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ABSTRACT

Intended to help Head Start programs recruit and include children with significant disabilities and their families, this guide offers Head Start staff tools to work more collaboratively to plan and implement integrated services for all children, especially children with significant disabilities. Following an introductory section, the guide presents three training modules. Each module details expected outcomes, key concepts, background information, learning activities, and next steps. Handouts are included for each module. Module One, "Getting Ready," helps participants identify how their own experiences and assumptions influence their relationships with children with significant disabilities and offers strategies that can be used to be more family centered. Module Two, "Making it Work," helps participants adapt their practices and develop strategies to support the participation of children with significant disabilities in their Head Start Programs. Module Three, "Promoting Collaboration," helps managers work more effectively with service providers and community agencies to recruit and include children with significant disabilities and their families. The final sections of the guide offers continuing professional development and resource lists that staff can use to learn more about the key issues presented in the guide. (Contains 14 appendices that detail specific disabilities.) (SD)

HEAD START®

# Training Guides for the Head Start Learning Community

## Including Children with Significant Disabilties in Head Start

**U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES**
Administration for Children and Families
Administration on Children, Youth and Families
Head Start Bureau

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HEAD START®

# Including Children with Significant Disabilities in Head Start

## *Training Guides for the Head Start Learning Community*

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Administration for Children and Families
Administration on Children, Youth and Families
Head Start Bureau

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# Preface

## WELCOME TO HOLLAND*

I am often asked to describe the experience of raising a child with a disability—to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this . . .

When you're going to have a baby, it's like planning a fabulous vacation trip—to Italy. You buy a bunch of guide books and make wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say, "What do you mean, Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a *different* place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around. . .and you begin to notice Holland has windmills . . . and Holland has tulips. Holland even has Rembrandts.

But everyone you know is coming and going from Italy . . . and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away . . . because the loss of that dream is a very, very significant loss.

But . . . if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things . . . about Holland.

---

*Reprinted with permission from Emily Perl Kingsley. 1997. In J. Canfield (Ed.), *Chicken Soup for the Mother's Soul: 101 Stories to Open the Hearts and Rekindle the Sprits of Mothers.* Deerfield Beach, Florida: Health Communications.

# Preface

What is it like to have a child with a significant disability? Most of us will never know. We will never truly understand the sorrow and pain many parents feel: "a pain that will never, ever, ever, ever go away . . . because the loss of that dream is a very, very significant loss." We will also never understand the love and appreciation and wonder that parents discover along the way. But we can learn about a parent's point of view from stories we hear, movies we see, books we read. Most importantly, we can and must learn from families, by asking them directly about what they want and need for themselves and their children. Only then can Head Start staff support families, and effectively translate parents' needs and wants into meaningful programs for their children.

In order for Head Start programs to successfully include children with significant disabilities, staff must take steps to get ready. They must acquire special knowledge and skills to help children with disabilities and their families take full advantage of the opportunities created by evolving laws and regulations. They must work in more connected and organized ways with each other to promote inclusive programming. They must also collaborate with early intervention programs, local education agencies (LEAs), and many other community partners. Successfully including children with significant disabilities in Head Start demands a comprehensive, coordinated approach that involves all the players, and responds to the special needs and strengths of children and their families.

That is the purpose of this technical guide: to provide Head Start teaching staff, family service workers, home visitors, and managers with skills to recruit and include children with significant disabilities and their families; and to offer Head Start staff tools to work more collaboratively with parents, related service and health care professionals, and each other to plan and implement integrated services for all children, especially children with significant disabilities.

Head Start managers play a critical role in the process. They can set the tone by serving as models when they reach out and work collaboratively with LEAs, early intervention programs, and other agencies involved with children and families in their program. In addition, Head Start managers can demonstrate their support for staff by allocating time for training, planning for follow-up from the very start of the process, and being involved as participants themselves.

Each program will need one key person to coordinate this staff development effort and identify suitable trainers. We recommend selecting trainers who are knowledgeable about working with young children with significant disabilities and their families, understand the day-to-day realities of Head Start staff, and have experience facilitating partnerships with outside agencies. This guide is one in a series of five Disabilities Services training guides. The foundation guide, *Setting the Stage: Including Children with Disabilities in Head Start,* lays the groundwork for the skills introduced in this technical guide. Other guides, such as the Social Services guides, *Building a Supportive Community* and *Community Partnerships: Working Together*, the Health guide, *Caring for Children with Chronic Conditions*, and the Transition guide, *Effective Transition Practices: Facilitating Continuity,* are also relevant to the issues and skills this guide addresses. We hope that, taken together, these materials will strengthen Head Start's capacity to better serve all children and their families.

# Introduction

## Overview

### *Purpose*

In 1972, Head Start began to reserve at least 10 percent of its enrollment for children with disabilities. In the years since, Head Start has become the largest community-based preschool program providing services to children with disabilities and their families. In order for Head Start programs to effectively reach out to and include children with significant disabilities—children who require more intensive services and collaboration among Head Start staff, families, and outside service providers—staff must take steps to get ready. That is the goal of this technical guide: to help Head Start programs recruit and include children with significant disabilities and their families; and to offer Head Start staff tools to work more collaboratively to plan and implement integrated services for all children, especially children with significant disabilities.

### *Definition*

What is a significant disability? A significant disability is not defined solely by diagnosis; rather, it is related to the extent of adaptations and services that a child needs. In general, children with significant disabilities require more everyday modifications (for example, use of adaptive materials and equipment) and more intensive coordination with outside specialists.

Children with significant disabilities may be able to participate in every aspect of the Head Start program. The challenge for staff is to find ways to adapt routines and activities in the most natural ways possible to promote full participation, while also meeting Individualized Education Program (IEP) goals and objectives. Collaboration is key: Head Start staff must work as a team with each other, as well as with other professionals and with parents, to plan, implement, and evaluate strategies to help children with significant disabilities participate and succeed.

### *Audience*

This technical guide is written for Head Start teaching staff, family service workers, home visitors, and managers.

### *Performance Standards*

This guide applies Head Start core values, as well as the Head Start Program Performance Standards including, but not limited to, the Standards on Services for Children with Disabilities.

# Introduction

## Organization of the Guide

This guide includes the following sections:

*Module 1: Getting Ready* helps participants identify how their own experiences and assumptions influence their relationships with children with significant disabilities and offers strategies they can use to be more family centered.

*Module 2: Making It Work* helps participants adapt their practices and develop strategies to support the participation of children with significant disabilities in their Head Start programs.

*Module 3: Promoting Collaboration* helps managers work more effectively with service providers and community agencies to recruit and include children with significant disabilities and their families.

*Continuing Professional Development* offers strategies that supervisors can use to help staff apply new skills and extend their learning.

*Resources* lists print and audiovisual materials and other resources that staff can use to learn more about the key issues presented in the guide.

## Organization of the Modules

In order to accommodate the needs of different grantees, each module offers two delivery strategies: workshop and coaching. Workshops are suitable for groups of 10 or more participants. Workshops can build strong site-based teams, as well as help staff from multiple sites develop a programwide identity. Coaching permits one, two, or three staff members to work together under the guidance of a coach, who could be a Head Start manager, head teacher, or outside consultant. Coaching provides individual flexibility and helps participants work on actual issues and challenges in their program. While activities vary according to the type of delivery strategy, the content and objectives are the same for each approach.

Each module is organized so that workshop leaders and coaches can easily implement the activities. All modules contain the following sections:

- The *Outcomes* section summarizes the skills participants will learn in the module.
- The *Key Concepts* section describes the critical issues addressed.
- The *Background Information* section provides a rationale for the module.

- The *Activities* section provides step-by-step instructions for workshop or coaching sessions.
- The *Next Steps: Ideas to Extend Practice* section includes strategies to help participants practice the skills learned in the module.

Some activities include a Discussion Guide to help workshop leaders and coaches think through the session's key ideas and anticipate participants' responses. Handouts and transparencies appear at the end of each module.

Ideally, participants should complete all the workshops or all the coaching activities in each module sequentially. Similarly, Modules 1 and 2 should be used sequentially, since activities build on one another. If possible, allow participants to complete the modules over an extended period of time, perhaps over a four- to six-month period. With *Next Steps: Ideas to Extend Practice* and *Continuing Professional Development,* training could extend into a year-long process.

## Definition of Icons

| | |
|---|---|
| ***Coaching*** | A training strategy that fosters the development of skills through tailored instruction, demonstrations, practice, and feedback. The activities are written for a coach to work closely with one to three participants. |
| ***Workshop*** | A facilitated group training strategy that fosters the development of skills through activities which build on learning through group interaction. These activities are written for up to 25 participants working in small or large groups with one or two trainers. |
| ***Next Steps: Ideas to Extend Practice*** | Activities assigned by the trainer immediately following the completion of the module to help participants review key information, practice skills, and examine their progress toward expected outcomes of the module. |
| ***Continuing Professional Development*** | Follow-up activities for the program to support continued staff development in the regular use of the skills addressed in a particular training guide. It includes:<br>1. Opportunities tailored to the participant to continue building on the skills learned in the training.<br>2. Ways to identify new skills and knowledge needed to expand and/or complement these skills through opportunities in such areas as higher education, credentialing, or community educational programs. |

## At A Glance

| Module | Activity | Time | Materials |
|---|---|---|---|
| *Module 1: Getting Ready* | Activity 1-1: Viewpoints (W)<br>Participants use viewpoints about including a child with significant disabilities as a springboard for examining their own assumptions. | 90 minutes | Handout 1–One Mother's Story<br>Handout 2–Viewpoints<br>Handout 3–Leading the Discussion<br>Easel, chart paper, markers, tape |
| | Activity 1-2: Families First (W)<br>Participants identify essential elements that contribute to a positive, family-centered approach. | 90 minutes | Handout 4–Role Plays<br>Handout 5–Observer Worksheet<br>Handout 6–What is Family-Centered Care?<br>Handout 7–Principles for Providing Family-Centered Care<br>Opening Letter from the Preface–Welcome to Holland<br>Easel, chart paper, markers, tape |
| | Activity 1-3: Are You Ready? (C)<br>Teaching teams assess their readiness to include children with significant disabilities and develop steps to enhance their efforts. | 60–90 minutes | Handout 8–Taking Stock<br>Handout 9–Moving Ahead<br>Next Steps: Ideas to Extend Practice<br>Easel, chart paper, markers, tape |

**W = Workshop**

**C = Coaching**

| Module | Activity | Time | Materials |
|---|---|---|---|
| *Module 2: Making It Work* | Activity 2-1: Lara's Story (W)<br>Through role play and observation, participants identify strategies for promoting collaboration as they plan, coordinate, and provide services for Lara. | 90–120 minutes | Handout 10–Lara<br>Handout 11–Planning Worksheet<br>Appendix C–Spina Bifida Fact Sheet<br>Easel, chart paper, markers, tape |
| | Activity 2-2: Preparing Your Classroom (W)<br>Participants analyze the strengths and needs of children with significant disabilities, and then plan adaptations to promote full participation. | 90 minutes | Handout 12–Adaptations<br>Handout 13–Worksheet<br>Handout 14–Integration Checklist<br>Easel, chart paper, markers, tape |
| | Activity 2-3: Making Changes (C)<br>A coaching adaptation of Activity 2–2: Preparing Your Classroom. | 60–90 minutes | Handout 12–Adaptations<br>Handout 14–Integration Checklist<br>Handout 15–A Closer Look<br>Easel, chart paper, markers, tape |

**W = Workshop**

**C = Coaching**

| Module | Activity | Time | Materials |
|---|---|---|---|
| ***Module 2: Making It Work (continued)*** | Activity 2-4: Specialists in the Classroom (W)<br>Participants identify strategies for working with specialists to meet the needs of children with disabilities. | 90 minutes | Handout 16–Scenes from the Classroom<br>Handout 17–Problems and Solutions<br>Handout 18–Finding the Right Consultant<br>Handout 19–Orienting Consultants<br>Easel, chart paper, markers, tape |
| | Activity 2-5: Working As a Team (C)<br>A coaching adaptation of Activity 2-4: Specialists in the Classroom. | 90 minutes | Handout 16–Scenes from the Classroom<br>Handout 17–Problems and Solutions<br>Handout 18–Finding the Right Consultant<br>Handout 19–Orienting Consultants<br>Next Steps: Ideas to Extend Practice<br>Easel, chart paper, markers, tape |

**W = Workshop**

**C = Coaching**

| Module | Activity | Time | Materials |
|---|---|---|---|
| *Module 3: Promoting Collaboration: From Recruitment to Transition* | Activity 3-1: A Family We Know (W)<br>Managers examine systems that are currently in place, and those that are still needed, to support the inclusion of children with significant disabilities. | 60–90 minutes | Handout 20–Ryan's Sister Comes to Head Start<br>Handout 21–Worksheet<br>Appendix A–Services for Children with Disabilities<br>Appendix B–About Significant and/or Multiple Disabilities<br>Easel, chart paper, markers, tape |
| | Activity 3-2: How Can I Help? (C)<br>A coaching adaptation of Activity 3-1: A Family We Know, designed for new managers. | 60–90 minutes | Handout 21–Worksheet<br>Appendix A–Services for Children with Disabilities<br>Appendix B–About Significant and/or Multiple Disabilities<br>Next Steps: Ideas to Extend Practice<br>Easel, chart paper, markers, tape |

**W = Workshop**

**C = Coaching**

| Module | Activity | Time | Materials |
|---|---|---|---|
| ***Module 3: Promoting Collaboration: From Recruitment to Transition (continued)*** | Activity 3-3: Building and Sustaining Relationships (W)<br>Managers evaluate existing relationships with outside organizations, and develop plans for improving and expanding their network of support to include children with significant disabilities. | 60–90 minutes | Handout 22–Troubleshooting<br>Handout 23–Assessment Chart<br>Handout 24–Action Plan<br>Easel, chart paper, markers, tape |
| | Activity 3-4: You Can Do It! Making New Connections (W)<br>Managers examine how they can expand their recruitment efforts to reach more families of children with significant disabilities. | 60–90 minutes | Handout 25–Success Stories<br>Handout 26–Tips for Successful Interagency Collaboration<br>Handout 27–Plan for Recruiting Children with Significant Disabilities<br>Easel, chart paper, markers, tape |

**W = Workshop**

**C = Coaching**

## Getting Started

While there are no simple recipes for a successful staff development experience, here are some key steps to follow:

- *Learn about the program.* If you are not a Head Start staff member, identify background information about the particular program and the real concerns that teachers, specialists, and administrators struggle with daily as they work to meet the diverse needs of children and families. The more relevant the session is to staff's immediate needs, the more effective the experience will be.

- *Become familiar with the guide.* Before conducting any activities, familiarize yourself with the guide, its contents, and its goals. Remember, inclusion can feel like an abstract concept. In order for participants to understand what it means to fully include children with significant disabilities, they need concrete images of what inclusion looks like on the playground, in a classroom, or in the community. As you get ready to conduct the training, choose examples from your experience and from families you know so you can bring the concepts alive.

- *Learn more about the content.* For more information about significant disabilities, refer to the appendices and the Resources section. Also become familiar with state and local laws, regulations, and policies governing services for children with disabilities.

- *Develop links with supervisors.* Supervisors can help you assess the interests and needs of staff; they can also give you a picture of the day-to-day issues that arise. Lay the foundation for a positive partnership by meeting with supervisors before you begin.

- *Develop links with participants.* Just as children need a supportive, safe environment to learn and grow, staff, too, need a climate that facilitates team building and open communication. They need encouragement and time to reflect on their practice as they develop strategies for meeting the individual needs of children and their families. We hope that this guide will help you provide Head Start staff with the tools they need to successfully include children with significant disabilities and their families.

**Trainer and Coach Preparation Notes:**

Throughout the training, remind participants that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before participants share their descriptions of children and families in the program, make sure they fully understand issues around confidentiality.

Also emphasize that while it is important to learn about specific disabilities, it is even more critical to learn about the child's interests, strengths, and individual needs. Staff need to consider the whole child first, not the disability.

## Getting Ready

***Outcomes***

After completing this module, participants will be able to:

- Identify how their own experiences and assumptions can directly influence their relationships with children with significant disabilities and their families.
- Identify ways they can be more family centered in their interactions with parents.
- Assess current strengths they can build on to facilitate the inclusion of children with significant disabilities.

***Key Concepts***

- People have a wide range of thoughts and feelings about including children with significant disabilities in Head Start programs. It is important to understand how these thoughts, as well as experiences, influence one's readiness and ability to contribute to successful inclusion.
- In order to be family centered, Head Start staff must respect and honor families as children's first teachers, as well as the key caregivers and decisionmakers for their children.
- By assessing staff attitudes and existing relationships with families and community partners, programs can identify the next steps they need to take to prepare and plan for children with significant disabilities and their families.

***Background Information***

Thirty years ago, before the enactment of federal laws that ensure all children's right to a public education in the least restrictive environment (LRE), children with significant disabilities were often excluded from public education. Others were served in segregated classrooms that included children with a broad range of disabilities and ages. Because many programs were regionally based, children often traveled long distances, some spending three to four hours each day in vans and buses. Yet classmates shared a common bond: a disability that "prevented" them from playing and learning side-by-side with children in their neighborhood schools.

Fortunately, federal laws have been passed over the years which protect the right of all children with disabilities to an appropriate education in the least restrictive environment. Public Law 94-142, the Education of the Handicapped Act, was passed by Congress and signed into law in 1975.

In 1986, the Education of the Handicapped Act (EHA) was amended through Public Law 99-457. It extended the age of eligibility for special education and related services to children ages three to five. In 1990 the name of the law was changed to the Individuals with Disabilities Education Act (IDEA), and many discretionary programs were expanded to meet the needs of children with disabilities and their families. During this time, Head Start continually renewed its commitment to including children with disabilities.

Head Start staff have considerable experience in meeting the needs of children with varying strengths and abilities. However, with the growing awareness of the value of inclusion, Head Start programs may begin to serve more children with significant disabilities. To get ready, Head Start staff will need to assess their own attitudes and beliefs, their relationships with families and community partners, and specific areas where improvement is needed.

Throughout the planning process, it is especially critical that staff be sensitive to the unique viewpoints of parents of children with significant disabilities. Head Start staff can never assume that they know what parents want or need for their children; nor can they ever completely understand what a family is going through or feeling. Rather, staff must actively solicit parents' input and seek their guidance. Only then can Head Start staff effectively translate parents' needs and wants into meaningful programs for their children.

For an overview of the activities in this module, see At A Glance on p. 5.

**Trainer and Coach Preparation Notes:**

What is a significant disability? A significant disability is not defined solely by diagnosis. Rather, it is related to the extent of adaptations and services that a child needs. In general, children with significant disabilities require more everyday modifications (for example, use of adaptive materials and equipment) and more intensive coordination with outside specialists.

For more information about specific disabilities, review the appendices. While the information covered is not the focus of the training, participants may have questions about these topics during activities.

Throughout the training, emphasize that learning about specific disabilities is only one step in the process. Just as with any child, it is important to know about the child's interests, strengths, and needs.

**Trainer and Coach Preparation Notes (continued):**

Also remind participants that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before participants share their descriptions of children and families in the program, make sure they fully understand issues of confidentiality.

## *Activity 1-1: Viewpoints*

**Purpose:** In this workshop activity, participants will examine a variety of viewpoints about including children with significant disabilities and their families. These viewpoints will serve as a springboard for helping participants identify what steps they can take, both individually and as a program, to include children with significant disabilities.

### *Preparation*

Arrange for: Easel, chart paper, markers, and tape

Duplicate: Handout 1–One Mother's Story (p. 29): one for each participant
Handout 2–Viewpoints (pp. 30-32): one for each group of 5
Handout 3–Leading the Discussion (p. 33): one for each small-group leader

Make: A piece of chart paper with the ground rules for discussion that appear on page 17.

**Trainer Preparation Notes:**

The results from this activity can help the management team better understand staff perspectives and areas where program improvement may be needed. Make a time to share with managers what you learned and possible implications for next steps. Also save the results for use in Activity 3-1: A Family We Know.

In your discussion with the management team, make sure to respect the confidentiality of workshop participants; do not mention participants' names unless you have their permission first.

### *Leading the Activity*

1. Introduce the activity and review the agenda with participants. Tell participants that in general, children with disabilities need minor modifications and a limited number of outside services. Explain that children with significant disabilities require more everyday modifications (for example, use of adaptive materials and equipment) and more intensive coordination with specialists outside of Head Start who provide services.

2. Before beginning the Viewpoints activity, use an icebreaker to help participants think about including children with significant disabilities. Give participants 10 minutes to work with one or two partners to complete this sentence: "Getting ready for children with significant disabilities is like taking a journey because . . ." While small groups are working, write this sentence stem on three different sheets of chart paper. Hang up the chart paper around the room.

