, J. F., & Frasure-Smith, N. (1979). Child-Rearing Values: A Cross-National Study. New York: Praeger Publishers.
- Langer, E. (1975). The illusion of control. Journal of Personality and Social Psychology, 32, 311-328.
- Lazarus, R. (1966). Psychological stress and the coping process. New York: McGraw Hill.
- Lazarus, R. (1968). Patterns of adjustment. New York: McGraw Hill.
- Lazarus, R., Averill, J., & Opton, E. (1970). Towards a cognitive theory of emotion. In Arnold, M. (Ed.). Feelings and emotions (pp. 207-232). New York: Academic Press.
- Lefcourt, H. (1982). Locus of control: Current trends in theory and research (2nd ed.). London: Lawrence Erlbaum Associates.
- Levy, J., Levy, P., & Nivin, B. (Eds.). (1989). Strengthening families: New directions in providing services to people with developmental disabilities and their families. New York: The Young Adult Institute Press.

- Linz, M. H., McAnally, P. & Wieck, C., Eds. (1989). Case Management: Historical, Current & Future Perspectives. Cambridge, MA: Brookline Books.
- Louisiana family support cash subsidy: Survey of program participants. Salem, OR: Human Services Research Institute.
- Lynch, E. W. & Hanson, M. J. (1996). Developing Cross-Cultural Competence: A Guide for Working with Young Children and Their Families, 2nd Edition. Baltimore: Brookes.
- Maguire, P. (1987). Doing participatory research: A feminist approach. Amherst, MA: The Center for International Education, Univ. of MA.
- Maier, S. F. & Seligman, M. E. P. (1976). Learned helplessness. Theory and evidence. J. Exp. Psychol. General 105, 3-46.
- Marion, R. L. (1981). Educators, Parents and Exceptional Children. Rockville, MD: Aspen Systems Corporation.
- Maslow, A. (1970). Motivation and Personality (2nd. ed.). New York: Harper & Row.
- Mason, M. (1981). Proposed draft liberation policy for people with disabilities. London, England.
- Mason, M. (1998). A history of exclusion. Present time, January.
- McAdoo, H.P. (1999). Family Ethnicity (2nd Ed.). Thousand Oaks, CA: Sage Publications.
- McCubbin, H. & Patterson, J. (1983). Family stress adaptation to crises: A double ABCX model of family behavior. In McCubbin, H., Sussman, M., & Patterson, J. (Eds.). Social stresses and the family: Advances and developments in family stress theory and research (pp. 7-37). New York: Haworth.
- McCubbin, H., Sussman, M., & Patterson, J. (Eds.) (1983). Social stresses and the family: Advances and developments in family stress theory and research. New York: Haworth.
- McGoldrick, M. (1982). Ethnicity and Family Therapy: An Overview. In M. McGoldrick, J. K. Pearce, & J. Giordano (Eds.), Ethnicity and Family Therapy (pp. 3-30). New York: The Guilford Press.
- McGoldrick, M., Pearce, J. K., & Giordano, J. (Eds.). (1982). Ethnicity and Family Therapy. New York: The Guilford Press.
- Melda, K. Personal communication, November, 1992.
- Miller, N.B. (1994). Nobody's Perfect: Living and Growing with Children who Have Special Needs. Baltimore: Brookes.

- Mindel, C. H., & Habenstein, R. W., (Eds.). (1976). Ethnic Families in America: Patterns and Variations. New York: Elsevier Scientific Publishing Co.
- Moseley, C. & Nerney, T. (2000). Emerging best practices in self-determination. AAMR News & Notes, Vol. 13, No. 6, 1-5.
- Murray, J. B., & Murray, E. (1975). And say what he is: The life of a special child. Cambridge, MA: M.I.T. Press.
- National Council of State Legislatures Task Force on Developmental Disabilities. Recommendations for State Action on Family Support.
- Nerney, T. (1998). The poverty of human services. Concord, NH: Robert Wood Johnson Foundation.
- Nerney, T. & Shumway, D. (1996). Beyond managed care. Concord, NH: Robert Wood Johnson Foundation.
- Nichols, P. (1967). A day in the death of Joe Egg. London: Faber and Faber.
- Osborne, D. & Gaebler, T. (1992). Customer driven government: Meeting the Needs of the customer, not the bureaucracy. In Osborne and Gaebler, Reinventing government: How the entrepreneurial spirit is transforming the public sector. Reading, MA: Addison-Wesley Pub. Co., 166-194.
- Park, C. C. (1967). The siege. Boston: Little, Brown.
- Parnes, S. J. (1988). Visionizing. East Aurora, NY: D.O.K. Publishers, pp. 35-37.
- Patton, M. Q. (1990). Qualitative Evaluation and Research Methods. Newbury Park, CA: Sage.
- Paul, J. L., & Simeonsson, R. J. (1993). Children with Special Needs: Family, Culture, and Society, 2nd Ed. New York: Harcourt Brace Jovanovich.
- Pinderhughes, E. (1989). Understanding Race, Ethnicity, and Power. New York: The Free Press.
- Powell, T. H., & Ogle, P. A. (1985). Brothers & sisters: A special part of exceptional families. Baltimore: Paul H. Brookes.
- Powers, M.D. (1989). Children with Autism: A Parents' Guide. Rockville, MD: Woodbine House.
- Powers, L.E. (1996). Family and consumer activism in disability policy. In Singer, G.H.S., Powers, L.E. & Olson, A.L. Redefining Family Support. Baltimore: Brookes, pp. 413-433
- Precis: Americans with Disabilities Act of 1990: What Should You Know?
Supplement to Exceptional Children, 57(2) October/November 1990.