3. As groups finish, ask them to record how they completed the sentence on one of the posted pieces of chart paper.

4. Reconvene the group and summarize the different responses. Explain that with the growing awareness of the value of all children learning together, Head Start programs are likely to include more children with significant disabilities. Taking an active role in preparing for their journey and their destination will make their trip an easier and more enjoyable one.

5. Introduce the Viewpoints activity. Tell participants that it will serve as a starting point for their journey, as they examine a number of existing attitudes and beliefs about including children with significant disabilities.

6. Distribute Handout 1–One Mother's Story. Read it aloud to the entire group.

7. Tell participants to imagine that Tyler is coming back to *their* Head Start program. Ask them to take a few minutes to jot down how they feel, and what their thoughts are about Tyler's arrival.

8. Distribute Handout 2–Viewpoints. Tell participants they will now hear a variety of perspectives about Tyler's return to Head Start. Ask for volunteers to take turns reading one viewpoint aloud to the entire group.

9. Display the chart paper with ground rules* for the Viewpoints discussion. Review the rules with participants:

   - Speak to the group, not to the group leader.
   - Listen carefully to others.
   - Speak your mind freely, but don't monopolize the discussion.
   - Don't withdraw from the discussion.
   - It is fine to challenge someone else's idea. ("I disagree with that, Jim.")
   - It is not acceptable to challenge anyone in the group personally. ("Jim, you're all wrong about that!")

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*Adapted with permission from *The Role of the Participant.* 1992. Study Circles Resources Center, P.O. Box 203, Pomfret, CT 06258. (203) 928-2616.

- Ask participants if there are other ground rules they would like to add. If so, add them to the chart paper.

10. Assign participants to small groups of 4 to 6 people. Ask a volunteer from each small group to lead the small-group discussions. Ask for a second volunteer to take notes and report to the large group 3 main points from their small-group discussion.

11. While participants move to their small groups, take participants who volunteered to lead the discussion aside. Give each group leader a copy of Handout 3–Leading the Discussion, which offers guidance for facilitating small-group discussions. Explain that their job is to help keep the conversation on track and make sure everyone follows the posted ground rules.

12. Have the leaders return to their small groups. Tell participants they will have 30 minutes to react to the viewpoints. Explain that you will be available to answer any questions, but will not participate in any one group.

13. After 30 minutes, reconvene the large group and ask the reporters to take 5 minutes to share 3 main points from their small-group discussion. Then lead a large-group discussion using the questions from the Discussion Guide below. Allow 20 minutes for the discussion.

### Discussion Guide

Use the following questions to guide the large-group discussion.

- How did you feel about the viewpoints? Which viewpoint(s) did you identify with? Which surprised you? Which made you angry or sad?
- What did your responses to the viewpoints reveal about the range of perspectives people have about including children with significant disabilities and their families? What are the similarities and differences between your own program and Tyler's program?
- How, as a program, can (do) you acknowledge diverse viewpoints about including children with significant disabilities, while at the same time committing to this effort?
- What steps can you, as an individual, take to get ready to include children with significant disabilities?
- What steps can your program take to get ready to include children with significant disabilities? What areas (existing relationships with

community service providers, facilities, curriculum, communications with families, etc.) do you need to work on? What existing strengths and processes can you build on?

**Tip for the Trainer:**

Ask participants to take notes about areas where improvement is needed and those steps they can take, individually and as a program, to get ready to include children with significant disabilities. Encourage participants to use their notes as a basis for creating a "Back Home Plan" (see Next Steps: Ideas to Extend Practice, on p. 27).

### *Summing Up*

Summarize the key ideas generated during the discussion. Point out that reflecting on attitudes and beliefs is an important step in their "journey." Staff will also need to assess other areas of the program, and identify what systems they need to have in place to get ready to include children with significant disabilities in their program. Remind participants that the system they use will depend on the unique needs and strengths of each child, the perspectives of the child's family, and the needs and strengths of staff.

## *Activity 1-2: Families First*

**Purpose:** In this role-playing activity, participants identify essential elements that contribute to positive, family-centered interactions. Such interactions are essential for forming family partnerships as outlined in the Head Start Program Performance Standards. This workshop activity emphasizes the importance of soliciting input from parents, listening to what they want and need for their children, and following their lead.

### *Preparation*

Arrange for: Easel, chart paper, markers, and tape

Duplicate:
Handout 4–Role Plays (pp. 34-37): two copies
Handout 5–Observer Worksheet (pp. 38-39): one for each participant
Handout 6–What Is Family-Centered Care? (p. 40): one for each participant
Handout 7–Principles for Providing Family-Centered Care (p. 41): one for each participant
Opening Letter from the Preface–Welcome to Holland (p. viii): one for each participant

Make: Name tags indicating the different roles in the fishbowl activity.

**Trainer Preparation Note:**

For a more in-depth discussion about family-centered care, see the Health training guide in this series, *Caring for Children with Chronic Conditions.*

### *Leading the Activity*

1. Introduce the activity and review the agenda with participants. Explain that in this fishbowl activity, participants will observe 4 different scenarios that depict interactions between Head Start staff and families who have children with significant disabilities.

2. Ask for 8 volunteers to role-play the fishbowl scenarios. Divide the volunteers into 4 pairs. Give each pair copies of the role play they will be acting out from Handout 4–Role Plays, as well as corresponding name tags to wear so that observers can easily identify the different roles played. Tell actors they will have 10 minutes to read the role plays, choose their roles, and make up a 3- to 5-minute skit.

3. Send role-play volunteers to another room to rehearse. While they are rehearsing, distribute Handout 5–Observer Worksheet to the other

participants. Review the handout with them and answer any questions they may have. Emphasize that as they observe each role play, they should put themselves in the parent's place. Ask them to note, from the parent's perspective, when the role-play conversation is going well, when there are trouble spots, and what clues they use for each (tone of voice, words used, body language, etc.).

4. Give each group up to 5 minutes to perform their role play. Do not discuss the role plays until all 4 are completed.

5. After the role plays, ask participants to share their *general* feedback about the role plays. Use the following questions as a guide:

   - In general, what did you notice? What did you see? What did you hear?

   - In general, what did you feel? What surprised you? What made you happy? Angry?

6. Hang up 2 pieces of chart paper in the front of the room. Then ask participants to share their specific responses to Handout 5–Observer Worksheet, one role play at a time. On chart paper, note observations that focus on positive family-staff interactions on one piece of chart paper, and places where improvement is needed on the other. Do not discuss the difference between the lists with participants. Allow 25 minutes.

7. Ask participants to review the different pieces of chart paper. Then ask them to identify what the answers on each piece of paper have in common. After participants share their ideas, tell them that many of the items on the "positive family-staff interactions" list are elements of strong partnerships with families. They are also elements of family-centered care.

8. Distribute Handout 6–What Is Family-Centered Care? and read it aloud. Tell participants that family-centered care offers staff new ways to think about and strengthen family partnerships. Use the following Discussion Guide to briefly discuss family-centered care and address common challenges to its practice.

9. Distribute one copy of Handout 7–Principles for Providing Family-Centered Care to each participant. Read it aloud. Point out the similarities between the elements participants identified as essential for family-centered interactions (steps 6 and 7) to the points listed on Handout 6–What Is Family-Centered Care? and Handout 7–Principles for Providing Family-Centered Care. Emphasize that such elements are essential for forming true family-staff partnerships as outlined in the Head Start Program Performance Standards.

## Discussion Guide

During the discussion, emphasize the following points:

***Staff must actively engage families.*** Family-centered care may *seem* to suggest that staff play a passive role with families and simply agree with their decisions. This is not the case, although knowing when to raise a different point of view and when to respect and accept the parents' point of view can be a challenge. In family-centered care, staff need to be actively involved—helping parents identify and explore options and weigh decisions as needed, as well as raising concerns in a respectful way when necessary.

***Staff must work with parents as collaborative partners.*** It is easy to follow a family's lead when staff agree with a family's choices. It is more difficult, though, when staff disagree with the approach the family wants to take. Emphasize that while staff may share their thoughts, ideas, differences, and concerns with parents, parents are the ultimate decisionmakers. When needed, staff must relinquish the role of the expert and respect that parents are experts in their own right. Even when there are differences of opinion, the role of staff will continue to be to assist and support parents.

***Staff must be aware of and respect cultural differences.*** Judgments about what is best for children are often very subjective, and may in fact be "culture bound." That is, what one culture considers inappropriate, might be common practice, and reinforced, in another. Staff should keep this in mind when dealing with children with significant disabilities and their families. If the family's decisions and practices are not harmful, staff should gather facts about the family's decisions within the context of their culture. On the other hand, if staff feel the family's decisions and practices may be potentially harmful, advise staff to seek consultation from professionals who are cultural "experts" and knowledgeable about disabilities.

## Summing Up

Summarize the key points from the session. Remind participants to keep in mind that staff can never presume to know what families need and want for their children, and to remember that what families want and need may change. In order to be truly family centered, staff must take the time and make the commitment to understand families from their point of view. This involves asking families directly and in different ways over time—during informal conversations in the hallway or on the phone, through letters written home, or in parent-teacher conferences.

Distribute the opening letter from the Preface–Welcome to Holland and read it aloud. Tell participants that through ongoing, honest communication with parents, staff can help parents and children on their journey; and in the process, they can even learn a bit about Holland.

## *Activity 1-3: Are You Ready?*

**Purpose:** This coaching session will help teaching teams assess their readiness to include children with significant disabilities, and develop steps to enhance these efforts.

### *Preparation*

This session has three parts: 1) discussing a child with significant disabilities who is entering the program; 2) assessing participants' readiness to include the child in terms of attitudes, knowledge about the specific disability, ability to work with parents and specialists, facilities issues, etc., and 3) using the results of the assessment to develop an action plan. At the end of the session, participants will receive an assignment: to implement the plan they developed, and evaluate their plan's effectiveness. To prepare for this session:

- Review all the directions and handouts for this session.
- Duplicate Handout 8–Taking Stock (p. 42); Handout 9–Moving Ahead (p. 43); and Next Steps: Ideas to Extend Practice (pp. 27-28): one for each participant.
- Develop a handout that describes a child with a significant disability who is entering your program. In your description, include details that will help participants examine their readiness to include the child in terms of the different issues covered in Handout 8–Taking Stock.

**Coach Preparation Notes:**

Ideally, this coaching session will be used to help teaching teams prepare for an actual child with a significant disability who is entering the program. If you do not have a child with a significant disability entering the program, you can create a description of a child the program served in the past, or may likely serve in the future. As an alternative, you can use Handout 1–One Mother's Story (p. 29) or Handout 10–Lara (p. 63).

Throughout the training, remind participants that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before participants share their descriptions of children and families in the program, make sure they fully understand issues around confidentiality.

## Conducting the Session

1. Welcome participants and briefly discuss the purpose of the session.
2. Help participants think about including children with significant disabilities by using this icebreaker. Ask participants to brainstorm endings for this sentence: "Getting ready for children with significant disabilities is like taking a journey because . . ."
3. Briefly discuss the different responses. Explain that with the growing awareness of the importance of inclusion, Head Start programs will be including more children with significant disabilities who require intensive coordination with specialists outside of Head Start. To get ready for their "journey," staff need to take stock of available resources and potential trouble spots, and then, as a team, design strategies to prepare.
4. Distribute the handout you developed that describes a child with a significant disability. Use the handout to provide participants with a "picture" of a child who will be entering the program. Encourage participants to briefly share their thoughts and feelings about having this child in their program.
5. Distribute Handout 8–Taking Stock and review it with participants. Give participants 15 minutes to complete the handout.
6. Use the following Discussion Guide to discuss participants' responses.
7. After the discussion, ask participants to describe the 2 areas they think are most important to work on now to successfully include children with significant disabilities and their families in the program.
8. Distribute Handout 9–Moving Ahead to each participant. Help participants use this handout to generate an action plan that includes 2 concrete action steps for each area targeted as needing improvement.

## Discussion Guide

Emphasize the following points during the discussion:

- ***Take time to learn about the whole child.*** Head Start staff routinely take steps to learn more about a child entering Head Start, and the process is no different when a child has disabilities. Staff can learn about the child's disability, as well as the child's past experiences, by looking at the child's records and by talking to people who know the child. For example, staff can find out what other preschools or early intervention programs the child may have attended; what her experiences were like in those settings; what outside services the child may be receiving; what types of adaptations she needs; and what kinds of resources are available in the community to assist the child and her family. If this information is not available, or if the child's parents have not signed a release form, a supervisor can suggest how to approach family members to get necessary and appropriate information. Emphasize that learning about the child's disability is an important step, but it is only the beginning. Just as with any child, it is important to learn about the child's interests and strengths, as well as her individual needs.

- ***Form family partnerships.*** The child's parents are a critical source of information as well as the ultimate decisionmakers. The partnership should begin with understanding the parents' hopes, dreams, and goals for their child. Parents can also offer important information about their child's strengths and interests, situations that the child finds difficult, strategies that they have used that were effective, and connections they have with other agencies, organizations, and specialists. (For more information about the family-centered approach, see Activity 1-2: Families First in this guide, and the Health guide in this series, *Caring for Children with Chronic Conditions*. For guidance on communicating with parents of children with disabilities, see the Disabilities Services foundation guide, *Setting the Stage: Including Children with Disabilities in Head Start,* Module 2, Activity 1: Learning from an Expert.)

- ***Help children understand the needs of their classmates.*** Children are naturally curious: if a classmate uses special equipment or has special needs, they are bound to ask questions. In order for children with disabilities to be an integral part of the program, staff must be able to communicate respectfully with and about them, so that children will feel valued for who they are and what they have to offer. (For guidance on communicating about children with disabilities, see the foundation guide, *Setting the Stage: Including Children with Disabilities in Head Start*, Module 2, Activity 3: What Should I Say?)

- ***Know the laws.*** Including children with disabilities is best practice and required by the Head Start Program Performance Standards, and is based on federal law. The laws and regulations provide individuals with disabilities and their families with essential rights to have access to and participate in critical services and program facilities. Only when staff understand these laws and regulations can they advocate for the rights of children with disabilities and their families within the program and the larger community. (For more information about the laws and regulations, see Appendix A–Services for Children with Disabilities; also see the foundation guide, *Setting the Stage: Including Children with Disabilities in Head Start*, Module 3, Activity 1: It's the Law; and the Disabilities Services guide, *Leading the Way: Disabilities Services and the Management Team,* Module 2.)

- ***Use the Individualized Education Program (IEP) or the Individualized Family Service Plan (IFSP) as a road map.*** The IEP and the IFSP provide an individualized "road map" that Head Start programs can use to meet the educational and family needs of children with disabilities. Families are the key decisionmakers in the process. Teachers and other Head Start staff also play an important role in working with parents and specialists, and in translating IEP/IFSP goals and objectives into practice. In order for Head Start staff to meet this challenge, they must first understand the language of the IEP/IFSP and key points/destinations in the IEP/IFSP process. (For more information about IEPs/IFSPs, see the Disabilities Services guide in this series, *Translating the IEP into Everyday Practice*.)

- ***Collaborate with specialists.*** Health professionals such as physical and occupational therapists, speech and language therapists, mental health professionals, and primary medical care providers offer a wide range of services to children, families, and staff. The challenge is to find the best ways to share expertise and plan services to meet a child's individual goals and objectives within a developmentally appropriate curriculum. Specialists can also help ease the child's transition from early intervention programs to Head Start, and from Head Start to public schools. (For more information about working with specialists, see *Translating the IEP into Everyday Practice,* Module 3; and Activity 2–3: Specialists in the Classroom in this guide. Also see the Social Services guide, *Community Partnerships: Working Together* and the Health guide, *Caring for Children with Chronic Conditions.*)

### *Wrap-Up and Next Steps*

Summarize the key ideas generated during the discussion. Point out that an assessment is an important step in their "journey." Ask participants, over the course of the next few weeks, to implement the action plan they created, then report back to their teaching team and supervisor about their progress.

Give participants a copy of Next Steps: Ideas to Extend Practice. Help participants choose the Next Step(s) they would like to pursue.

Emphasize that including children with significant disabilities requires a comprehensive approach: Head Start staff must work together, as well as with parents and with other professionals, to develop, implement, and evaluate concrete strategies on an ongoing basis to help children succeed.

## *Next Steps: Ideas to Extend Practice*

As a supervisor, you can encourage and support staff members to practice what they have learned in this module. Some suggestions include:

- Ask participants to use their notes from Activity 1–1: Viewpoints about steps they can take to include children with significant disabilities in order to develop a "Back Home Plan."* Each plan should include a specific goal or goals, strategies to reach those goals, and a target date for completion. For example, goals might include developing a strategy to let people in the community know that the Head Start program enrolls children with significant disabilities; adapting common classroom materials to meet the specific needs of an individual child; or working more closely with parents and specialists. Ask staff to share their plans with at least one other person.

- Feature a parent panel. Invite parents who have children with significant disabilities to talk about their experiences. Ask parents to focus on positive ways professionals have responded to the unique, evolving needs of their families and their children; and offer concrete examples of family-centered practice.

  As an alternative, ask a team (parent, teacher, manager, specialist, etc.) that has successfully included a child with a significant disability to make a presentation to other staff, parents, and consultants. Presenters may share their experiences, focusing on what strategies they used that helped them to work effectively as a team; major challenges they encountered during the process; and the benefits that were realized for children, parents, and teachers as a result of including children with significant disabilities.

  Your local speakers' bureau, state Parent Training Information Center, or your regional Training and Technical Assistance (T/TA) provider can help you identify speakers for this session.

- Arrange for participants to see the award-winning video *When Billy Broke His Head and Other Tales of Wonder* (see the Resources section). This documentary follows Billy Golfus, an award-winning journalist, who became brain injured in a motor scooter accident. Viewers see Billy on the road, talking with people with disabilities around the country. Use the video as a springboard for discussing the barriers faced by adults with significant disabilities, what inclusion really means, and the role Head Start staff can play in promoting full participation. Your regional Training/Technical Assistance (T/TA)

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*Adapted with permission from B. Wolfe. Spring/Summer 1994. Spotlight on Training Strategies: Follow-Up: A Key Component of Successful Training. *Inclusion Forum.* 2(1): 1.

provider with an expertise in disabilities services may have a copy of the video. Also check with your library or local video store.

- Another award-winning video, *Breathing Lessons: The Life and Work of Mark O'Brien* (see the Resources section), is a poignant documentary about a poet and journalist who, because of post-polio syndrome, now spends most of his life in an iron lung. *Breathing Lessons* breaks down barriers and promotes understanding by asking the provocative question, "What makes life worth living?" Your regional T/TA provider with an expertise in disabilities services may have a copy of the video. Also check with your library or local video store.

- Ask staff to compile a list of community resources for parents. Include information about parent-to-parent programs, family support groups, disability organizations, respite opportunities, and education opportunities. Be sure the resource list includes current information—complete with addresses, phone numbers, contact person, fees, hours, and exactly where services or supports are available.

  Also consider asking staff to put together a list of resources for themselves. The list could include disability organizations, as well as other training opportunities through Head Start, the local education agency (LEA), community colleges, and the regional T/TA providers.

- Create an informal support system for program and staff. Find staff from nearby early care and education programs (Head Start, child care, preschools) in your community who welcome and serve children with disabilities. Create a buddy system for individual support, and provide opportunities for staff to meet and visit each other's programs.

- Ask staff to assess toys, posters, and other materials displayed throughout the program. Do these materials include images of individuals with disabilities that focus on the individuals, their capabilities, and their activities? For instance, are there puzzles, books, and posters that show people with disabilities engaged in activities and pursuing interests? After the assessment, involve staff in developing a plan for making needed improvements. As they develop their plan, encourage staff to learn more about children's books and materials that sensitively reflect the lives and abilities of individuals with disabilities. Refer staff to the Resources section of the Disabilities foundation guide, *Setting the Stage: Including Children with Disabilities in Head Start,* which includes information about books, toys, and posters showing individuals with disabilities participating in schools and in their communities.

## Handout 1: One Mother's Story

It all started in October. Tyler was four then. He had been vomiting and his fever was high. The doctor said it was just a flu, not to worry, just to make sure he had lots to drink. But he didn't get better. On October 22, he had his first seizure. After that, the testing began. I remember going for the CAT scan. On the way to the hospital, Tyler said he wanted french fries. "Later, Tyler," I told him, remembering that the doctors had given a "no food" order before the procedure. "But mommy, I'm hungry," he said. I just started crying. It wasn't just the french fries. It was that Tyler needed something, and I couldn't give it to him. In so many ways, I just couldn't help him.

That fall was such a whirlwind. We practically lived in doctors' offices. It was the neurologist who noticed right away that Tyler's gait was off. And things began to click then—why Tyler always had so many black and blues, why he was always falling. And it wasn't just that he had inherited my clumsiness. The MRI revealed the tumor. On November 15 at 8 A.M., Tyler was wheeled into the operating room. Seven hours later, the surgeon told us Tyler had a rare brain tumor. Then he patted my shoulder, and said, "I know how you must feel." I hit the roof. I yelled, "Have you ever watched your child just slip away? So you can barely recognize the person you love the most?" The surgeon looked away then. "No," he said quietly. "Well, then," I replied, beginning to break down, "please don't tell me you know how I feel."