- Ramey, S., Krauss, M., Simeonsson, R. (1989). Research on families: Current assessment and future opportunities. American Journal on Mental Retardation, 94, (3), ii-vi.
- Redford, D. P. (1996). What is "able-bodiedism"...and how do I get rid of it anyway? Phoenix, AZ: ABIL.
- Rimland, B. & Edelson, S. (1995). Brief report: A pilot study of auditory integration training in autism. Journal of Autism and Developmental Disorders, 25(1), 61-70.
- Rodin, J., Schooler, C., & Warner Schaie, K., Eds. (1990). Self-Directedness: Cause and Effects Throughout the Life Course. Hillsdale, New Jersey: Lawrence Erlbaum Associates.
- Rogers, D. E. (1953). Angel unaware. Los Angeles: Fleming H. Revell.
- Rosin, P., Whitehead, A., Tuchman, L., Jesien, G., & Begun, A. (1993). Partnerships in Early Intervention: A Training Guide on Family-Centered Care, Team Building, and Service Coordination. Madison: University of Wisconsin.
- Rotter, J. (1966). Generalized expectancies for internal versus external control of reinforcement. Psychological Monographs. 80, (1), 1-28.
- Rush, W. L. Write with dignity: Reporting on people with disabilities. Lincoln, Nebraska: Univ. of Nebraska School of Journalism.
- S1809. Developmental Disabilities Assistance and Bill of Rights Act of 2000, Title II—Family Support.
- Salisbury, C. L. & Intagliata, J. (1986). Respite Care: Support for Persons with Developmental Disabilities and Their Families. Baltimore: Brookes.
- Samuda, R. J., & Wolfgang, A. (1985). Intercultural Counselling and Assessment. Toronto: C. J. Hogrefe, Inc.
- Schaefer, N. (1982). Does she know she's there? Ontario: Fitzhenry & Whiteside Limited.
- Scheier, M. & Carver, C. (1994). Life Orientation Test. American Psychological Association.
- Scott, R., Sexton, D., Thompson, B., & Wood, T. (1989). Measurement characteristics of a short form of the Questionnaire on Resources and Stress. American Journal on Mental Retardation, 94, (3), 331-339.
- The Seattle 2000 declaration on self-determination and individualized funding.
<http://members.home.net/directfunding>.
- Shane, H.C. (1994). Facilitated Communication: the Clinical and Social Phenomenon. San Diego, CA: Singular Pub. Group.

- Shapiro, J. & Simonsen, D. (1994). Educational/Support Group for Latino Families of Children with Down Syndrome. Mental Retardation, 32, (6), 403-415.
- Silverstein, R. (2000). An overview of the emerging disability policy framework: A guidepost for analyzing public policy. (Appendices). Iowa Law Review, Vol. 85: 5.
- Simpson, R. L. (1990). Conferencing Parents of Exceptional Children (2nd ed.). Austin, TX: Pro-ed.
- Singer, G., & Irvin, L. (1989). Support for caregiving families. Baltimore: Brookes.
- Singer, G., & Irvin, L. (1989). Family caregiving, stress, and support. In Singer, G., & Irvin, L. (1989). Support for caregiving families (pp. 3-25). Baltimore: Brookes.
- Singer, G., Irvine, A., & Irvin, L. (1989). Expanding the focus of behavioral parent training. In Singer, G. & Irvin, L. (Eds.). Support for caregiving families (pp. 85-102). Baltimore: Brookes.
- Singer, G., & Powers, L. (1993). Families, Disability, and Empowerment: Active Coping Skills and Strategies for Family Interventions. Baltimore: Brookes.
- Singer, G. H. S., Powers, L. E., and Olson, A. L., Redefining Family Support: Innovations in Public-Private Partnerships. Baltimore: Brookes.
- Snyder, C. R., Harris, C., Anderson, J. R., Halleran, S. A., Irving, L. M., Sigmon, S. T., Yoshinobu, L., Gibb, J., Langelle, C., & Harney, P. (1992). The will and the ways: Development and validation of an individual difference measure of hope. Journal of Personality and Social Psychology, 60, p. 585.
- Summers, J., Behr, S., Turnbull, A. (1989). Positive adaptation and coping strengths of families who have children with disabilities. In Singer, G., & Irvin, L. (Eds.). Support for caregiving families (pp. 3-26). Baltimore: Brookes.
- Taylor, S. (1983). Adjustment to threatening events: A theory of cognitive adaptation. American Psychologist, 38, 1161-1173.
- Taylor, S. & Brown, J. (1988). Illusion and well-being: A social psychological perspective on mental health. Psychological Bulletin, 103(12), 193-210.
- Taylor, S. & Brown, J. (1994). Positive illusions and well-being revisited: Separating fact from fiction. Psychological Bulletin, 116(1), 21-27.
- Thomas, K. W. & Kilmann, R. H. (1974). Conflict mode instrument. Tuxedo, NY: Xicom Inc.
- Thompson, S. (1981). Will it hurt less if I can control it? A complex answer to a simple question. Psychological Bulletin, 90, 96-101.