They say that when Tyler recovers from surgery, he can go home. But he'll need a lot of help every day—from teachers, occupational therapists, physical therapists, speech therapists, and from us. I know that the little boy that's coming home won't *seem* like the same Tyler we knew three months ago. Because of the operation, he may still have seizures. He can barely talk now. He's practically deaf in one ear. He stumbles a lot. Going up stairs is like climbing mountains. They just don't know how much, or if, he will improve. He has so many needs! But I also know what Tyler really needs right now—to be home with his family, and to be with his friends at Head Start.

## Handout 2: Viewpoints

### Viewpoint 1

I am excited about Tyler going back to Head Start. I mean, he needs to be there. But I'm nervous. I know people have been really supportive. His friends send him cards. His teachers have visited. But I know that the Tyler who's going back won't *seem* like the same little boy they knew three months ago. I just hope that he won't be seen for what he's NOT but for what he is, what he has to offer, and what he can be. And what if other kids make fun of him?

### Viewpoint 2

I'm really afraid about Tyler coming back. There's so much we need to know to take care of him. What if something happens? Will we know what to do?

### Viewpoint 3

I feel bad for Tyler. But I don't want my kid to lose out because of him. Everyone knows that the teachers are going to end up spending lots of time with Tyler when he comes back. He just needs *so* much. And as a result, the other kids won't get the time and attention they deserve. It isn't fair.

## Handout 2: Viewpoints (page 2)

### Viewpoint 4

We've all been holding our breath, just hoping Tyler would pull through. When his mom called us a few weeks after the operation to say he was going to pull through, we all cheered. I'm happy he's coming back, but I'm nervous, too. What if he has a seizure? What if we end up hurting him? And how much can I really take on? Already, so much falls on my shoulders. If someone spills their juice, or has an accident, or needs to be held, I'm the one who's expected to be there. So what's going to happen when the "extra pair of hands" needs a few extra pair of hands?

### Viewpoint 5

Change has always been hard for me. It's not easy for any of the kids in my classroom either. And things are *really* going to change when Tyler gets back. I mean, there will be occupational therapists and physical therapists and speech therapists parading in and out of my classroom, working with Tyler, working with me. Whose classroom will it be then?

### Viewpoint 6

I don't see what the big deal is. I mean, we *know* Tyler. So now he walks a little funny, he can't hear as well, and his speech is off. Maybe if I hadn't been in Vietnam I wouldn't think this way. But during the war, too many guys came home disabled; and I swear, people acted like they had "reject" stickers plastered all over them. No one deserves that kind of treatment!

## Handout 2: Viewpoints (page 3)

### Viewpoint 7

I used to think that Head Start shouldn't accept kids with significant disabilities. It's not that they didn't belong, but more that we don't have the resources or the training to give them what they need. But Tyler's situation has helped me think about things differently. He *is* coming back, and we need to do the best we can to welcome him and provide a program that gives him what he needs. Yes, it will mean lots of work, conversations, and negotiations, but it's something we *need* to do. For Tyler and for other kids like him.

### Viewpoint 8

I'm sorry, but I just don't think Tyler belongs here anymore. Yeah, I feel bad for him and his family. But we all have to face the facts. Head Start isn't the right place for him. He should be in a special program.

### Viewpoint 9

I'm excited about Tyler coming back. If that happened to my child, I would be devastated. I don't know how his mother is doing it. But it's nice to know, no matter what, Head Start will be there to help.

## Handout 3: Leading the Discussion

**The story and viewpoints will probably generate discussion on their own. As you lead the discussion, keep these points in mind:**

- Keep the conversation focused on the topic. Gently remind participants to focus on the topic if they begin to "wander off."
- If the discussion lags, don't panic. Give the group a few moments to think about what they are hearing, and how they would like to respond.

**Use the following questions to guide your discussion:**

- Which viewpoint(s) do you identify with?
- Which viewpoint(s) surprised you? Why?
- Did any of the viewpoints offend you? Why?
- What viewpoint(s) do you think are missing?
- How, as a program, can you acknowledge diverse viewpoints about including children with significant disabilities without undermining the effort?

As a group, choose 3 main ideas from your discussion that the reporter will share with the large group.

## Handout 4: Role Plays

### ROLE PLAY 1

Read the descriptions of the different roles. Then, with your partner, decide which role you will each play and plan a 3- to 5-minute skit. When the scene begins, the disabilities services manager is meeting with Alma.

### Alma, Parent

Your child, Jesse, is enrolled in Head Start. You always suspected there was something different about her. But then you'd tell yourself she'd just grow out of it, whatever it was. But now you have a diagnosis. Autism. How can a word with six letters seem so big, so dark? You feel so lost and confused. The professionals keep trying to explain what it means, what you'll need to do, who Jesse will have to see, what can be helpful, what to avoid, what choices you'll need to make . . . But you can't follow it anymore. You can't hear anything anymore. You now have a meeting with the disabilities services manager. You know what you want from her. You just want her to decide what's best!

### Tina, Disabilities Services Manager

You don't want to make any decisions for Alma. You feel like it's your job to help *her* decide what is best. Even if Alma asks you what to do, continue to remind her it's her decision and that you are there to support her.

## Handout 4: Role Plays (page 2)

### ROLE PLAY 2

Read the descriptions of the different roles. Then, with your partner, decide which role you will each play and plan a 3- to 5-minute skit. The scene takes place at a parent-teacher conference. In this skit, the parent and teacher disagree about the best way to provide disabilities services.

### Tracy, Parent

Your two-year-old child, Kabir, is enrolled in Early Head Start. Now that it's getting warmer, his asthma is starting to act up, especially when he plays outside. He's wheezing more, coughing more, and it's hard for him to catch his breath. You tell his teacher that you don't want him playing outside anymore. It's just not healthy for him. His teacher disagrees.

### Catherine, Teacher

Kabir loves to play outside with his friends. Now his mother wants you to keep him indoors all the time, even when his friends are playing outside. Staff coverage is certainly a problem. But it's more than that. Kabir needs to be with his friends, and why shouldn't he be, if his asthma can easily be controlled with medication? You know we're supposed to be "family centered," but when kids suffer as a result, how can you go along with it?

## Handout 4: Role Plays (page 3)

### ROLE PLAY 3

Read the descriptions of the different roles. Then, with your partner, decide which role you will each play and plan a 3- to 5-minute skit. The scene takes place during a home visit.

**Kenny, Parent**

Your child, Lara, is enrolled in Head Start. It's the first time she's ever been in a class without other children with disabilities. She loves to be with other kids, but you're so afraid they won't understand how fragile she is. Just six months ago she fractured her leg, and no one figured it out! So what will happen when her friends decide to play rough? Or bump into her? In her early intervention program, there were always nurses and therapists around. You knew she was safe. You knew she was getting the help she needed. You're just not sure Head Start is the right place for her.

**Margarita, Family Advocate**

When you visit with Lara's father, you tell him Lara is going to have a great time at Head Start. You say that she'll really benefit from being around her peers and that other children will learn a lot from her. When he talks about his fears, you tell him that he has nothing to worry about. She's in the right program and everything will be fine.

## Handout 4: Role Plays (page 4)

### ROLE PLAY 4

Read the descriptions of the different roles. Then, with your partner, decide which role you will each play and plan a 3- to 5-minute skit. When the scene begins, the bus driver bumps into Emily and they talk briefly.

**Emily, Parent**

Your child, Tyler, is returning to Head Start after major surgery to remove a brain tumor. Because of his surgery, he is a different kid in lots of ways. He has a lot more needs. You want him to get the attention he needs from teachers and specialists and doctors. But more than anything, you want him to have what all kids deserve—a chance to be part of a community—to laugh, and play, and sing, and work side by side with his friends.

**Joseph, Bus Driver**

You have always liked Tyler. He was always quite the comedian. And sweet, too—would never go anywhere without Otis, his pet moose. Sometimes you'd call Tyler "Moose" and this great smile would break out on his face. You haven't seen Tyler since he had surgery, but you know he'll be coming back soon. You get sad just thinking about all he's been through. When you see Emily, you ask about how she's doing, and about "Moose." You talk about the upcoming meeting to plan for Tyler's return. Then you ask if there's something that you could do to help Tyler when he starts riding the bus again.

## Handout 5: Observer Worksheet

As you observe each role play, consider the interaction from the parent's point of view. Then note, also from the parent's perspective, when the interaction is going well, when there are trouble spots, and what clues you use for each (tone of voice, words used, body language, etc.).

### Role Play 1

| Positive (explain why) | Needs to be different (explain why) |
|---|---|
| | |

### Role Play 2

| Positive (explain why) | Needs to be different (explain why) |
|---|---|
| | |

## Handout 5: Observer Worksheet (page 2)

### Role Play 3

| Positive<br>(explain why) | Needs to be different<br>(explain why) |
|---|---|
| | |

### Role Play 4

| Positive<br>(explain why) | Needs to be different<br>(explain why) |
|---|---|
| | |

## Handout 6: What Is Family-Centered Care?

Since its inception, Head Start has been committed to respecting parents as the primary teachers and caretakers of their children. Head Start has also always valued strong family partnerships.

Family-centered care, a growing practice within the medical community, can offer Head Start useful ways to think about and strengthen family partnerships.

**Family-centered care represents a fundamental shift in thinking and practice:***

- ✓ from a disease and deficit focus to one that identifies and builds on individual and family strengths;
- ✓ from reliance on professional and institutional expertise towards partnerships and collaboration; and
- ✓ from practices that foster dependency to those that empower children and families.

Information sharing, respect, and collaboration between families and staff are cornerstones of family-centered care.

Family-centered care encourages service providers to actively engage parents as collaborative partners and to give up the role of "expert."

In family-centered programs, staff actively invite and respond to the *family's* preferences, priorities, and choices. Families are honored and respected as the key decisionmakers and caregivers for their children.

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* Reprinted with permission from B. Johnson and M. Fondrick. 1997. *Moving Toward Family-Centered Care: Examining Policies, Programs, Design, and Practices*. Bethesda, MD: Institute for Family-Centered Care.

## Handout 7: Principles for Providing Family-Centered Care*

Head Start staff can strengthen their partnerships with families and promote family-centered care by incorporating the following principles into practice and policy:

- ✓ Recognize that the family is the constant in a child's life, while the program, staff, and services within the delivery system change over time.
- ✓ Actively solicit and respond to the family's preferences, questions, and needs.
- ✓ Exchange complete and unbiased information with families which takes into account their different needs and coping strategies.
- ✓ Honor individual, family, and cultural diversity and strengths.
- ✓ Assure that the program's support systems are flexible, accessible, comprehensive, and responsive to the needs of all children and their families.
- ✓ Facilitate and encourage family-to-family support and networking.
- ✓ Strengthen family partnerships at all levels in the way you:
  - ✓ care for children with disabilities and their families
  - ✓ develop, implement, evaluate, and refine programs for children with disabilities
  - ✓ form and strengthen policies for children with disabilities and their families.
- ✓ Appreciate families as families and children as children. Recognize that all families and children possess a wide range of strengths, concerns, emotions, and aspirations beyond their need for specialized health and educational services and support.

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*Adapted with permission from T. Shelton and J. Stepanek. 1994. *Family-Centered Care for Children Needing Specialized Health and Developmental Services.* Mount Royal, NJ: Association for the Care of Children's Health.

## Handout 8: Taking Stock

Rate each of the following items on a scale of 1 to 10. Then prioritize the items and place an asterisk (*) next to the 2 areas you would like to work on.

| 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
|---|---|---|---|---|---|---|---|---|---|
| **Always** | | | | **Sometimes** | | | | | **Never** |

| Areas | Rating |
|---|---|
| 1. I am knowledgeable about the specific disability. | |
| 2. I feel comfortable gathering information from different sources to better understand the child's needs, strengths, and interests. | |
| 3 I feel comfortable working with the child. | |
| 4. I am able to see the child first, and not the child's disability. | |
| 5. I am willing to understand the child's family from their point of view, and follow their lead in doing what they believe is best for their child. | |
| 6. I understand how to identify and tap into existing community resources and services that may be responsive to families' needs and interests. | |
| 7. I feel comfortable answering other children's and parents' questions about the child's disability. | |
| 8. I understand the laws and regulations that protect the rights of persons with disabilities, and how they apply to the program, to my role, and to this particular child. | |
| 9. I understand how to evaluate the accessibility of program facilities and services and develop strategies for reasonable accommodation. | |
| 10. I understated my role in implementing the child's Individualized Education Program (IEP)/ Individualized Family Service Plan (IFSP). | |
| 11. I feel comfortable accessing the resources I need to better understand the child's IEP/ IFSP, and translating the goals contained in it into everyday practice. | |
| 12. I feel comfortable working with outside specialists and incorporating their expertise into my day-to-day practice. | |
| 13. I understand how assistive technology can aid a child with disabilities. | |
| 14. I understand my role, and the resources I can use, in planning for the child's transition as she moves from early intervention to Head Start, and/or from Head Start to public schools. | |

## Handout 9: Moving Ahead

| Area to Work On | Two Action Steps | Target Date for Completion |
|---|---|---|
| <u>Example</u><br>The laws and regulations that protect the rights of persons with disabilities | 1. Talk with the disabilities services manager and the T/TA provider in my region | March 15 |
| | 2. Contact the regional Disability and Business Technical Assistance Center | March 30 |
| | | |
| | | |
| | | |
| | | |

# Making It Work

## *Outcomes*

After completing this module, participants will be able to:

- Identify and formulate strategies for collaborating more effectively with parents of children with significant disabilities, related service providers, and other Head Start staff.
- Develop a systematic approach for adapting the environment and the curriculum to support the meaningful participation of children with significant disabilities in Head Start programs.

## *Key Concepts*

- Children with significant disabilities, like all children, do best in a developmentally appropriate program where they can grow and learn at their own individual pace with their peers.
- Including children with significant disabilities requires additional supports and services and ongoing collaboration between parents, Head Start staff, and related service providers. The Individualized Education Program (IEP) and the Individualized Family Service Plan (IFSP) provide the road map for such supports and services.
- Parents of children with significant disabilities have a deep understanding of their child's strengths and needs. Head Start staff must use parents' expertise, experience, preferences, and skills to plan and implement quality education programs for their children.

## *Background Information*

According to the Head Start Program Performance Standards, teachers must develop and implement a curriculum that is individualized to support each child's social, emotional, cognitive, language, and physical development. A child with significant disabilities will also require an IEP or an IFSP to meet the child's individual needs for special education and related services.

What kind of adaptations and interventions will Head Start programs need to make as they reach out to, and include, increasing numbers of children with significant disabilities? Head Start staff will need to work with parents and specialists to adapt the curriculum, including the physical environment, materials, routines, and transitions.

Within the classroom, physical or environmental adaptations may vary from rearranging the room for easy access for a child who uses a wheelchair, to making sure that a child who is learning sign language has a clear view of the speaker in group situations.

Many adaptations that initially seem specialized for a child with a disability can ultimately benefit all children. Art materials and toys that are clearly organized and accessible support independent exploration by all children. Likewise, outdoor play equipment adapted for children with disabilities will often be safer and more accessible for all children.

Other adaptations, like building a ramp or putting support bars in the bathroom, will require an initial outlay of extra time and money. Once done, however, the program will be ready for other children and adults with similar needs.

Head Start staff will not have to "go it alone" as they plan and implement adaptations for children with significant disabilities. Community partners such as special education professionals and related service providers, as well as parents, are essential team members in this effort.

The success of a child's educational program depends on a seamless blend of individualized and developmentally appropriate curriculum, collaboration with family members and specialists, responsive supports and adaptations, and integration of goals and objectives from the IEP or IFSP into the child's daily routine. Developing a systematic approach requires an ongoing partnership among staff, parents, and service providers.

For an overview of the activities in this module, see At A Glance on pp. 6-7.

**Trainer and Coach Preparation Notes:**

What is a significant disability? A significant disability is not defined solely by diagnosis. Rather, it is related to the extent of adaptations and services that a child needs. In general, children with significant disabilities require more everyday modifications (for example, use of adaptive materials and equipment) and more intensive coordination with outside specialists. For more information about specific disabilities, review the appendices. While the information covered is not the focus of the training, participants may have questions about these topics during activities.

Emphasize that learning about specific disabilities is only one step in the process. Just as with any child, it is important to know about the child's interests, strengths, and needs.

Also remind participants that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before participants share their descriptions of children and families in the program, make sure they fully understand issues of confidentiality.

## *Activity 2-1: Lara's Story*

**Purpose:** Including children with significant disabilities and their families involves careful planning and collaboration. This workshop activity is designed to help staff identify strategies for promoting collaboration between a child's parents, Head Start staff, and related service providers as they plan, coordinate, and provide services.

## *Preparation*

| | |
|---|---|
| Arrange for: | Easel, chart paper, markers, and tape |
| Duplicate: | Handout 10–Lara (p. 63): one for each participant<br>Handout 11–Planning Worksheet (pp. 64-65): one for each participant |

**Trainer Preparation Note:**

This activity focuses on Lara, a child with spina bifida. For more information about spina bifida, review Appendix C–Spina Bifida Fact Sheet. To learn more about best practices for including children with special health needs, see the Health guide in this series, *Caring for Children with Chronic Conditions.*

## *Leading the Activity*

1. Introduce the activity and review the agenda with participants.
2. Distribute Handout 10–Lara, one to each participant. Read it aloud to the entire group.
3. Tell participants to imagine that Lara is enrolling in *their* Head Start program, and that they will be Lara's teacher. Ask participants to take a few minutes to jot down how they would feel about having Lara in their classroom.
4. Ask for volunteers to share some of the reactions they jotted down. During the discussion, point out that although including children with significant disabilities requires extra time and energy to coordinate, plan, and implement the program, Head Start staff do not have to "go it alone." Community partners, such as special education professionals and related service providers, as well parents, are essential team members in this process.
5. Tell participants that in the next part of the activity, they will work in small groups to identify how they, as teachers, would collaborate with Lara's mother, her occupational and physical therapists, her home health care nurse, and the program's health and disabilities services

managers to plan Lara's smooth entry into the program. Distribute Handout 11–Planning Worksheet and review it with participants.

6. Divide participants into groups of 4 to 6 people. Ask for one volunteer from each group to facilitate the small-group discussion, using Handout 11–Planning Worksheet as a guide. Ask for another volunteer from each group to record the main ideas and then report the information to the larger group. Allow 25 minutes for the small-group discussion.

7. At the end of the 25 minutes, ask the volunteers from each small group to report back to the larger group, using their completed Handout 11–Planning Worksheet.

8. Summarize the responses from the small groups, using the Discussion Guide below to focus on key points.

## Discussion Guide

*What else do you need to know to facilitate Lara's smooth entry into Head Start? Whom might you ask?*

As the teacher, you will be in charge of Lara's day while she is in the program. You need to ask *every* question that you have and use every resource you think might help to promote Lara's full participation. This might include asking team members for help in developing strategies for adapting the curriculum, classroom materials, and the environment. You can also consult other resources: other staff, managers, your regional Training and Technical Assistance (T/TA) provider with an expertise in disabilities services, other specialists who work with Lara and her family, including her primary medical provider, and national and community agencies that offer information and support for children with disabilities and their families.

*What else do you need to know to promote Lara's participation in the daily routine? Consider such topics as curriculum, classroom setup, outdoor play area layout, bathroom setup, lunch table arrangement, field trips, scheduling, and transportation.*

The key to successful inclusion is planning together with the team how a child with significant disabilities will participate in the daily program routine. Specialists who have worked with Lara and her parents are important sources of information. In your conversations with them, for instance, you may discover that a simple rearrangement of furniture may make it easier and safer for Lara to use her walker in the classroom. You may also realize that you do not need to change the curriculum, or that simply placing materials within Lara's reach will make her more independent. A safety swing might enable Lara to swing with the other children. A special private area set aside in the bathroom might help Lara with her toileting needs. Planning ahead, and thinking through the details with parents, staff, and specialists who already know Lara and her family, is key.

*What logistics do you need to work out before Lara enters the program?*

Before Lara arrives at the program, you need to work out a range of logistics. This includes transportation; emergency planning; the nature and extent of in-class service delivery; getting Lara from one activity to another, both indoors and outside; using the bathroom; classroom set-up; and scheduling her therapy. Making sure that you work out these logistics ahead of time, and that specific plans are in place, will make Lara's entry into the program much easier for her and her family as well as for program staff.

*How will you continue to involve Lara's mother in planning, implementation, and evaluation?*

Point out that parents of children with significant disabilities face complex challenges in many areas of their child's care. They are the experts about their child's individual strengths and needs, and will be their child's primary support and advocate far into the future. Staff must not only listen to parents; they should also support parents' development as their child's advocate. Trust between parents, teachers, and specialists depends on ongoing communication about specific concerns and possible solutions.

It is also important to remember that Lara's mother is just learning about your "system." You need to help her learn about the program, and at the same time, be willing to make whatever adjustments you can to respond to Lara's needs. Emphasize that parents are a primary resource of information, as well as the ultimate decisionmakers about their children's lives. The process of collaboration should begin with understanding Lara's mother's hopes, dreams, and goals for her daughter.

*How will you continue to involve other team members in planning for and documenting Lara's progress?*

In addition to planning ahead, staff must also be prepared for unexpected changes and resulting needs. For Lara, new medication for a bladder infection, for example, may make her sleepy. Her leg braces could become too small, and irritate her skin or get in the way of her walking. Informal, consistent communication such as a daily journal which goes home every day can help parents, staff, and specialists stay in touch, sharing successes as well as staying aware of changing needs.

Furthermore, regular contact with her primary care provider or "medical home" will facilitate effective communication among all parties as questions arise.

*What other questions, concerns, or fears do you have?*

Point out that including children with significant disabilities requires extra time and energy for planning, coordination, and implementation. Even when participants enter the process with a positive attitude, anxiety about dealing with new and challenging problems, fear of hurting a child, and concern about more work added to an already overloaded schedule, can create negative feelings. Careful planning, strong cooperation, and open communication between parents, staff, and specialists, as well as a flexible approach to each day's activities, can lead to positive feelings of accomplishment and pride. In learning about Lara and how to include her in the program, staff are expanding their knowledge and skills, which will benefit other children, with and without disabilities.

Finally, remind participants that Lara is a three-year-old child. Her moods, wants, and reactions will most often be typical for a child her age. Staff should therefore be sure to react first to Lara as they would to any child her age, and then consider factors that may be related to her disability.

## Summing Up

Successfully including a child with significant disabilities involves careful planning, coordination, and integration of information and services. Parents are the experts on the strengths and needs of their children, and are always the ultimate decisionmakers. Head Start staff must collaborate on an ongoing basis with parents, specialists, and each other to plan programs, make appropriate adaptations, and communicate needs as the child grows and learns.

## *Activity 2-2: Preparing Your Classroom*

**Purpose:** This workshop activity will help participants analyze the needs and strengths of children with significant disabilities, then plan adaptations to promote full participation.

## *Preparation*

Arrange for: Easel, chart paper, markers, and tape

Duplicate: Handout 12–Adaptations (p. 66 ): one for each participant
Handout 13–Worksheet (pp. 67-69): one for each participant
Handout 14–Integration Checklist (pp. 70-72): one for each participant

## *Leading the Activity*

1. Introduce the activity and review the agenda with participants. Point out that including children with significant disabilities requires that they understand the child's Individualized Education Program (IEP), and then make adaptations so that each child can participate in every aspect of the program.

2. Ask for volunteers to describe how they have adapted a routine and/or activity to meet the needs of a child with disabilities in their program.

3. Distribute Handout 12–Adaptations and review it with participants. Ask participants for other examples to include under each category.

4. Divide participants into small groups of 3 to 5. Ask for a volunteer from each group to read the vignettes, a second volunteer to record the main ideas from the group's discussion, and a third volunteer to report back to the entire group.

5. Distribute Handout 13–Worksheet and review it with participants. Assign each group at least 2 vignettes to work on. Make sure that more than one group is working on the same vignette so that during the follow-up discussion, small groups can compare their responses. Encourage participants to be creative with their responses.

6. Give small groups 15 minutes to read the vignettes and identify possible adaptations to promote full inclusion. Midway through the time allotted, remind participants to move on to their second vignette.

7. At the end of 15 minutes, reconvene the entire group. Ask the reporter from each small group to briefly describe the children they were assigned, the types of adaptations they felt were needed, and any questions they had. Note similarities and differences between the groups' responses. During the discussion, emphasize that the child's IEP provides a road map for meeting specific goals and objectives, and also pinpoints specialists who can serve as resources in planning adaptations.

8. Distribute Handout 14–Integration Checklist and review it briefly. Ask participants how they might use the checklist to plan adaptations to promote full participation in the future.

### *Summing Up*

Children with significant disabilities can and should participate in every aspect of the Head Start program. The challenge for staff is to adapt routines and activities in the most natural ways possible so that every child can participate in a developmentally appropriate program, while also meeting individual goals and objectives. Analysis of needs, careful planning, and collaboration are the keys to successful inclusion.

## *Activity 2-3: Making Changes*

**Purpose:** During this coaching session, participants analyze the strengths and needs of children with significant disabilities, then use their analysis to plan adaptations to promote full participation.

### *Preparation*

This session has two major parts: 1) discussing environmental, curriculum, and material adaptations; and 2) identifying which types of adaptations participants can make in their own classrooms to promote full participation. At the end of the session, participants choose which Next Step(s) they will work on to extend their learning. To prepare for this session:

- Review all the directions and handouts for this session.
- Duplicate Handout 12–Adaptations (p. 66); Handout 14–Integration Checklist (pp. 70-72); and Handout 15–A Closer Look (p. 73): one for each participant.
- **Important Note**: Prior to the session, distribute Handout 15–A Closer Look (p. 73) to participants, and ask them to complete it and bring it to the session.
- Arrange for an easel, chart paper, markers, and tape.

**Coach Preparation Notes:**

All families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Therefore, if more than one participant is involved in this coaching session, suggest that they remove any information that would identify the child they will be discussing before the session begins.

If participants do not have a child with a significant disability in their classroom, you may create descriptions of children with significant disabilities who have been, or may soon be enrolled in the program. The descriptions should include information about the children themselves, the types of activities the children enjoy, what situations they have difficulty with and why, and particular strengths and weaknesses in different developmental domains (social, emotional, cognitive, language, and physical) that impact their ability to fully participate in the classroom. As an alternative, you may have participants analyze the needs of children described in Handout 13–Worksheet (pp. 67-69).

## Conducting the Session

1. Introduce the session and review the agenda with participants. Point out that including children with significant disabilities requires reviewing and understanding the child's Individualized Education Program (IEP), and then making adaptations based on the IEP so that each child can participate in every aspect of the program.

2. Distribute Handout 12–Adaptations to each participant and review it together. Then lead a *brief* discussion about the importance of careful planning for each part of the day for a child with significant disabilities, including adapting the environment, curriculum, and materials, as well as planning for transitions. Ask participants for other examples of each type of adaptation.

3. Tell participants that during this part of the activity, they will analyze descriptions of children with significant disabilities, and then plan for their inclusion in specific activities. Ask participants to take turns reading aloud the handout they completed prior to this session, Handout 15–A Closer Look.

4. For each child described, ask participants to identify environmental, curriculum, and material adaptations they could make to promote full inclusion. During the discussion, encourage participants to take into account not only the children's difficulties, but also their interests and strengths. Point out that Head Start staff can often capitalize on a child's strengths and interests to meet IEP objectives and goals.

5. Distribute Handout 14–Integration Checklist and review it with participants. Together, brainstorm how they might use the checklist to promote full participation for individual children in their classroom.

## Wrap-Up and Assignment

Close the discussion by emphasizing that children with significant disabilities may be able to participate in every aspect of the Head Start program. The challenge for staff is to find ways to adapt routines and activities in the most natural ways possible to promote full participation, while also meeting IEP goals and objectives. Emphasize that collaboration is key: Head Start staff must work as a team with each other, as well as with other professionals and with parents, to plan, implement, and evaluate strategies to help children participate and succeed.

Over the course of the next few weeks, ask participants to implement the adaptations they identified in this session to promote the full inclusion of a child in their classroom. Suggest that participants carefully observe and document the child's responses, and share the results with the child's parents and others who work with the child.

## *Activity 2-4: Specialists in the Classroom**

**Purpose:** Health professionals such as physical and occupational therapists, speech and language therapists, mental health professionals, and primary medical care providers offer a wide range of services to children, families, and staff. The challenge is to find the best ways to work as a team. In this workshop activity, participants read a series of vignettes and then discuss implications for working with specialists in their program.

### *Preparation*

| | |
|---|---|
| Arrange for: | Easel, chart paper, markers, and tape |
| Duplicate: | Handout 16–Scenes from the Classroom (p. 74): one for each participant<br>Handout 17–Problems and Solutions (pp. 75-76): one for each participant<br>Handout 18–Finding the Right Consultant (pp. 78-79): one for each participant<br>Handout 19–Orienting Consultants (p. 79): one for each participant |

**Trainer Preparation Note:**

Before beginning this activity, refer to Activity 3-2: I Can Do It Myself, in the Disabilities Services guide, *Translating the IEP into Everyday Practice.* Information and handouts from the activity may be useful during this session when discussing specialists' roles and responsibilities, and strategies for collaboration.

### *Leading the Activity*

1. Introduce the activity and briefly review the agenda. Remind participants that there are different ways that specialists become involved in a classroom. In most cases, specialists will be identified in the child's Individualized Education Program (IEP). Some specialists will have worked with Head Start before, while others may have little experience in working in Head Start or with preschool-age children. The challenge for consultants and Head Start staff is to find the best way to share expertise and plan services together in order to meet a child's IEP goals and objectives within a developmentally appropriate curriculum.

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* Adapted with permission from M. Enright, M. Antes, and J. Brophy. 1992. *Making the Most of Consultants*. Newton, MA: Education Development Center, Inc.

2. Ask participants if they have worked with specialists in their programs before. Then ask several volunteers to share one experience with a consultant that worked well, and one experience with a consultant that they wish they could change. Remind participants not to mention any names of children or consultants. Ask participants what they could have done to make negative experiences more positive.

3. Tell participants that in the next part of the activity, they will first identify problems that may arise when working with specialists, and then come up with solutions. Divide participants into small groups of 4 to 6 people. Distribute Handout 16–Scenes from the Classroom, and Handout 17–Problems and Solutions, one to each participant. Briefly review each handout with participants.

4. Read aloud the scenarios from Handout 16–Scenes from the Classroom to the entire group. Then allow small groups 15 to 20 minutes to discuss the vignettes and complete Handout 17–Problems and Solutions.

5. While the groups are working, title 3 pieces of chart paper "Scene 1," "Scene 2," and "Scene 3," and then write "Problems" and "Solutions" on each. Hang these 3 sheets in the front of the room.

6. After 20 minutes, ask one person from each small group to record their group's problems and solutions for the 3 scenes on the corresponding piece of posted chart paper. Then reconvene the large group for discussion. Use the Discussion Guide below to highlight common problems and solutions.

7. Distribute Handout 18–Finding the Right Consultant, and Handout 19–Orienting Consultants, one to each participant. Review these handouts briefly and explain that they can be used as guides to help Head Start staff and specialists establish clear communication about responsibilities and expectations, and create a truly collaborative team spirit.

## *Discussion Guide*

### *Whose Classroom Is This, Anyway?*

*What causes "turf" issues? How do you think they could have been avoided in this situation?*

Turf issues can easily arise when there is no well-defined plan for how specialists work in the classroom. Individual solutions will depend on the experiences, perceptions, and needs of the people involved. But there are some ways that the problems might have been avoided in the first place. In this situation, the teacher and therapist could have agreed at the beginning of the relationship that they will discuss any change in procedure ahead of time. Once the incident did occur, the teacher could have taken a moment to speak with the therapist, rather than assume disregard on the part of the specialist—an assumption which would only lead to increased tensions.

In general, it is important for teachers and therapists to clearly communicate their own needs and expectations, and to respect each other's role and responsibilities. Figuring out ahead of time what the schedule is, how and where services will take place, and how progress and changes will be communicated, can help to avoid problems in the long run.

### *This Teacher Must Not Care . . .*

*Why is communication between parents, teachers, and therapists so important? How can communication be improved?*

Unfortunately, it is sometimes difficult to know how and when the specialist will connect with a child's parents, teachers, and other staff who work with the child. However, this communication is critical for several reasons. First, it enables the specialist both to provide services that reinforce the goals of therapy and to update Head Start staff and parents on the child's progress. Second, it gives teachers and parents an opportunity to provide feedback or recommendations, ask questions, or find solutions to problems together with the specialist. Creating time for this communication also reinforces the notion that the specialist is available to support the child, parents, and teachers.

Most specialists' schedules cover time to work with children on a one-to-one basis or with small groups. They are often expected to produce billable hours, and these hours are generally for direct client contact only. Unfortunately, private and third-party payers usually do not reimburse specialists for meeting time with the classroom staff, parents, or other consultants.

Yet, there are a number of solutions to problems in this scenario. For example, the teacher and the specialist could have agreed ahead of time not to discuss Beth's progress during class time, especially in front of other children, except very briefly. The teacher could have acknowledged how well Beth is doing, then tell Beth and the specialist she is busy right now, but would like to plan to observe therapy on another day. Lastly, the teacher could have let the therapist know when the therapist first came into the room that she could not take time to observe Beth today. One of the most effective solutions is for the teacher, specialist, and parents to set up a system of formal and informal communication, ahead of time, to share information on a regular basis.

### *She Should Get Her Priorities Straight!*

*Why don't some specialists understand how a preschool classroom is run? How can a teacher make sure specialists understand classroom routines and procedures when they are not there every day?*

Without a proper orientation to the program and the classroom, the teacher might assume that the specialist knows or can quickly understand the philosophy, rules, and routines of the classroom. The specialist, however, is focused on completing Timmy's evaluation. Specialists often find themselves in many classrooms, each with their own set of expectations and rules, so it is not reasonable to assume the specialist will automatically know what is appropriate for your classroom.

Teachers can help specialists understand their own classrooms in a number of ways. For instance, the teacher and specialist could have had an orientation meeting to discuss classroom procedures and philosophy (see Handout 19–Orienting Consultants). The contract could have stipulated that before the specialist provided services, she must observe or participate in the classroom, then meet with the teacher to discuss mutual concerns and issues. The program staff could also develop a packet of information to be given to all consultants. The packet might include the program philosophy, rules and routines of the classroom, and any special procedures or activities that could influence how the specialist works in the program.

## *Summing Up*

Working together, families, staff, and specialists can provide a child with significant disabilities with a developmentally appropriate program which supports the child's individual needs, while also ensuring full participation. The challenge is for everyone to recognize that each person brings different skills, knowledge, and experience to the process, and that the child and her family will benefit most if they receive a comprehensive, consistent, and unified program. In such collaborative efforts, communication is key.

## *Activity 2-5: Working As a Team**

**Purpose:** In this coaching session, participants identify strategies for working with specialists in their program.

### *Preparation*

This session has two major parts: 1) reading a series of vignettes that highlight some of the challenges Head Start staff experience in working with specialists; and 2) identifying strategies staff can use to share expertise and plan services together with specialists in order to meet a child's Individualized Education Program (IEP) goals and objectives. At the end of the session, participants choose which Next Step(s) they will work on to extend their learning. To prepare for this session:

- Review all the directions and handouts for this session, and Next Steps: Ideas to Extend Practice (pp. 61-62).
- Duplicate Handout 16–Scenes from the Classroom (p. 74); Handout 17–Problems and Solutions (pp. 75-76); Handout 18–Finding the Right Consultant (pp. 77-78); Handout 19–Orienting Consultants (p. 79); and Next Steps: Ideas to Extend Practice (pp. 61-62): one for each participant.
- Arrange for an easel, chart paper, markers, and tape.

**Coach Preparation Note:**

Before beginning this activity, refer to Activity 3–2: I Can Do It Myself in the Disabilities Services guide, *Translating the IEP into Everyday Practice.* Information and handouts from the activity may be useful when discussing specialists' roles and responsibilities, and strategies for collaboration.

### *Conducting the Session*

1. Introduce the activity and briefly review the agenda. Remind participants that specialists become involved in a classroom in different ways. In most cases, specialists will be identified in the child's IEP. Some specialists will have worked with Head Start before, while others may have little experience in working in Head Start or with preschool-age children.

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* Adapted with permission from M. Enright, M. Antes, and J. Brophy. 1992. *Making the Most of Consultants*. Newton, MA: Education Development Center, Inc.

2. Ask participants if they have worked with specialists in the classroom. If so, ask them to share a positive experience. During the discussion, ask participants to identify elements that contributed to the success, and strategies they used to make it positive. Then ask participants to share an experience with a specialist that they wish they could change. Remind participants not to mention any names of children or consultants. Ask what they could have done to make this negative experience more positive, and record ideas on chart paper.

3. Tell participants that in the next part of the activity, they will identify common problems that may arise when working with specialists, then come up with some solutions. Distribute Handout 16–Scenes from the Classroom, and Handout 17–Problems and Solutions, one to each participant, and review them briefly.

4. Read aloud all the scenarios from Handout 16–Scenes from the Classroom. Then discuss the vignettes with participants, and ask them to complete Handout 17–Problems and Solutions together. Allow 15 to 20 minutes. Use the Discussion Guide that appears in Activity 2-4: Specialists in the Classroom (pp. 56-58) to highlight important points.

5. Point out the similarities and differences between the problems and solutions participants identified earlier in the session (step 2) and the problems and solutions that emerged from the discussion about the vignettes.

6. Distribute Handout 18–Finding the Right Consultant, and Handout 19–Orienting Consultants, one to each participant. Review these handouts briefly and explain that they can be used as guides to help Head Start staff and specialists establish clear communication about responsibilities and expectations, and create a truly collaborative team spirit.

## *Wrap-Up and Next Steps*

Working together, families, staff, and specialists can provide a child with significant disabilities with a developmentally appropriate program which supports the child's individual needs, while also ensuring full participation. The challenge is for everyone to recognize that each person brings different skills, knowledge, and experience to the process. The child and her family will benefit most if they receive a comprehensive, consistent, and unified program. In such collaborative ventures, communication is key.

Give participants a copy of Next Steps: Ideas to Extend Practice. Help participants choose the Next Step(s) they would like to pursue, or encourage them to develop their own next steps. Then, set a date and time to follow up with participants.

### *Next Steps: Ideas to Extend Practice*

Developing the knowledge and skills needed to include children with significant disabilities requires experience and practice. You can encourage and support staff members to practice what they have learned in this module. Some suggestions include:

- Identify early childhood programs in your community that successfully include children with significant disabilities. You may locate these through the local education agency (LEA) or the your regional Training and Technical Assistance (T/TA) provider with an expertise in disabilities services. These programs could be run by Head Start, a private organization, or the public education system. Arrange for staff to observe different programs and children with a variety of needs. If possible, and with the permission of parents, have staff observe particular children in the program, and meet with teachers and/or managers to discuss the child's disabilities and how staff members have worked with families, specialists, and one another to provide appropriate services to the child and family.

- Invite a teacher with experience in including children with significant disabilities, a related service provider, a parent of a child with disabilities, or an adult with disabilities to survey and assess your building and program. Ask 3 staff members to prepare for this event by planning the route for the tour and developing a set of questions for the consultant. Have staff walk with the consultant, and ask the consultant to consider the classrooms and common spaces. Which areas are accessible and which are not? What are the barriers, and how can they be corrected? Ask for both simple, inexpensive solutions and long-range, more expensive structural adaptations which might be needed. Encourage staff who meet with the consultant to discuss possible needs and changes with other staff and managers.

- Invite participants to form support teams. The team can meet on a regular basis to report on progress to date, discuss innovative ideas and adaptations, solve problems, and seek outside information and resources. You may serve as a member of the group or as a facilitator; specialists may be valuable resources as well.

- Field trips can be a special and important part of your program. When you have a child with significant disabilities, planning a field trip involves thinking about the child's special needs the same way you consider them in the classroom. For example, if you are going on a bus, is special seating needed? If you are going to the library or a museum, is the facility accessible? What about the toilet facilities? Are there long stairways? Will there be activities which are appropriate for all the children, including those with significant disabilities? Staff also need to think about timing for medication administration and health procedures, and should receive training in advance emergency medication and equipment if needed. Help participants practice thinking about what is involved in planning a field trip, either with an actual child with disabilities in your program, or Lara (see Activity 2-1: Lara's Story). Using a typical field trip your program might take, ask participants to work with their team to carefully plan the entire trip.

Remind participants that it is critical to involve parents in this planning process. Parents will be able to teach staff about how they manage their children's lives and routines, at home, at parties, during outings, and in other situations in the community.

- Ongoing communication between parents, teachers, and specialists is critical for children with significant disabilities. With participants, develop creative strategies for communicating information with families about such areas as what the child is doing well, what the child finds challenging, special accomplishments, and other important information. One Head Start teacher, for example, used beads to make special necklaces. On each necklace, she attached a handmade notebook (several pieces of paper stapled together). Children liked wearing their jewelry; and the notebook provided parents, teachers, and specialists with an opportunity to exchange daily notes about the child's progress. If you decide to use a method such as this, make sure to write notes in a way that all can understand, and to be mindful of confidentiality.