- Thousand, J. S., Villa, R. A., & Nevin, A. I. (1994). Creativity and collaborative learning. Baltimore: Brookes.
- Turnbull, A. (1989). Positive contributions of children with disabilities to their families. In Levy, J., Levy, P., & Nivin, B. (Eds.). Strengthening Families (pp. 27-32). New York: The Young Adult Institute Press.
- Turnbull, A.P., Blue-Banning, M., Turbiville, V., & Park, J. (1999). From parent education to partnership education: A call for a transformed focus. Topics in early childhood special education 19:3.
- Turnbull, A., Patterson, J. M., Behr, S. K., Murphy, D. L., Marquis, J. G., & Blue-Banning, M. J. (1993). Cognitive Coping, Families & Disability. Baltimore: Brookes.
- Turnbull, A.P., Turbiville, V., & Turnbull, H.R. (2000). Evolution of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In Shonkoff, J.P. & Meisels, S.J., Handbook of early childhood intervention (2nd Ed.), Cambridge, Cambridge University Press, 630-650.
- Turnbull A., & Turnbull, H. (1989). Report on consensus conference on principles of family research. Lawrence, KA: Bureau of Child Research.
- Turnbull, A. P., & Turnbull, H. R. (1985, October). Stepping back from early intervention: An ethical perspective. Paper presented at the DEC/CEC Early Childhood Conference, Denver, CO.
- Turnbull, A. P., & Turnbull, H. R. (1985). Parents Speak Out: Then and Now. Columbus: Merrill.
- Turnbull, A. P., & Turnbull, H. R. (1990). Families, Professionals, Exceptionality: A Special Partnership (2nd ed.). Columbus, OH: Merrill Publishing Co.
- Ury, W. (1993). Getting past no: negotiating your way from confrontation to cooperation, Revised edition. New York: Bantam Books.
- Van der Klift, E. & Kunc, N. (1994). Beyond benevolence. In Thousand, J., Villa, R., & Nevin, A. (Eds.). Creativity and collaborative learning. Baltimore: Brookes.
- Vermont Agency of Human Services, the Department of Mental Health and Mental Retardation, the Vermont Department of Education, the Mental Retardation Advisory Board. (1993). The 1993 Vermont System of Care Plan for Services to Persons with Mental Retardation and Their Families. Waterbury, VT.
- Vermont Coalition for Disability Rights, Committee on Family Support (1992, March). Position Paper on Family Support. Montpelier, VT.
- Vermont Developmental Disabilities Council. (1993). Family Support Services for People with Disabilities: Why We Need Legislation. Waterbury, VT.
- Vermont Family Support Bill of 1993, H.344, S152.

- Vermont State Team for Children and Families. (1995). Outcomes and Indicators. Waterbury, VT: Vermont Interagency Team.
- Wikler, L. (1986). Family stress theory and research on families of children with mental retardation. In Gallagher, J., & Vietze, P. (Eds.). Families of handicapped persons (pp. 167-195). Baltimore: Brookes.
- Woodruff, G. & Hanson, C. (1987). Table 9. Three models for early intervention. Brighton, MA: Project KAI.
- Yuan, S., Baker-McCue, T., & Witkin, K. (1996). Coalitions for Family Support and the Creation of Two Flexible Funding Programs. In Singer, G. H. S., Powers, L. E., and Olson, A. L., Redefining Family Support: Innovations in Public-Private Partnerships. Baltimore: Brookes, pp. 357-385.
- Zirpoli, T. J., Wieck, C., Hancox, D., & Skarnulis, E. R. (1994). Partners in Policymaking: The First Five Years. Mental Retardation, 32, (6), 622-625.