## Handout 10: Lara

Lara is a verbal and sociable three year old who is excited about going to Head Start. She loves to sing, do arts and crafts, and play on the swings and slide. She knows colors and most shapes, and is beginning to identify letters. Lara wants to be a ballerina when she grows up.

Lara was born with spina bifida, a condition which left her spinal column incompletely formed. She was also born with hydrocephalus, which causes fluid and pressure to build on her brain, and could possibly cause brain damage. When Lara was a newborn, she had surgery to close the small hole in the back of her spine, and to insert a small "shunt" tube which drains the extra fluid from her brain to her abdomen.

Lara has full use of her head and neck, upper trunk, arms, and hands. She has some muscle control of her hips and thighs, but no movement, strength, or sensation from her knees to her feet. She crawls very quickly, but prefers to get around scooting on her behind. She has recently decided that "only babies crawl" and refuses to do it. She wears braces on both legs, and is learning to use a walker with the help of her physical therapist, whom she sees twice a week. Eventually, Lara will learn to use crutches. For long walks, she uses a wheelchair.

Lara has no bladder or bowel control and it is doubtful that she ever will. She wears diapers, but has recently been asking to wear "big girl pants."

Lara has had early intervention services since she was two months old. She sees an occupational therapist (OT) three times a week. The OT is now helping Lara learn to dress herself, which is one of the goals in Lara's Individualized Education Program (IEP).

## Handout 11: Planning Worksheet

You meet with Lara's mother, her occupational and physical therapists, her home health care nurse, and your program's health and disabilities services managers. The purpose of the meeting is to plan Lara's smooth entry into the program.

- What else do you need to know to facilitate Lara's smooth entry into Head Start? Whom might you ask?

- What else do you need to know to promote Lara's participation in the daily routine? Consider such topics as curriculum, classroom setup, outdoor play area layout, bathroom setup, lunch table arrangement, field trips, scheduling, and transportation. Whom might you ask?

- What logistics do you need to work out before Lara enters the program? Whom might you ask?

## Handout 11: Planning Worksheet (page 2)

- How will you continue to involve Lara's mother in planning, implementation, and evaluation?

- How will you continue to involve other team members in planning for and documenting Lara's progress?

- What other questions, concerns, or fears do you have?

## Handout 12: Adaptations

The key to successful inclusion is planning how a child with significant disabilities can participate in the daily routine. When thinking about what types of adaptations to make, consider three different categories:

- **environmental adaptations:** for example, clearing paths in and out of buildings and within a room; arranging materials so that every child can reach them; making sure that bathrooms and eating areas are fully accessible
- **curriculum adaptations:** for example, slowing the pace of discussion or an activity; using visual cues, auditory cues, and body language to convey information; adjusting timing and sequence of activities; providing physical assistance
- **materials adaptations:** for example, using contrasting, colorful toys for children with visual problems; attaching thick upright handles to toys for children with fine motor problems; installing a child safety swing seat for children with poor balance

Remember, inclusion demands a comprehensive approach that involves *all* team members. Working in collaboration with parents, managers, specialists, teachers, home visitors, and other service providers, Head Start staff can use the Individualized Education Program (IEP) and the Individualized Family Service Plan (IFSP) as road maps for helping children succeed.

## Handout 13: Worksheet

**MILAGRO:** Milagro is a three-year-old girl who speaks Spanish at home. She has very expressive eyes, a beautiful smile, and a gentle demeanor. Many of the children seem drawn to her. Milagro was born with a neurological disability. All the muscles on her right side are much weaker than those on the left. She learned to walk when she was two, but still has poor balance and needs help on the stairs. She can only hold objects in her left hand. She tends to ignore her right hand completely. Milagro understands simple requests in English, but rarely speaks.

Think about Milagro during a finger-painting activity. What environmental, curriculum, or material adaptations can you make to help her participate during this activity?

**Environment:**

**Curriculum:**

**Material:**

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**TYSON:** Tyson likes to paint and look at books. A very shy boy, he often withdraws from other children. He avoids group games, as well as gross motor activities. He especially avoids going to the playground. When it's time to go out, he often cries or says his belly hurts. Tyson was born with a club foot. It has been surgically repaired, but his right leg is shorter than the left, and he must wear special orthopedic shoes. Tyson walks with a limp and falls easily when he tries to run.

Think about Tyson during outdoor play on the playground at your program. What environmental, curriculum, or material adaptations can you make to help him participate during this activity?

**Environment:**

**Curriculum:**

**Material:**

## Handout 13: Worksheet (page 2)

**SANDRA:** Sandra loves to eat ice cream and play ball with other children. She is three years old and has a significant developmental delay. Sandra communicates with gestures and some noises which her mother can understand. She sometimes has tantrums, usually during transitions from one activity to another. You have a routine that helps her calm down and refocus, but sometimes this can take 15 minutes. Though Sandra is very eager to have friends, the other children tend to avoid her.

Think about Sandra during snack time. What environmental, curriculum, or material adaptations can you make to help her participate during this activity?

**Environment:**

**Curriculum:**

**Material:**

**HIRO:** Hiro, who is almost two, loves music, playing with cars and trucks, and being read to. Most of Hiro's muscles are very weak, and he is just beginning to stand on his own. His expressive speech is delayed, but he communicates easily with gestures and facial expressions. Some of his fine motor skills are above age level. Because he does not crawl or walk, and is the youngest of four children, Hiro stays wherever he is placed and waits for toys and other objects to be brought to him. He rarely initiates social interactions or activities.

Think about Hiro in Early Head Start. What environmental, curriculum, or material adaptations can you make to help him become more active and independent?

**Environment:**

**Curriculum:**

**Material:**

## Handout 13: Worksheet (page 3)

**CARALEE:** Caralee is an active, talkative three year old who has just been diagnosed as legally blind. She can see shadows of light and dark, and outlines of large objects. Her parents have been told that her condition may stay the same or get worse. Caralee is fearless and tends to wander around, often bumping into things and falling. While her parents want her to become independent, they are also very concerned about her safety.

Think about Caralee at lunchtime. What environmental, curriculum, or material adaptations can you make to help her participate during this activity?

**Environment:**

**Curriculum:**

**Material:**

---

**BENJAMIN:** Benjamin is a curious but reserved four year old who loves to play by himself in the housekeeping area. There, he stacks the kitchen utensils, sometimes humming to himself. Benjamin does not speak, but his hearing is fine. Benjamin appears to understand simple requests like "come to me" and "sit down," although his responses to more complex sentences are inconsistent. Recently, Benjamin has become more aggressive, screaming when he wants something and sometimes hitting other children who have toys or books he wants. Benjamin's parents have been told he has a pervasive developmental delay.

Think about Benjamin during circle time. What environmental, curriculum, or material adaptations can you make to help him participate during this activity?

**Environment:**

**Curriculum:**

**Material:**

## Handout 14: Integration Checklist*

Record Y for yes or N for no on the blank before each item. If your response is N, explain what changes you will need to make.

### Talking Straight

Do you ensure that:

__ the child has a way to communicate with classmates?

__ classmates know how to communicate with the child?

__ the child is given the opportunity to greet others in a manner similar to that of her classmates?

__ the child socializes with her classmates?

__ classmates socialize with the child?

__ the child has the opportunity to interact with adults in the room?

__ adults in the room interact with the child?

__ adults in the room (e.g., classroom teachers, volunteers, specialists) provide the same type of feedback (e.g., praise, discipline) for the child as they do for her classmates?

If the child uses an alternative communication system, do you ensure that:

__ the system is always available to the child?

__ the classmates know how to use it?

__ the teachers know how to use it?

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*Adapted with permission of T. Vandercook and J. York. 1990. A Team Approach to Program Development and Support. In W. Stainback and S. Stainback (Eds.), *Support Networks for Inclusive Schooling: Interdependent Integrated Schooling*.Baltimore, MD: Brookes Publishing Co.

## Handout 14: Integration Checklist (page 2)

### Looking Good

Do you ensure that:

__ the child has the same opportunity as all children to tend to his appearance (for example, checking appearance in a mirror)?

__ staff members tend to the child's dress and appearance throughout the day, as they do for all children?

__ clothing that is needed for activities is age appropriate (for example, napkins instead of bibs, 'cool' paint shirts?)

__ the child has a way to carry personal supplies or belongings discreetly (if this is the wish of the child or the family)?

__ staff members help the child keep his equipment (such as wheelchair, leg braces) clean throughout the day?

### Go With the Flow

Do you ensure that:

__ the child enters the classroom at the same time as classmates?

__ the child is seated or positioned so that she can see and participate in all of the daily activities?

__ the child is seated or positioned so that classmates and teachers can easily interact with her?

__ the classmates are seated or grouped during activities so the child can easily interact with them?

__ the child is involved in the same activities as her classmates?

__ the child engages in classroom activities at the same time as everyone else?

__ the child makes transitions in the classroom at the same time as everyone else?

## Handout 14: Integration Checklist (page 3)

### Acting Cool

Do you ensure that:

___ the child is actively involved in class activities?

___ staff members encourage the child to follow the same classroom and social rules as classmates (for example, hugs only when appropriate, stays in seat when necessary)?

___ adults assist the child only when necessary to support maximum independence?

___ staff members encourage classmates to ask the child for assistance as appropriate?

___ the child uses the same or similar materials as his or her classmates during activities?

___ staff members suggest that the child bring in possessions that other children might find interesting?

## Handout 15: A Closer Look

Think about a child with a significant disability you are currently serving (or have served in the past), then complete the form below.

Child's interests and strengths:

Activities child prefers:

Activity where child has most difficulty:

Describe why the activity is difficult for the child (if possible, include examples to illustrate your points):

Changes you have already made to help the child participate during this activity:

Changes you feel are still needed:

Note: All families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Therefore, if more than one participant is involved in this session, remove any information that would identify the child before the session begins.

## Handout 16: Scenes from the Classroom*

### 1. WHOSE CLASSROOM IS THIS, ANYWAY?

Lennie is a pleasant four year old who likes puzzles and playing with blocks. He has autism and a significant speech and language delay. Lennie's speech therapist generally works with him in the classroom. Today, however, she has decided to work with him one-on-one outside the classroom to assess his progress more closely, since his mother has expressed some new concerns.

When the speech therapist arrives in the classroom, Lennie is listening to a story with a small group of children. The therapist goes over to Lennie, whispers something in his ear, takes his hand, and starts to leave the room. On the way out of the room, she stops to gather some books and toys. The classroom teacher watches this and thinks, "Whose classroom is this, anyway?"

### 2. THIS TEACHER MUST NOT CARE . . .

Beth is a quiet three year old who loves to play with her physical therapist. Beth has Down syndrome and sees the physical therapist twice a week in the classroom. In order to increase the muscle tone in Beth's legs, her therapist is doing a gross motor activity with a large ball. Suddenly, the therapist interrupts the teacher, who is reading to a group of children. "Come here," the therapist says. "Look how well Beth is doing." The therapist then explains some activities the teacher can do to help Beth strengthen her muscles. The teacher tries to listen. She also glances anxiously around the classroom, trying to keep track of what is going on with the other children in the classroom. Finally, in frustration, the teacher blurts out, "I can't talk about Beth right now. I'm in the middle of an activity!" The therapist thinks, "This teacher must not care very much about Beth's progress."

### 3. SHE SHOULD GET HER PRIORITIES STRAIGHT!

The teacher is looking forward to meeting the occupational therapist who will work with Timmy, a bright four year old who has cerebral palsy. The therapist arrives shortly before lunch to assess Timmy's adaptive skills during classroom time. She quietly observes Timmy during lunch. After a few minutes, she tells Timmy, "Clean your plate, kiddo, and we'll play some games together." The teacher firmly informs the therapist that none of the children are required to "clean their plates," and that no one leaves the table until everyone has finished eating.

The teacher feels that the therapist does not respect or understand the classroom rules or routine. The therapist questions why the teacher reacted so strongly to such a minor issue. Each is left feeling that the other's priorities are off-base.

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* Adapted with permission from M. Enright, M. Antes, and J. Brophy. 1992. *Making the Most of Consultants.* Newton, MA: Education Development Center, Inc.

## Handout 17: Problems and Solutions

For each of the vignettes, list 3 problems you think are important. When you have finished, rate the issues from 1 to 3, with 1 being the *most* important. Then, together with your group, brainstorm solutions for the most pressing problem.

**Scene Title**________________________________________

| Problems: | Rating: |
|---|---|
| | |
| | |
| | |

Solution:

If *you* were the teacher, what could you have done to prevent the most pressing problem (the problem your group rated #1 above) from occurring?

---

**Scene Title**________________________________________

| Problems: | Rating: |
|---|---|
| | |
| | |
| | |

Solution:

If *you* were the teacher, what could you have done to prevent the most pressing problem (the problem your group rated #1 above) from occurring?

## Handout 17: Problems and Solutions (page 2)

**Scene Title**______________________________

Problems: Rating:

____________________________________________ __________

____________________________________________ __________

____________________________________________ __________

Solution:

If *you* were the teacher, what could you have done to prevent the most pressing problem (the problem your group rated #1 above) from occurring?

## Handout 18: Finding the Right Consultant*

### Specialist's Name, Address, and Phone Number:

### Type of Specialist:

| Type of Services Available: | Yes | No |
|---|---|---|
| Provides evaluations | ☐ | ☐ |
| Provides direct services to children | ☐ | ☐ |
| Conducts trainings for staff and parents | ☐ | ☐ |
| Provides consultation to staff and parents | ☐ | ☐ |

### References:

Use the space below to list at least 2 references from staff of other early childhood programs where the consultant has worked.

Program Name and Address:

Name and Position of Individual to Contact:

Phone and Fax Number:

Program Name and Address:

Name and Position of Individual to Contact:

Phone and Fax Number:

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* Adapted with permission from M. Enright, M. Antes, and J. Brophy. 1992. *Making the Most of Consultants*. Newton, MA: Education Development Center, Inc.

## Handout 18: Finding the Right Consultant (page 2)

Ask references to describe the types of services (evaluation, direct service, training, consultation to staff and parents) that the consultant provided. Record the information below.

Ask references to describe the consultant's abilities in the following areas. Encourage references to share specific examples whenever possible.

| Areas | Reference's Comments |
|---|---|
| Ability to communicate with staff | |
| Ability to communicate with parents | |
| Ability to communicate with children | |
| Understanding of families your program serves | |
| Alignment with program philosophy | |
| Sensitivity to demands on classroom teacher | |
| Sensitivity to demands on parents | |
| Recognition that staff and parents are part of the team | |
| Flexibility with regard to schedule changes | |
| Other: | |

## Handout 19: Orienting Consultants*

Below are some points to discuss before the consultant begins working in a classroom:

- **Typical schedule for the day**
- **Rules and procedures of the classroom:**

  Sharing
  Eating/cleaning up
  Choosing activities
  Putting toys away
  Responding to unacceptable language and behavior
  Using "please" and "thank you"
  Greeting visitors to the classroom
  Other: ______________________________

- **Communication with children:**

  Recognizing a job well done
  Intervening when a child is aggressive
  Intervening when a child says or does something unacceptable
  Other: ______________________________

- **Communication among adults (teacher, specialists, parents):**

  Best time to discuss progress/problems (remember confidentiality!)
  Circumstances when in-class discussion is acceptable
  Types of conversation appropriate and inappropriate with children and/or other adults present
  How and when the specialist will deliver written progress reports to the teacher
  Availability of the specialist for phone calls
  Other: ______________________________

- **Scheduling:**

  Handling child absences and rescheduling
  Handling specialist absences and rescheduling
  Other: ______________________________

- **Other:**

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* Adapted with permission from M. Enright, M. Antes, and J. Brophy. 1992. *Making the Most of Consultants.* Newton, MA: Education Development Center, Inc.

# *Module 3*

## Promoting Collaboration: From Recruitment to Transition

**Important Note:**

The activities in this module are designed for *Head Start management teams*. Ideally, a team should complete the activities together, with an outside trainer/consultant with expertise in disabilities services as the facilitator. Contact your regional Training and Technical Assistance (T/TA) provider for recommendations.

This training builds on the vision a Head Start program has created for including children with disabilities. We therefore recommend that before completing this module, the program use a tool to help Head Start staff, specialists, and families create a common vision for inclusion. Conducting Activity 1–5: A Vision for Our Program, from the Disabilities Services foundation guide *Setting the Stage: Including Children with Disabilities in Head Start*, is one way to accomplish this goal.

### *Outcomes*

After completing this module, managers will be able to:

- Identify objectives and approaches for improving collaboration with community agencies to promote Head Start as a viable placement option for children with significant disabilities.
- Develop strategies to enhance relationships with service providers and community agencies to support the ongoing inclusion of children with significant disabilities and their families in Head Start.

### *Key Concepts*

- In order for Head Start programs to enroll children with significant disabilities, staff must engage in proactive recruitment efforts and promote Head Start as a viable option.
- Including children with significant disabilities demands a comprehensive approach, involving close collaboration between parents, specialists, and Head Start staff.

### *Background Information*

Head Start managers may not think of themselves as public relations experts, but in fact they are, as they promote the work of Head Start in the communities they serve and reach out to low-income families with young children. Head Start management teams also establish and sustain relationships with other organizations that serve the families in their communities. For example, family advocates may provide necessary links to needed services for families, such as assistance with housing or food. Head Start staff also support parents in securing regular health care for themselves and their children. Efforts such as these require staff to form partnerships with local agencies—partnerships that are built on mutual trust and respect, as well as a common commitment to the well-being of young children and families.

This module will help Head Start managers build on the foundation of collaboration that exists in Head Start programs to reach out to families of children with significant disabilities. Since at least 10 percent of Head Start program enrollment consists of children with disabilities and their families, managers and staff already know how to make program modifications to accommodate children with disabilities. Managers and staff also know how to coordinate services with other providers in order to meet individualized goals and objectives for children with disabilities in their program.

The complex needs of children with significant disabilities will draw on these established skills and engage managers and staff in more challenging ways. Children with significant disabilities will require more adaptive materials, equipment, and services from specialists, as well as active collaboration among families, staff, and specialists as they translate the child's Individualized Education Program (IEP) into everyday practice. Teaching staff will also need increased resources, as well as ongoing supervision and support.

Preparing the program to include children with significant disabilities goes hand in hand with reaching out to their families and a wide range of community organizations that provide services to them. Head Start program staff must begin by understanding that they are not alone. They should not expect to meet all the needs of a child with significant disabilities on their own. Rather, they will need to work closely with parents and local education agency (LEA) personnel and specialists identified in the child's IEP to effectively coordinate services to meet the needs of the individual child and her family. Managers and staff will also need to engage in ongoing, careful planning from the moment a child enters their program, to the time when this child will transition out of Head Start.

As managers reach out to children with significant disabilities and their families, they will need to consider questions such as:

- Which agencies in our community (Part C providers and LEAs) currently provide services to children with significant disabilities?

- What can Head Start learn from these providers?
- How can we coordinate efforts with these agencies to best serve children and families who are eligible for Head Start (or Early Head Start)—children whose IEPs or Individualized Family Service Plans (IFSPs) identify Head Start as an appropriate placement?
- How can we market our program so that eligible families with children with significant disabilities will consider Head Start as an option?
- What additional supports does our Head Start program need?
- What can our Head Start program contribute to this collaborative effort?

This module will guide managers through the process of assessing what systems currently exist in their program to facilitate the inclusion of children with significant disabilities. They will consider which collaborative relationships exist, which existing ones can be strengthened, and which are still needed in order to support their efforts. Management team members will also develop a plan for reaching out, through existing and new relationships, to recruit, enroll, and include children with significant disabilities in their program.

For an overview of the activities in this module, see the At A Glance section on pp. 8-9. For more in-depth information about collaboration, see the Social Services guide, *Community Partnerships: Working Together.*

**Trainer and Coach Preparation Notes:**

What is a significant disability? A significant disability is not defined solely by diagnosis. Rather, it is related to the extent of adaptations and services that a child needs. In general, children with significant disabilities require more everyday modifications (for example, use of adaptive materials and equipment) and more intensive coordination with outside specialists.

For more information about specific disabilities, review the appendices. While the information covered is not the focus of the training, participants may have questions about these topics during activities.

**Trainer and Coach Preparation Notes (continued):**

Throughout the training, emphasize that learning about specific disabilities is only one step in the process. Just as with any child, it is important to know about the child's interests, strengths, and needs.

Also remind participants that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before participants share their descriptions of children and families in the program, make sure they fully understand issues of confidentiality.

## *Activity 3-1: A Family We Know*

**Purpose:** In this workshop activity, managers examine the systems that are currently in place to support the inclusion of a child with significant disabilities. Managers then consider what else might be needed on a program level, and define their role as managers in meeting those needs.

### *Preparation*

| | |
|---|---|
| Arrange for: | Easel, chart paper, markers, and tape |
| Duplicate: | Handout 20–Ryan's Sister Comes to Head Start (p. 102): one for each participant<br>Handout 21–Worksheet (p. 103): one for each participant<br>Appendix A–Services for Children with Disabilities: one for each participant<br>Appendix B–About Significant and/or Multiple Disabilities: one for each participant |
| Review: | Results from Activity 1-1: Viewpoints (pp. 16-19) |

### *Leading the Activity*

1. Introduce the activity and review the agenda with managers.

> **Tip for the Trainer:**
>
> Throughout the activity, remind managers that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before managers share descriptions of children and families in the program, make sure they fully understand and respect issues around confidentiality.

2. Ask managers to think of a child with a disability they know in Head Start. Ask participants to take a few moments to individually jot down responses to the following statements:

   - Identify one special accommodation the program has made to include this child and his family.
   - Describe one benefit that including this child had for him and his family.
   - Describe one benefit that including this child had for other children in the program.

- Describe one benefit that including this child had for program staff.

3. Lead a brief discussion on each point, inviting participants to share their individual responses. Record responses on chart paper. Use Discussion Guide #1 below to focus on key points.

4. Explain to managers that in the next part of the activity, they will analyze the story of a family with a child currently enrolled in Head Start. The family also has a younger child with a significant disability, and because they have had a good experience with Head Start, the parents are considering enrolling their second child in the program as well. Distribute Handout 20–Ryan's Sister Comes to Head Start, and Handout 21–Worksheet. Allow managers about 5 minutes to read Handout 20 to themselves.

**Tip for the Trainer:**

In some communities, an LEA segregated program might be the only choice the school system offers for young children with significant disabilities. In these situations, parents along with program staff, must advocate for other options, such as placement in Head Start.

5. After managers have finished reading Handout 20, ask them to answer the questions on Handout 21–Worksheet. Tell them that as they answer the questions, they should imagine that Dan is currently a teacher in *their* program, and that Felicia will be enrolling in *their* program. Be certain they understand that they should complete the questions independently before discussing them with the rest of the group.

6. Use Discussion Guide #2 to lead the group in discussing their responses to each question on Handout 21–Worksheet. Remind managers that the discussion should focus on *their* program (not an imaginary one), and the steps they need to take. Record the responses to question 5 on chart paper. Allow for space next to each item to record any follow-up steps that are needed. Ask managers to agree on how to follow up on each question, as well as how to inform one another about the answers they find. For example, they may plan to meet again in a few weeks, or follow up via e-mail. Complete the process by discussing responses to question 6. Record these steps on a separate piece of chart paper.

## Discussion Guide #1

During your discussion, highlight the following points:

- Head Start staff have experience in making adjustments and adaptations as they individualize for *all* children, not just those with disabilities.
- The Head Start Program Performance Standards require that at least 10 percent of their enrollment consist of children with disabilities. This means that programs have considerable experience in making accommodations for children with disabilities and their families as well.
- The program's experience also connects it to a number of other agencies or organizations that provide services to children with disabilities and their families.
- The experience of Head Start staff has provided them with evidence that supports including children with disabilities in their classrooms. Integrated settings can benefit children who are typically developing and children with disabilities, as well as adults.

## Discussion Guide #2

1. *What are the first things you need to consider to prepare for enrolling Felicia? What else do you want to know?*

   The goal of this question is to provide the team with an opportunity to see Felicia's enrollment as a team effort, requiring the skills and knowledge of each team member. Remind managers that they cannot simply dismiss the idea of enrolling Felicia if they think their program is not equipped. There are laws that protect Felicia's and her family's right to equal access to the program if Felicia's parents want to enroll her and if her Individualized Education Program (IEP) recognizes Head Start as an appropriate placement.

   Ask managers to consider how they will collaborate/communicate with Felicia's parents. It is crucial to consider her parents a primary resource for information about Felicia, as well as the ultimate decisionmakers about her participation in the program. The process of collaboration must begin with understanding Felicia's parents' hopes, dreams, and goals for their daughter.

   Each member of the management team should think specifically about the area they are responsible for and how they can contribute to Felicia's enrollment. For example, an education supervisor/manager may consider which classroom, and perhaps more importantly, which teaching team, would be the best match for Felicia, as well as what supports the teaching team needs to translate Felicia's IEP goals and objectives into classroom practice.

2. *What existing program resources can facilitate including Felicia and her family (for example, experienced staff, transportation, safety bars in the bathroom)?*

   As the team discussed earlier, they already have experience with including some children with disabilities and their families in their program. The personal experience of staff, as well as that of other parents, is also a valuable resource. Some of the resources the program has used before, as well as the systems they have already developed, may be useful for including Felicia. For example, the program may already have established a system in which teaching teams meet on a regular basis to share ideas about children's progress and solve problems together. They probably have plans for ongoing training and professional development. Perhaps they have made adaptations for other children that can also benefit Felicia.

3. *What connections do you already have with agencies or organizations outside of Head Start that will help facilitate Felicia's enrollment in the program and support her participation?*

   Since the program is currently serving children with disabilities, managers have probably already established relationships with early intervention programs, the LEA, and some outside service providers. The program may want to make new connections with organizations that provide services to children with hearing loss and other disabilities, and connect Felicia's parents to these resources as well. Staff can also ask the family for permission to get relevant information about Felicia's IEP, her identified needs, goals, objectives, and services provided.

   Staff should also ask Felicia's family what connections they have, now or in the past, with agencies, organizations, and specialists. Questions might include: Are these the people and agencies that will continue to be involved with Felicia? Are there people who help Felicia or her family now who would be good to draw into our Head Start team, either temporarily or longer? Are there people whom Felicia's parents want involved? Don't want involved?

4. *What additional supports and information will classroom staff need in order to successfully include Felicia?*

   Staff first need to find out about what they would want to know about any child: namely, Felicia's individual interests, skills, and needs. Then they will need to know the nature and extent of her disabilities, as well as the goals and objectives of her IEP. Staff will also require information from Felicia's family and specialists, as well as support in developing a system for communicating with Felicia and helping her to express her needs, thoughts, and feelings.

   Finally, this is a good time to use the results from Activity 1-1: Viewpoints to help managers better understand the perspectives and needs of teaching staff as they strive to include children with significant disabilities in their program.

5. *What additional questions do you have?*

   Record the group's responses on chart paper. Allow for space next to each item to record any follow-up steps. Have managers agree on how to follow up on each question, and decide how to inform one another about the answers they find. For example, they may plan to meet again in a few weeks, or communicate via e-mail.

6. *In general, what steps should Head Start staff follow when preparing to include a child with significant disabilities?*

   Some important steps include:

   - Work with the child's parents to assess their hopes and goals for their child, and to find out which community service providers they may already work with.

   - Get permission from parents to access the child's IEP and to contact other agencies which currently serve the child and her family, or may be able to provide services to them in the future.

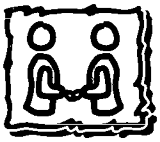
   - Make connections with outside agencies that may provide necessary information, materials, or training for staff, or additional services to the child and her family.

- Examine the systems in place to determine what modifications may be needed to accommodate the child and her family (transportation, environment, curriculum, materials).
- Assess the physical environment to determine what modifications may be needed to accommodate the child and her family (safety features, outdoor play areas).
- Begin the process of planning for the child's smooth transition out of Head Start.

### *Summing Up*

Conclude the session by reviewing some of the comments managers made as you began, particularly regarding the benefits for including children with disabilities and their families in Head Start. Distribute Appendix A–Services for Children with Disabilities, and Appendix B–About Significant and/or Multiple Disabilities, and review both briefly with participants. Explain that the process of including a child with a significant disability will require more effort, but that resources, such as the family and specialists in the community, are available to Head Start staff. If staff remember the benefits for everyone when they include children with significant disabilities in the program, and access the resources available to them, they will stay focused and be successful in their efforts.

## *Activity 3-2: How Can I Help?*



**Purpose:** In this coaching session, new managers work with a more experienced manager to identify a range of resources that are necessary for including children with significant disabilities in Head Start. In the process, new managers begin to define their role and responsibilities as members of a team that provides quality services for all children and families, including children with disabilities.

### *Preparation*

This session has two major parts: 1) a discussion about a family who is considering enrolling their child with significant disabilities in Head Start; and 2) identifying both internal and external resources that participants can use as they work to provide quality services for children with significant disabilities in their own program. At the end of the session, participants choose which Next Step(s) to work on to extend their learning. To prepare for this session:

- Review all the directions and handouts for this session. Also review Discussion Guides #1 and #2 for Activity 3–1: A Family We Know (pp. 87-90) in preparation for a discussion of the circumstances surrounding the enrollment of a child with significant disabilities in the program.
- Duplicate Handout 21–Worksheet (p. 103); Appendix A–Services for Children with Disabilities; Appendix B–About Significant and/or Multiple Disabilities; and Next Steps: Ideas to Extend Practice (pp. 100-101): one for each participant.
- Develop a handout that you can use with participants, describing a child with a significant disability who is enrolling in the program. In your description, provide specific details about the child and his family, as well as the child's disability.

**Coach Preparation Notes:**

Ideally, this coaching session will be used to help new managers prepare for the enrollment of an actual child with a significant disability. Before beginning this activity, participants should have already completed Activity 1–3: Are You Ready?

If you do not have a child with a significant disability entering the program, use one of the following handouts as the basis for the activity's discussion: Handout 1–One Mother's Story (p. 29); Handout 10–Lara (p. 63); or Handout 20–Ryan's Sister Comes to Head Start (p. 102).

## Conducting the Session

1. Welcome participants and outline the purpose of today's session.

2. Give each participant a copy of either the handout that you created about a child with a significant disability who is enrolling in the program, or one of the other handouts you selected. Allow participants 5 to 10 minutes to read the handout.

**Tip for the Coach:**

Throughout the training, remind participants that all families have a right to confidentiality. That is, information about Head Start children and families can only be shared within Head Start on a "need-to-know" basis. Before participants share their descriptions of children and families in the program, make sure they fully understand issues regarding confidentiality.

3. Tell participants to imagine that the child described in the handout is enrolling in *their* program. Encourage participants to share some of their general reactions. Ask: What are your thoughts, feelings, and concerns about this situation? What would you do if this child were coming to your classroom?

**Tip for the Coach:**

In some communities, an LEA segregated program might be the only choice the school system offers for young children with significant disabilities. In these situations, parents along with program staff, must advocate for other options, such as placement in Head Start.

4. Explain to participants that in the next part of the session, they will use the story of the child they just read about as a springboard for identifying internal as well as external resources they can use to support children with significant disabilities and their families in the program.

**Tip for the Coach:**

Remind participants that both the Individualized Education Program (IEP) and the Individualized Family Service Plan (IFSP) provide a blueprint for Head Start staff in preparing and adapting routines and activities to ensure the meaningful participation of children with disabilities in all aspects of the program.

Also explain that Head Start staff are never alone in this effort. The IEP identifies specialists, outside service providers, LEA personnel, and other members of the community who will provide services to the child. Head Start staff need to be proactive in their efforts to collaborate with community partners as they work together to implement the IEP/IFSP.

5. Give each participant a copy of Handout 21–Worksheet (Note: if you are using your own handout, or one of the handouts other than Handout 20–Ryan's Sister Comes to Head Start, change Felicia's name on Handout 21–Worksheet to the name of the child you are discussing). Help participants use the worksheet to identify their ideas about specific action steps they can take to prepare for the enrollment of children with significant disabilities in the program, and record them on the handout. As part of your work together, discuss with participants how the action steps they take can best meet the needs not only of children with significant disabilities, but of *all* children in the program.

6. Point out to participants that providing quality disabilities services must be a collaborative effort between all Head Start staff, the management team, families, and community partners. In addition, managers must be able to recognize when they don't have all the answers, and know when, and whom, to ask for assistance. Together, discuss how they might go about asking for help in making sure that appropriate supports are identified and secured. For instance, they might consult another manager who has supported staff in designing and implementing disabilities services in the program, a parent of a child with a significant disability, or a teacher who has experience in providing quality services to children with significant disabilities in her classroom. Ask participants to record their ideas on the back of Handout 21–Worksheet for future reference.

7. Distribute and briefly discuss Appendix A–Services for Children with Disabilities, and Appendix B–About Significant and/or Multiple Disabilities. Explain that both handouts offer additional information

which may be helpful to managers as they think about their roles and responsibilities in enrolling and working with children with significant disabilities in Head Start.

Remind participants that they should contact their regional Training and Technical Assistance (T/TA) provider with an expertise in disabilities services for help when searching for resources that they can use to address the needs of children with significant disabilities. The Appendices and Resources section also lists organizations and materials that may be helpful.

### Wrap-Up and Next Steps

Briefly summarize the session with participants. Emphasize that taking stock of situations, knowing when and whom to ask for help in solving problems, and learning how to gather resources are important steps in responding effectively to the needs of all children and families, including those with significant disabilities. Point out that, when they work collaboratively, Head Start managers and staff can draw on their own knowledge and experience and that of others, as well as resources both within and outside the program, to find solutions.

Distribute and review Next Steps: Ideas to Extend Practice, and help participants decide which Next Step(s) they would like to pursue. Or, you might encourage them to create their own next steps based on their interests and experience, being as specific as possible about what they want to accomplish.

### *Activity 3-3: Building and Sustaining Relationships*

**Purpose:** In this workshop activity, managers identify how their program's relationships with outside organizations can help them include children with significant disabilities. They will evaluate existing relationships, discuss how to enhance them, and make plans for expanding their network of support.

### *Preparation*

Arrange for: Overhead projector, screen, easel, chart paper, markers, and tape

Duplicate: Handout 22–Troubleshooting (pp. 104-108): one for each pair of participants
Handout 23–Assessment Chart (p. 109): one for each participant
Handout 24–Action Plan (p. 110): one for each participant

Make: Overhead of Handout 23–Assessment Chart (p. 109)

### *Leading the Activity*

1. Explain the purpose of this activity and outline the agenda for managers. Remind participants that Head Start programs should never expect to "go it alone" when including children with significant disabilities and their families. The complex needs of children with significant disabilities demands a collaborative effort among parents, Head Start staff, and outside service providers as they implement the child's Individualized Education Program (IEP).

2. Distribute Handout 22–Troubleshooting. Explain that the handout contains a series of vignettes, outlining 5 different problems involving services to a child with significant disabilities in a Head Start program. Ask managers to work in pairs to identify possible solutions. Allow managers 25 to 30 minutes to complete this step.

3. Distribute Handout 23–Assessment Chart, one to each participant. Tell participants that you will complete the chart together, identifying available as well as still-needed resources to resolve each problem.

4. Use the Assessment Chart overhead to pinpoint and record the types of internal and external supports participants think are necessary to resolve the problem posed in each vignette. Use the third column on the chart, "Creative Solutions," to record ideas that don't fit neatly into the other two categories. For example, if the team cannot think of any existing resources they can use, what might they do? Repeat this process for each of the vignettes. Encourage managers to record responses on their copy of the handout.

5. With participants, review the Assessment Chart, looking for places where solutions seem difficult to achieve. Then, have the group reach consensus about 2 areas they feel are important to work on immediately.

6. Distribute Handout 24–Action Plan. Ask managers to write down the 2 priorities they chose in step 5. Lead a brief discussion on each priority, helping managers identify concrete steps they can take to find a solution.

7. Ask for one volunteer to take the lead on each priority. Then ask each manager to specify 1 or 2 concrete steps she will take to support the lead person for each task, and record these decisions on the Action Plan. Encourage managers to record decisions on their own copy of the handout as well.

## *Summing Up*

Conclude the session by reminding managers that in order to meet the complex needs of children with significant disabilities, they must work closely as a team, tapping into resources within the program and establishing links to outside help. If necessary, make copies of the completed Action Plan to post and distribute to other staff. Schedule a time to reconvene the group on each of the target completion dates to evaluate efforts and plan next steps.

## *Activity 3-4: You Can Do It! Making New Connections*

**Purpose:** In this workshop activity, managers examine their current recruitment practices to consider how they might expand their efforts to reach families of children with significant disabilities.

> *Once a program has success with a child with significant disabilities, they've dealt with their own barriers, helping everyone, including themselves, realize that Head Start can be a viable placement.*
>
> —Head Start Manager

### *Preparation*

Arrange for: Easel, chart paper, markers, and tape

Duplicate: Handout 25–Success Stories (p. 111): one for each participant
Handout 26–Tips for Successful Interagency Collaboration (p. 112): one for each participant
Handout 27–Plan for Recruiting Children with Significant Disabilities (p. 113): one for each participant

### *Leading the Activity*

1. Introduce the activity and review the agenda with managers.

2. Begin the activity with this icebreaker: Ask participants to complete the sentence, "Head Start managers are like public relations experts when . . ." Record answers on chart paper.

3. After recording participants' responses, lead a brief discussion, asking such questions as: What does public relations mean to you? How do you feel when you are in that role? What are you comfortable with? Uncomfortable with? What difference do you think it makes?

   Use the Background Information section from this module (pp. 81-84) to highlight key ideas. During the discussion, emphasize that Head Start managers take steps daily to promote the work of Head Start and to reach out to low-income families with young children. Point out that Head Start managers must also look for ways to expand their efforts to reach the families of children with more significant disabilities.

4. Explain that a first step in reaching out to families with children with significant disabilities involves assessing the program's relationships with organizations in the community that provide services to these children and their families. Have managers assess their current partnerships. Ask:

   - What organizations in the community currently serve children with significant disabilities and their families?

- What is our program's relationship to these organizations?
- What next steps do we need to take to ensure successful partnerships?

Record responses on chart paper and save for later in the discussion.

5. Distribute Handout 25–Success Stories. Explain that the stories are excerpted from actual interviews with managers of Head Start programs that have successfully included children with significant disabilities. Give managers a few minutes to read the scenarios.
6. Use the Discussion Guide below to discuss the stories and help managers plan next steps.

**Tip for the Trainer:**

While collaboration with community groups can improve services for all children, this discussion should focus on collaboration to meet the needs of children with significant disabilities.

7. Distribute Handout 26–Tips for Successful Interagency Collaboration. Ask managers to think of other suggestions they would like to add to the list. Prompt them to think about the successful partnerships that currently exist within the program and what specific steps they have taken to make those relationships successful.

## Discussion Guide

*What do these managers do that is similar to your current recruitment practices?*

Emphasize that there are some aspects of recruitment that will not change in a targeted recruitment of children with significant disabilities and their families. For example, staff will continue to reach out to low-income families through agencies that provide income assistance or food assistance to local families. They will also continue to use links to other organizations. Refer to the previous discussion about agencies that currently serve children with disabilities (step 4).

*What do these managers do that is different from the current recruitment practices you've tried?*

Ask managers to identify strategies they have not tried. Ask them to discuss the strengths and weaknesses of each, then pinpoint those strategies that might be appropriate for their program.

*What are some new strategies that you could try that would lead to enrolling a child with significant disabilities?*

Prompt managers to consider at least one new strategy, then discuss clear steps with a timeline for completing each step. For example, if they would like to develop a relationship with the local Easter Seals Society, decide now who will take the lead in establishing and nurturing that relationship over time, and steps they will take to accomplish their goal. Discuss as a team how they expect to benefit from this partnership. What can they bring to the relationship?

*What next steps do we need to take to ensure successful partnerships?*

This question refers to existing partnerships as well as new ones the team is considering forming. Again, emphasize that managers should consider the benefits of collaboration for themselves, the other partner(s), and ultimately the children and families they include. Managers should brainstorm strategies for forming new relationships, such as becoming a board or committee member at another agency; or offering to give a talk or lead a free training session to the staff of other agencies.

### Summing Up

End the session by completing Handout 27–Plan for Recruiting Children with Significant Disabilities together. Use this form to outline 2 or 3 action steps that the group will take to enhance their efforts to recruit children with significant disabilities. Arrange a time to meet with the team to discuss their progress as well as barriers they encountered in reaching their targets.

### *Next Steps: Ideas to Extend Practice*

As the management team, there are ways you can extend what you have accomplished during these sessions, both as a team and with the entire staff. Ways to continue your work in this area include:

- Meet with managers from other early childhood programs who have successfully included children with significant disabilities and their families. Find out what internal and external resources they use to recruit and support children and families, and the creative ways they solve problems that arise. Connecting with and spending time "shadowing" one other manager who has experience in this area (perhaps in another program) can be the beginning of an important collaborative relationship that both managers can benefit from over time.

- Find ways to help parents become aware of programs available to them in the community. Involve staff and parents in developing a community resource list that parents (and other staff) can access (for example, parent support groups or respite care services). Staff might also plan different events to build alliances with, and foster awareness of, different community agencies.

  Some programs, for example, join with other agencies to sponsor a community fair that features different community organizations. Others sponsor a bi-annual breakfast with representatives from community agencies. Representatives provide Head Start staff and families with an overview of community resources, the types of services that each agency provides, and procedures for facilitating referrals and consultations. These breakfasts can help Head Start staff form networks with representatives from community agencies, providing the face-to-face contact that is so vital when making referrals for children and their families.

- Get to know the Part C provider in your community. Part C of the Individuals with Disabilities Education Act (IDEA) assures services to children with disabilities from birth to age three. If you don't already know which organizations are designated by your state as Part C providers, consult your state department of education's early childhood staff. Invite staff and administrators to visit your program so they can see Head Start "in action" and begin considering it as a viable placement for children who will be transitioning to preschool programs. If possible, arrange an "exchange" for your staff to visit Part C programs as well.

- Use other guides in this series. If members of your management team have not completed the guide *Leading the Way: Disabilities Services and the Management Team*, now would be a good time. Plan to see and discuss the two videos that accompanied that guide (with the first mailing of the guide only; both videos are on a single videotape).

  The video entitled *Shining Bright* shows a Head Start program that successfully included children with more significant disabilities. The video *Getting Together* illustrates the issues that Head Start programs and local education agencies (LEAs) confront as they provide services for children with disabilities. This video can help managers examine strategies for promoting collaboration in their own community. If you don't have these videos, see the Resources section for ordering information, or contact your regional training and technical assistance (T/TA) provider with expertise in disabilities services; they may have a copy you could borrow.

## Handout 20: Ryan's Sister Comes to Head Start

Four-year-old Ryan was in the middle of his second year at Park Avenue Head Start when his mother asked to meet with Dan, his classroom teacher. Naturally, Dan agreed to meet right away. He wondered what was on her mind. Ryan was a curious and playful child who seemed to really enjoy his time at Head Start.

When Ryan's mother, Alina, arrived that afternoon, Dan thought she seemed a little nervous. She sat across from him at one of the snack tables. "I'm coming to you first because I feel like I can talk to you," she said. "I've had something on my mind for a while now and I'm not sure where to start."

"I'm glad you're here," Dan replied. "Just take your time. I'll listen."

"The reason I wanted to talk to you . . . is my daughter Felicia. She's turning three in August. I'm thinking about maybe having her come to Head Start next year. Ryan loves it here. He's grown so much, made friends, and he's learning a lot. I was sort of thinking that Felicia might like coming here, too."

"I don't see why she wouldn't," Dan commented. "But you sound as if you have some doubts."

"I don't know how much you know about Felicia," Alina continued. "She's a great kid, but she has lots of problems, too. She has a hearing loss, so it's hard for her to understand what's going on around her. And it's hard for her to let others know what she needs or wants, or what she's thinking. I think she has some physical problems, too. She has a weakness on her right side that we're worried about. She falls a lot. She can't go up and down the stairs unless someone is there to help her. And it's hard for her to hold things in her right hand, even a crayon. She gets really frustrated when she can't do things she wants, or can't make herself understood."

Dan responded, "I met Felicia when we had our home visit, remember? And Ryan talks about her just like all the children talk about their brothers and sisters," Dan said. "If you think you'd like to bring Felicia to Head Start, then we should talk about it with your family advocate."

"We've just been so happy with how Ryan has been doing here and we think it could be a good place for Felicia, too. We had a big meeting about Felicia last week, and her therapists think Head Start would be a good place for her. But we're finding out about other places, too, where they work just with children who are deaf or have other special needs. But we think we'd like for her to be in a place where Ryan and her friends are, so she can learn and play with all kinds of different kids."

## Handout 21: Worksheet

Imagine that Felicia is enrolling in *your* program. Consider specifically what you could do as a member of the management team that would contribute to successfully including Felicia in the program.

1. What are the first things you need to consider in order to prepare for enrolling Felicia? For example, do you want to meet with specialists who work with her? Review her IEP? Take steps to prepare staff? Have more in-depth conversations with Felicia's parents?

2. What program resources exist that can help you include Felicia and her family (for example, experienced staff, transportation, safety bars in the bathroom)?

3. What connections do you already have with agencies or organizations outside of Head Start that will facilitate Felicia's enrollment in the program and support her participation? What connections do you need to be make?

4. What additional supports will classroom staff need in order to include Felicia successfully? (Will they need to know more about Felicia's disability? Will they need to better understand how to translate Felicia's Individualized Education Program [IEP] into everyday practice?)

5. What additional questions do you have? Where will you go or whom will you call for help?

6. In general, what steps should Head Start staff follow when preparing to include a child with significant disabilities?

# Handout 22: Troubleshooting

## VIGNETTE 1: FUNDING

Virginia uses braces to help her walk. Her physical therapist has asked the classroom staff to help by watching closely for signs that her braces might be irritating her skin. This would indicate that the braces do not fit properly, or that perhaps as Virginia is outgrowing them. When the teacher alerted her physical therapist that they noticed Virginia was getting sores from the braces, she told them it was probably time for a new pair. When the teacher spoke to Virginia's mother, she replied, "I noticed it, too, and she's starting to complain that she doesn't want to wear the braces anymore. I don't know what I'm going to do. I talked to someone at the Medicaid office and they told me they can't authorize purchasing new braces now. It's too soon from when they paid for the last ones. But she needs them. What can I do?"

**Resources Available Within the Program:**
What steps can program staff take to resolve this situation? What specifically can you do to help?

**Resources Available Outside the Program:**
Think about any additional help that must be obtained from outside your program. Do you need this help from a source your program currently works with?

- If yes, whom will you turn to?

- If no, what new organization(s) should the program contact? Why? What does Head Start need from them? What does Head Start have to offer in return?

- If you don't know an appropriate community agency, how will you find out where you can go for help?

- Are there laws and procedures that might help or govern this situation? If you are not sure, how might you find out?

## Handout 22: Troubleshooting (page 2)

### VIGNETTE 2: TRANSPORTATION

Josh's father brings him to Head Start every morning on his way to work. They live alone together and they call their morning commute "guy time." Josh's special educational needs have made it necessary for the program to work out wrap-around services for him with the local education agency (LEA). After his Head Start day, Josh is enrolled at a preschool for children with disabilities. Josh gets his physical therapy and occupational therapy services there. But once Josh's dad has gone to work, he cannot get away to bring Josh to the LEA preschool. The school is across town.

**Resources Available Within the Program:**
What steps can program staff take to resolve this situation? What specifically can you do to help?

**Resources Available Outside the Program:**
Think about any additional help that must be obtained from outside your program. Do you need this help from a source your program currently works with?

- If yes, whom will you turn to?

- If no, what new organization(s) should the program contact? Why? What does Head Start need from them? What does Head Start have to offer in return?

- If you don't know an appropriate community agency, how will you find out where you can go for help?

- Are there laws and procedures that might help or govern this situation? If you are not sure, how might you find out?

## Handout 22: Troubleshooting (page 3)

VIGNETTE 3: COMMUNICATION

Brianna has been at your Head Start program for several months and has been diagnosed as having autism. She has wrap-around services with a local education agency (LEA) special education preschool that she attends after her Head Start day. Brianna receives occupational therapy, sensory stimulation, and play therapy at the LEA preschool, and receives medical services through a hospital that has a clinic next to the school. A special education teacher consults with Brianna's Head Start teacher once a week on the phone. They talk about how to modify activities so that Brianna can participate fully. Since your program already has an arrangement with a speech and language specialist, Brianna has speech therapy at Head Start.

Today when Brianna's mother arrived she seemed tired and frustrated. "I just can't seem to keep anything straight," she explained. "There are so many people involved. The doctors, therapists, and teachers all give *me* updates, but sometimes I wonder if they ever talk to each other. How will we ever figure out if all these services are really helping?"

**Resources Available Within the Program:**
What steps can program staff take to resolve this situation? What specifically can you do to help?

**Resources Available Outside the Program:**
Think about any additional help that must be obtained from outside your program. Do you need this help from a source your program currently works with?

- If yes, whom will you turn to?

- If no, what new organization(s) should the program contact? Why? What does Head Start need from them? What does Head Start have to offer in return?

- If you don't know an appropriate community agency, how will you find out where you can go for help?

- Are there laws and procedures that might help or govern this situation? If you are not sure, how might you find out?

## Handout 22: Troubleshooting (page 4)

### VIGNETTE 4: COORDINATING SERVICES

Four-year-old Valerie is new to your program. She is supposed to receive services from a physical therapist who comes to the center to work with her three times a week. The nurse assigned to your center is responsible for administering Valerie's seizure medication and keeping track of any side effects. Due to a family history of abuse and neglect, a social worker has been working closely with Valerie and her mother since Valerie was about 9 months old. Sometimes she visits Valerie at the center and observes her in the classroom. Services for Valerie also include a play therapy group at a local community center one afternoon a week. Sometimes Valerie is at play group when the physical therapist is scheduled to work with her. Sometimes she is in another room with the nurse or social worker. The physical therapist tells the teacher, "I want to see Valerie. But I don't know if I can if she keeps missing appointments."

**Resources Available Within the Program:**
What steps can program staff take to resolve this situation? What specifically can you do to help?

**Resources Available Outside the Program:**
Think about any additional help that must be obtained from outside your program. Do you need this help from a source your program currently works with?

- If yes, whom will you turn to?

- If no, what new organization(s) should the program contact? Why? What does Head Start need from them? What does Head Start have to offer in return?

- If you don't know an appropriate community agency, how will you find out where you can go for help?

- Are there laws and procedures that might help or govern this situation? If you are not sure, how might you find out?

## Handout 22: Troubleshooting (page 5)

VIGNETTE 5: **TRANSITIONS**

The program director from the Early Head Start program in your community recently contacted you about Kensai, a little boy with Down syndrome who will soon be eligible for a Head Start preschool program. Kensai is currently receiving services from a Part C provider who is collaborating with the Early Head Start program. Kensai will turn three this summer and the Part C provider has begun planning with Kensai's family for his transition to preschool services. His parents are enthusiastic about the possibility of remaining in Head Start, and would like Kensai to attend your program.

**Resources Available Within the Program:**
What steps can program staff take to resolve this situation? What specifically can you do to help?

**Resources Available Outside the Program:**
Think about any additional help that must be obtained from outside your program. Do you need this help from a source your program currently works with?

- If yes, whom will you turn to?

- If no, what new organization(s) should the program contact? Why? What does Head Start need from them? What does Head Start have to offer in return?

- If you don't know an appropriate community agency, how will you find out where you can go for help?

- Are there laws and procedures that might help or govern this situation? If you are not sure, how might you find out?

## Handout 23: Assessment Chart

### Types of Support Needed to Resolve Problems

| | Internal Resources | External Resources | Creative Solutions |
|---|---|---|---|
| **Vignette 1**: Funding for Virginia's Braces | Existing<br>Needed | Existing<br>Needed | |
| **Vignette 2:** Transportation for Josh to the LEA Preschool | Existing<br>Needed | Existing<br>Needed | |
| **Vignette 3:** Communication between Specialists and Brianna's Mother | Existing<br>Needed | Existing<br>Needed | |
| **Vignette 4:** Coordinating Services for Valerie | Existing<br>Needed | Existing<br>Needed | |
| **Vignette 5:** Transitions for Kensai when He Turns Three | Existing<br>Needed | Existing<br>Needed | |

## Handout 24: Action Plan

**PRIORITY AREA 1:** ________________________________________

Who will take the lead in identifying needed resources?

What will each member of the management team do to support this?

| | |
|---|---|
| Lead Person: | Task: |
| Other Managers: | Tasks: |

Target deadline:

**PRIORITY AREA 2:** ________________________________________

Who will take the lead in identifying needed resources?

What will each member of the management team do to support this?

| | |
|---|---|
| Lead Person: | Task: |
| Other Managers: | Tasks: |

Target deadline:

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## Handout 25: Success Stories

A. Human contacts are so important. Over the years I've made connections with the administrators and teachers at the infant-toddler programs in our area. We've even attended training conferences together. I think it helps that they know me professionally, and know what Head Start has to offer children and families. That way, they start thinking about Head Start as an option even before a child is eligible for a preschool program.

B. I decided to reach out to the medical community, since children with significant disabilities are usually tied into many medical services. For example, the hospital in our area has a special clinic for children with spina bifida. The medical staff have been very helpful. They aren't just involved in the evaluation process. They've also observed in our classrooms and then offered suggestions for ways to modify the program so the children can participate fully.

C. I introduced myself to people at the school system's early childhood committee meetings. Every spring they have a meeting that involves the administrators from the regional preschool centers. I'm on the agenda of this meeting to share information about Head Start. I use this time to share examples of different scenarios of collaborations that have worked.

## Handout 26: Tips for Successful Interagency Collaboration

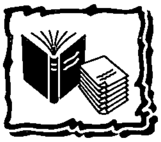
Interagency collaboration can help assure that all children with disabilities, including those with significant disabilities, have been located and identified so they can begin to receive needed services. It can also help assure that children with significant disabilities receive needed services in the least restrictive environment (LRE). In your efforts to provide a seamless, family-centered approach to assisting children with significant disabilities and their families, consider the following points:

- Successful collaboration is based on mutual respect and trust.
- Don't begin by expecting that you must defend "your turf."
- Remember that players bring their own unique perspectives to the process of collaboration, based on their understanding of the community and their organization's regulations.
- Acknowledge the expertise of the people you are collaborating with.
- Find out about the services and possible contributions of each group, being mindful of differing laws and policies that may govern them. Whether trying to collaborate around a specific child or a bigger effort, be prepared to contribute. For example, Head Start might offer transportation or the services of a mental health consultant who is already on the staff. These contributions can go a long way toward nurturing the relationship, and securing the best services for children and families.
- Remember, patience is one of the most important ingredients. Sometimes collaborative efforts start and grow slowly.

**Add your suggestions below:**

## Handout 27: Plan for Recruiting Children with Significant Disabilities

| Action Step | Lead Person | Target Date |
|---|---|---|
| | | |
| | | |
| | | |



Professional development experiences are most effective when there is follow-up support. Follow-up builds on the team's motivation and interest and helps them transfer new skills to the workplace. It can extend the learning that takes place in workshops or coaching sessions.

Research and practice indicate that follow-up is most effective when it is:

- planned as a key component of professional development activities
- supported by colleagues and supervisors
- designed together with the participant(s)
- based on the needs, interests, and learning styles of the participant(s)

A survey is a simple method to assess the needs and interests of staff in your program. A sample survey appears at the end of this section.

## *Follow-Up Strategies*

Once participants have selected their priorities, work together to design the content and approach of follow-up strategies. Below are several strategies that you can adapt to meet the needs of your staff. You can use them alone or together to help staff integrate what they have learned into their day-to-day practice.

### Personal Learning Plans

"Personal Learning Plans" are an extension of "Back Home Plans" (see p. 27). Staff members create written plans for themselves, and then commit to specific action. Learning Plans help staff specify what they would like to learn (working with consultants, advocacy skills), and how they would like to learn it (attend a course, observe others). As a supervisor, you can support participants by helping them create their plans. Once they have developed their plans, meet with participants regularly to discuss their progress, identify needed resources, or plan next steps.

### Peer Support Groups

In this strategy, a small group of staff (either a mixed group or staff in similar roles) meets regularly for information and support. They share successes, discuss concerns and problems, and try to find solutions together. Peer support groups can also help staff support each other with their Back Home Plans or Personal Learning Plans. Support groups have evolving agendas, based on the needs of the members and the tasks they select to work on together. Most frequently, support groups deal with practical issues and concerns that arise in the program. Depending on the needs and interests of the group, you may choose to be a member of the group, a facilitator, or an outside resource.

### Study Groups

Study groups can be used to refine and expand staff skills. In study groups, staff read journal articles and books, watch videos, or listen to speakers. They then meet to discuss how the content applies to their own roles in the program. Study group members meet regularly to learn more about research and practice, current thinking about inclusion, and new topics and issues. The Resources section in this guide offers suggestions for different sources that can be used for study group exploration.

### Follow-up Materials

Perhaps the least time-consuming follow-up strategy involves sending written materials and resources to staff after the training activities are finished. These materials might include a reminder of the results of a session, questions to encourage journal writing and self-reflection, a letter that discusses the participant's involvement in the training activities and her success in applying new skills on the job, or an interesting article to read. Such follow-up materials can match the needs and interests of staff to the specific content or skill being learned.

### Observation, On-the-Job Practice, and Feedback

Ideally, observation, practice, and feedback should be ongoing and routine. Observers can use a simple form to make notes for giving feedback. Forms can focus on specific skills (for example, adapting classroom activities to include children with disabilities), or more general issues (strategies used to foster inclusion in the program). As a supervisor, you might be the observer, or you might ask staff to observe you. Other possibilities include having new staff members observe more experienced staff or having peers take turns observing each other.

This strategy is time-consuming and a bit difficult to arrange, but it is very effective and worth the effort. By observing others, staff will see different methods actually being used and will learn new skills along the way. Observation also promotes greater self-reflection, an essential skill for working effectively with others. By being observed in a nonthreatening way, participants can receive feedback about what works well, and what alternatives to explore. It also gives them a chance to practice new skills in their current roles.

### Continued Training

Participants can extend their learning by taking courses at a local college, university, or adult learning center, or by attending other training sessions. Many institutions of higher learning offer courses in special education, psychology, and child and family development. Staff from the regional Head Start Training and Technical Assistance (T/TA) network may help teams identify and negotiate with colleges and universities for credited formal training that responds to members' needs.

Participants can also build on their skills by using the services of the T/TA network, by attending seminars sponsored by outside agencies, and by continuing to organize training sessions. When organizing, consider joining forces with other early intervention programs, preschools, the LEA, and other professional organizations. Co-sponsored training enables personnel to form networks, sets the stage for other cooperative ventures, and provides face-to-face contact between agencies. In addition, cosponsored training can multiply resources; when responsibility is shared, so are the costs.

### Taking Action

With collegial support and assistance, staff can also work to educate others in the program or in the community about inclusion. They might want to investigate resources in the community and start a resource directory for staff and families, or set up a resource library with materials for parents, staff, and children (in the classroom). Such activities will enable staff to take a more active role in advocating for children and adults with disabilities in their programs and in their communities.

# *Continuing Professional Development*

## Professional Development Survey

Now that you have successfully completed this guide, what else would you like to learn or do? Place a check next to the topics that interest you. Then rank your top 3 choices. Follow-up activities will be designed based on your responses.

| Top Three Choices | Check All that Apply | I would like to learn more about . . . |
|---|---|---|
| ________ | ☐ | The principles and practices necessary to meaningfully include children with significant disabilities in the program and the community. |
| ________ | ☐ | Effective strategies for providing family-centered support. |
| ________ | ☐ | Strategies for adapting the environment and curriculum as I translate IEP/IFSP goals and objectives into the daily routine. |
| ________ | ☐ | How I can better monitor the progress of children with disabilities. |
| ________ | ☐ | Specific disorders (their symptoms, different types of resources/interventions).<br>Specify disorders: ________________________________ |
| ________ | ☐ | How I can promote Head Start as a viable placement option for children with significant disabilities. |
| ________ | ☐ | How I can identify and tap existing community resources and services that respond to families' needs and interests. |
| ________ | ☐ | How I can facilitate referrals and consultations with related services and health care professionals. |
| ________ | ☐ | How I can build relationships with outside specialists and incorporate their expertise into my day-to-day practice. |
| ________ | ☐ | How assistive technology can aid children with disabilities. |
| ________ | ☐ | How the laws and regulations that protect the rights of persons with disabilities apply to the program and to my role. |
| ________ | ☐ | How we can evaluate the accessibility of program facilities and services for children and families, and develop strategies for reasonable accommodation. |
| ________ | ☐ | Ways to collaborate more effectively with parents, outside specialists, and other Head Start staff to support children with disabilities. |
| ________ | ☐ | Ways to ease the transition for children as they move from early intervention programs to Head Start, and from Head Start to public schools. |
| ________ | ☐ | Other (please specify): ________________________<br>________________________________<br>________________________________ |

## Professional Development Survey (page 2)

| Check All that Apply | Personal Learning Styles |
|---|---|
| | **How do you think you learn best? Check all that apply.** |
| ☐ | Reading and writing on my own, with occasional sessions with a colleague, a supervisor, or an expert consultant. |
| ☐ | Meeting with peers for an ongoing study group in which we read articles, have discussions, etc. |
| ☐ | Meeting with peers for an ongoing support group in which we discuss successes and concerns, and create solutions. |
| ☐ | Observing experienced staff members and peers, and having them observe me as I practice new skills. |
| ☐ | Meeting with my team (teacher, teaching assistant, parent, etc.) or staff in similar roles to develop Back Home Plans. |
| ☐ | Attending other training sessions or taking a course at a nearby college. |
| ☐ | Receiving written notes and material from my supervisor on topics that interest me. |
| ☐ | Other (please specify): ______________________________<br>______________________________ |

# Resources

Refer to the following resources to learn more about the key issues presented in this guide. This chapter is organized into four main sections: Print/Audiovisual Materials, Organizations, Journals/Periodicals, and Web Sites.

## *Print/Audiovisual Materials*

Adaptive Environments Center, Inc. and Barrier Free Environments, Inc. 1995. *The Americans with Disabilities Act checklist for readily achievable barrier removal 2.0.* Boston, MA: Adaptive Environments Center, Inc. (617) 695-1225.

> This checklist will help programs identify accessibility problems and solutions in existing facilities to support compliance with ADA requirements.

Association for the Care of Children's Health. 1986. *Seasons of caring.* Association for the Care of Children's Health, 19 Mantua Road, Mount Royal, NJ 08061 (609) 224-1742.

> This 40-minute video depicts services Head Start programs provide to children with chronic illness and disabilities. It stresses the importance of having skilled and knowledgeable service providers. It also discusses the challenges that parents face in raising a child with disabilities.

J. May (producer). 1989. *Special kids, special dads: Fathers of children with disabilities.* Association for the Care of Children's Health, 19 Mantua Road, Mount Royal, NJ 08061 (609) 224-1742.

> This training film focuses on fathers' emotional needs and the importance of involving fathers in the care of their children with special needs.

Blenk, K., and D.L. Fine. 1995. *Making school inclusion work: A guide to everyday practices.* Cambridge, MA: Brookline Books.

> This book offers practical suggestions for creating a truly inclusive program in terms of curriculum and materials, staffing, accessibility, evaluation, and specialists.

Disability Resources, Inc. 1995. *DISABILITY information at your fingertips: A guide to toll-free telephone resources.* Second Edition. Disability Resources, Inc. Four Glatter Lane, Centereach, NY 11720 (516) 585-0290.

> This easy-to-use guide lists national nonprofit organizations and government agencies that provide disability-related information.

Dickman, I., and S. Gordon. 1993. *One miracle at a time: Getting help for a child with a disability.* New York: Simon and Schuster.

> This inspiring book offers parents of children with disabilities encouragement, hope, and practical suggestions. Featured are current developments in assistive technology, medical advances, and strategies for taking the lead in the IEP process. An extensive resource section is also included.

Golfus, B. and D.E. Simpson. 1994. *When Billy broke his head and other tales of wonder.* Boston, MA: Fanlight Productions. (800) 937-4113; $195.00 plus shipping and handling.

> Golfus, an award-winning journalist, became brain injured in a motor scooter accident ten years ago. This video shows Billy on the road, meeting and talking with disabled people around the country. His travels offer important insights into disability, civil rights, and the search for intelligent life after brain damage.

Goodwin, T., and G. Wurzburg (producers). 1992. *Educating Peter.* New York: Ambrose Video Publishing (212) 265-7272; (212) 696-4545; $79.95 plus shipping and handling.

> *Educating Peter* is the Academy Award-winning story of a child with Down syndrome and his classmates as they test the limits of a classroom in which all students learn together. As the camera follows Peter, the trials of coping with his unpredictable behavior are evident, but so are the remarkable advances made by Peter and his classmates.

Kaiser, C.E., Ph.D. (producer). 1982. *Young and special: A video-based inservice for mainstreaming preschool children.* Circle Pines, MN: American Guidance Service (800) 328-2560.

> This inservice training course is designed to prepare early childhood teachers and aides for including children with disabilities in preschool settings. It includes leader and student guides, and 30 modules in documentary television format featuring scenarios, children, parents, and professionals in all major categories of special needs. The video in Module 27, *Let's Not Even Talk about It,* is particularly powerful. This video, which follows two families with young children with chronic and life-threatening illnesses, vividly demonstrates the power and value of including children with significant disabilities.

Kuschner, A., L. Cranor, and L. Brekken. 1996. *Project EXCEPTIONAL: A guide for training and recruiting child care providers to* *serve young children with disabilities. Volume 1.* California Department of Education, Bureau of Publications Sales Unit, P.O. Box 271, Sacramento, CA 95812-0271 (800) 995-4099.

Chapters in this book address a number of important issues, such as how myths about people with disabilities affect one's perceptions, attitudes, and actions; building partnerships with families; and administrative issues in serving children with exceptional care needs and their families.

Lindeman, D.P., and T. Adams. 1995. *Getting together: A Head Start / school district collaboration.* Parsons, KS.: Kansas University Affiliated Program. Available from Brookes Publishing Company (800) 638-3775. Stock # 2975; $46.00.

This video illustrates the issues that Head Start programs and local education agencies (LEAs) confront as they provide services for children with disabilities.

Lindeman, D.P., and T. Adams. 1995. *Shining bright: Head Start inclusion.* Parsons, KS.: Kansas University Affiliated Program. Available from Brookes Publishing Company (800) 638-3775. Stock # 2959; $45.00.

This video illustrates the collaboration and planning needed to make inclusion work in Head Start.

Note: The two videos listed above, *Getting Together: A Head Start / school district collaboration* and *Shining bright: Head Start inclusion* were packaged on a single videotape and sent to every Head Start grantee with the first mailing of the guide *Leading the Way: Disabilities Services and the Management Team* in 1997. Additional copies of these videotapes may be ordered together on one tape for $82.00 (stock #2983) from Brookes Publishing Company (800) 638-3755. Videos may also be purchased separately (see above for details).

McNellis, K., L. Hestness, G. Jesien, V. Petty, and B. Wolfe, Ph.D. 1987. *Special training for special needs.* Minneapolis, MN.: Project ETC/Exceptional Training for Caregivers and the Portage Project (612) 341-1177.

This is a comprehensive, competency-based training program for personnel working with young children with disabilities.

National Information Center for Children and Youth with Disabilities (NICHCY). 1993. *Questions and answers about the Individuals with Disabilities Education Act (IDEA).* Vol. 3, no. 3. Washington, D.C.: National Information Center for Children and Youth with Disabilities.

This free news digest installment answers many of the questions commonly asked by families and professionals about the mandates and requirements of the Individuals with Disabilities Education Act.

Porter, S., M. Haynie, T. Bierle, T. Caldwell, and J.S. Palfrey. 1997. *Children and youth assisted by medical technology in educational settings: Guidelines for care.* Second Edition. Baltimore, MD: Brookes Publishing Company (800) 638-3775. Stock # 2363.

This hands-on reference offers guidelines and procedures for working with a range of children, including those who rely on a ventilator, utilize tube feeding, or require catheterization. Forms and checklists are included to assist program staff with record keeping and planning.

Salisbury, C.L., and Smith, B.J. 1991. The least restrictive environment: Understanding the options. *Principal.* 71(1): 24–27.

This informative article provides information about the least restrictive environment and its importance for the educational and social success of children with disabilities.

Thompson, B., D. Wickham, J. Wegner, M.M. Ault, P. Shanks, and B. Reinertson. 1993. *Handbook for the inclusion of children with severe disabilities: Strategies for implementing exemplary full inclusion programs.* Learner Managed Designs, Inc. P.O Box 747, Lawrence, KS 66047 (913) 842-9088.

This book provides strategies for initiating inclusive programs, preparing personnel, orienting families, and taking concrete steps to facilitate full participation.

Yu, J. (producer) *Breathing lessons: The life and work of Mark O'Brien.* 1996. Boston, MA: Fanlight Productions. (800) 937-4113; $195 plus shipping and handling.

This award-winning documentary explores the unique world of Mark O'Brien, the poet-journalist who has lived for four decades paralyzed in an iron lung.

## Journals/Periodicals

*Exceptional Parent: The Magazine for Families and Professionals*
555 Kinderkamack Road
Oradell, NJ 07649
(800) 535-1910

Designed for parents of children with disabilities and special health care needs, and the professionals who work with them, this magazine offers the practical information and emotional support parents need to become effective advocates and informed consumers. The magazine's annual Resource Guide includes a directory of national organizations, Parent Training Information Centers, associations, and products and services.

## Organizations

AbleNet, Inc.
1081 Tenth Avenue, S.W.
Minneapolis, MN 55414
(800) 322-0956

AbleNet designs and manufactures assistive devices for individuals with disabilities. Their quarterly publication, *ALDetails,* focuses on applications of automated learning devices for play/leisure, domestic, vocational, and learning environments for persons with significant disabilities. A catalog of their products, which include toys and games, is also available on request.

Association for the Care of Children's Health (ACCH)
19 Mantua Road
Mount Royal, NJ 08061
(609) 224-1742
http://ww.ACCH.org/ACCH/

ACCH is a multidisciplinary organization of healthcare providers, family members, teachers, hospitals, and other individuals and organizations committed to improving the quality of care for children and their families through education, dissemination of resources, research, and advocacy.

Association for Persons with Severe Handicaps (TASH)
29 West Susquehanna Avenue, Suite 210
Baltimore, MD 21204
(410) 828-8274

TASH advocates for comprehensive, high-quality, inclusive education; disseminates research findings and their practical applications; and maintains a parent-to-parent network for putting parents in touch with others who have similar concerns.

Beach Center on Families and Disability
University of Kansas
3111 Haworth Hall
Lawrence, KS 66045-7516
(913) 864-7600
http://www.lsi.ukans.edu/BEACH/beachhp.htm

The Beach Center is a national rehabilitation research and training center with core funding from the National Institute of Disability and Rehabilitation Research and the University of Kansas. It engages in research, training, and dissemination of information relevant to families who have members with developmental disabilities, serious emotional disorders, and technology-support needs. The Center's *Families and Disability Newsletter* is published 3 times a year. A catalog listing many of the Center's publications, a descriptive brochure, and the newsletter are all free on request.

Council for Exceptional Children (CEC)
Division for Early Childhood (DEC)
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660
http://www.cec.sped.org

The Council for Exceptional Children (CEC) is the largest international professional organization committed to improving educational outcomes for individuals with disabilities. Their home page offers information about public policy and legislation, professional development events, and materials related to children with disabilities. This site also offers previews of articles in upcoming issues of CEC's journals, *Exceptional Children* and *TEACHING Exceptional Children*.

Disability and Business Technical Assistance Centers
(800) 949-4232 (voice/TDD)

This network of federally funded regional centers provides information, referral, technical assistance, and materials related to all aspects of the Americans with Disabilities Act.

Disability Rights Education and Defense Fund (DREDF)
2212 Sixth Street
Berkeley, CA 94710
(510) 644-2555 (voice) or (510) 644-2629 (TT)

This national, nonprofit organization offers concise, up-to-date information on the civil rights of persons with disabilities.

Federation for Children with Special Needs
95 Berkeley Street, Suite 104
Boston, Massachusetts 02116
(617) 482-2915 (voice/TTY)
http://www.fcsn.org/home.htm

Organized in 1975 as a coalition of parent groups representing children with a variety of disabilities, the Federation operates a Parent Center which offers a variety of services to parents, parent groups, and others who are concerned with children with special needs.

Head Start Training and Technical Assistance (T/TA) Network

The national T/TA network supports local Head Start programs around a range of issues, including improving services for children with disabilities. Contact your Administration for Children and Families Regional Office for the phone number for the T/TA provider in your region.

Institute for Family-Centered Care
7900 Wisconsin Avenue, Suite 405
Bethesda, MD 20814
(301) 652-0281
http://www.familycenteredcare.org/

This nonprofit organization provides essential leadership to advance the understanding and practice of family-centered care. Through the development of print and audiovisual resources, information dissemination, policy and research initiatives, and training and technical assistance, the Institute facilitates family-centered change in all settings where individuals and families receive care and support.

National Early Childhood Technical Assistance System (NEC*TAS)
500 NationsBank Plaza
137 E. Franklin Street
Chapel Hill, NC 27514
(919) 962-2001 (voice) or (919) 966-4041 (TDD)
http://www.nectas.unc.edu/

This national organization assists state agencies in developing and implementing comprehensive services for young children with disabilities and their families. The home page provides an overview of organizational goals and services, as well as reports related to developing and implementing comprehensive services for young children with disabilities and their families.

National Information Center for Children and Youth with Disabilities (NICHCY)
P.O. Box 1492
Washington, DC 20013-1492
(800) 695-0285 or (202) 884-8200
http://www.nichcy.org/index.html

NICHCY is a clearinghouse that provides information and services on disabilities and disability-related issues. NICHCY offers technical assistance to parent and professional groups, referrals to other organizations, and materials about a range of disability-related issues which are available in English and Spanish.

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673 or (203) 746-6518
http://www.pcnet.com/~orphan/

This organization is a unique federation of more than 140 not-for-profit, voluntary health organizations serving people with rare disorders and disabilities. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

National Parent Network on Disabilities (NPND)
1600 Prince Street, #115
Alexandria, VA 22314
(703) 684-6763
http://www.npnd.org/

This national network was established to provide a presence and voice for parents of children, youth, and adults with disabilities. NPND shares information and resources in order to promote and support the power of parents to influence and affect policy issues concerning the needs of people with disabilities and their families. The NPND includes organizations of parents of children, youth, and adults with any type of disability.

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(800) 346-2742 or (301) 588-9284
http://www.naric.com/naric

The National Rehabilitation Information Center (NARIC), funded by the National Institute on Disability and Rehabilitation Research (NIDRR), is a library and information center on disability and rehabilitation. NARIC offers a quick-reference and referral service; database searches on specific topics; and a database that describes assistive devices. The home site offers disability resources, an ADA guide, a list of NARIC publications, and a list of services offered by NARIC.

### *Other Web Sites*

http://www.edc.org/FSC/NCIP

The National Center to Improve Practice (NCIP) through Technology, Media, and Materials. This site, operated by NCIP at Education Development Center, offers a facilitated discussion forum on children with disabilities, a collection of resources about technology and special education, and links to other disability-related resources.

http://www.hood.edu/seri/serihome.htm

Special Education Resources on the Internet (SERI). SERI has links to numerous disability-related sites, including national organizations and resources for parents and educators.

# *Appendix A*

## Services for Children with Disabilities*†

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

The Education of the Handicapped Act, Public Law (P.L.) 94-142, was passed by Congress in 1975. In 1986, it was amended by P.L. 99-457 to encourage states to provide services to children with disabilities, beginning at birth. The Act was again amended in 1990, and the name was changed to the Individuals with Disabilities Education Act (IDEA). The 1997 reauthorization of IDEA, P.L. 105-17, aims to improve educational outcomes for the nation's 5.4 million children with disabilities in a number of ways: by increasing academic expectations and accountability, and integrating the goals and services for children with disabilities into their regular education program.

According to IDEA, "children with disabilities" are those who need special education and related services because they have any of the following types of disabilities:

- autism
- hearing impairments (including deafness)
- mental retardation
- orthopedic impairments
- other health impairments
- emotional disturbance
- specific learning disabilities
- speech or language impairments
- traumatic brain injury
- visual impairments (including blindness)

Children ages three through nine who need special education and related services due to developmental delays may also be eligible for services through IDEA at the discretion of the state and the local education agency (LEA).

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*Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet: General Information about Disabilities which Qualify Children and Youth for Special Education Services Under IDEA. 1996. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

†This fact sheet was revised with help from Sharon Walsh, Government Relations consultant for the Division for Early Childhood of the Council for Exceptional Children (CEC).

# *Appendix A*

## Services for Infants, Toddlers, and Preschoolers with Disabilities

P.L. 99-457, the Education of the Handicapped Act Amendments of 1986, amended the Preschool Program to encourage states to serve children with disabilities from age three, under Part B of IDEA. This program extends Part B rights to children starting at age three, including the provision of special education and related services, and procedural safeguards. The Individualized Education Program (IEP), a plan developed by a team including the child's parents, specifies the special education and related services the child will receive.

P.L. 99-457 also established the Part H program for infants and toddlers—renamed Part C in the 1997 reauthorization . This program is directed to the needs of children from birth to their third birthday who need early intervention services because they: 1) are experiencing developmental delays in one or more of the following areas: cognitive, physical, communication, social and emotional, or adaptive; 2) have a physical or mental condition that has a high probability of resulting in developmental delay, such as Down syndrome, cerebral palsy, etc.; or 3) at the state's discretion, are "at risk" of experiencing a substantial developmental delay if early intervention is not provided. In addition, the infant's or toddler's family may receive needed services under this program to help them foster the development of their child. Individualized Family Service Plans (IFSPs) specify the services to be made available for eligible children and their families.

While the criteria used to define eligibility under both Part B and Part C of IDEA vary from state to state, all states participate in both programs. Consequently, all eligible children are entitled to receive appropriate services as specified in their IEP or IFSP.

# About Significant and/or Multiple Disabilities*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

People with significant disabilities require ongoing, extensive support in more than one major life activity in order to participate in integrated community settings and enjoy the quality of life available to people with fewer or no disabilities. They frequently have additional disabilities, including movement difficulties, sensory losses, and behavior problems.

Children and youth with significant or multiple disabilities may exhibit a wide range of characteristics, depending on the combination and severity of disabilities and the person's age. Some of these characteristics may include:

- limited speech or communication
- difficulty in basic physical mobility
- trouble generalizing skills from one situation to another
- a need for support in major life activities (school, home, leisure, and recreation)

A variety of medical problems may accompany significant disabilities. Examples include seizures, sensory loss, hydrocephalus, and scoliosis. These conditions should be considered when establishing school services. A multidisciplinary team consisting of the child's parents, teachers, and related service and health care professionals should plan and coordinate necessary services.

### Educational Implications

Early intervention programs, preschool, and educational programs with the appropriate support services are important to children with significant disabilities. Assistive technology, such as computers and augmentative/alternative communication devices and techniques, may provide valuable instructional assistance.

In order to effectively address the needs of children with significant and/or multiple disabilities, educational programs must incorporate a variety of components, including language development, social skills development, and functional skilldevelopment (self-help skills). Related services are of great importance, and the appropriate therapists (such as speech and language, occupational, physical, behavioral, and recreational therapists) need to work closely with classroom teachers and parents. Best practices indicate that these services are most effective when offered during the natural routine of the school and community, rather than by removing the child from class for isolated therapy.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 10 (FS10): General Information about Severe and/or Multiple Disabilities. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

Classroom arrangements must take into consideration children's needs for medications, special diets, or adaptive equipment. A range of adaptive equipment and technology can enable children to increase their range of functioning. Communication boards, or other augmentative/alternative communication systems, allow children with significant disabilities to participate more fully in integrated settings.

Education of children with disabilities in the general classroom with their typically developing peers is another important component of the educational setting. Traditionally, children with significant disabilities have been educated in center-based, segregated schools. However, research is showing that attending their neighborhood school and participating in the same activities as their peers is crucial to thedevelopment of social skills and friendships of children and youth with significant disabilities. As a result, many schools are now effectively and successfully educating children with significantdisabilities in their neighborhood school within the regular classroom, ensuring that appropriate support services and curriculum modifications are available. Inclusion benefits not only children with disabilities, but also their nondisabled peers and the professionals who work with them.

Schools are addressing the needs of children in several ways that generally involve a team approach. Modifications to the regular curriculum require collaboration on the part of the special educator, the regular educator, and other specialists involved in the student's program. Community-based instruction is also an important characteristic of educational programming, particularly as children grow older and spend more time in the community.

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

# Appendix C

## Spina Bifida Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

Spina Bifida means "cleft spine," which is an incomplete closure in the spinal column. In general, there are three types of spina bifida, ranked by severity. The effects of the most serious form of spina bifida may include muscle weakness or paralysis below the area of the spine where the incomplete closure (or cleft) occurs; loss of sensation below the cleft; and loss of bowel and bladder control. In addition, fluid may build up and cause an accumulation of fluid in the brain, a condition known as hydrocephalus.

Although spina bifida is relatively common, until recently most children born with the most severe form died shortly after birth. Now that surgery to drain spinal fluid and protect children against hydrocephalus can be performed in the first 48 hours of life, children with this condition are much more likely to live. Quite often, however, they must have a series of operations throughout their childhood. Many children also need special training to learn to better manage their bowel and bladder functions. Some require catheterization, the insertion of a tube to permit passage of urine. Many children learn to catheterize themselves at a very early age.

Some children with spina bifida have learning disabilities, and others do not. Children with learning disabilities may have difficulty paying attention, expressing or understanding language, and grasping reading and math concepts. Early intervention with children who experience learning problems can help considerably to prepare them for school.

Successful integration of a child with spina bifida into the school environment sometimes requires changes in school equipment or the curriculum. Placement should be in the least restrictive environment (LRE), and the day-to-day school pattern should be as "normal" as possible. In adapting the school setting for the child with spina bifida, consider architectural factors, especially when the child uses crutches, braces, or a wheelchair. Section 504 of the Rehabilitation Act of 1973, as well as the Americans with Disabilities Act (ADA), requires that programs receiving federal funds make theirfacilities accessible. This can occur through structural changes(for example, adding elevators or ramps) or through schedule or location changes (for example, having the class on the ground floor).

It is important that all members of the school team as well as the child's parents understand the child's physical capabilities and limitations. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their classmates.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 12 (FS12): General Information about Spina Bifida. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# *Appendix C*

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about spina bifida, contact:

National Easter Seal Society
230 W. Monroe, Suite 1800
Chicago, IL 60606
(312) 726-6200; (312) 726-4258 (TT); (800) 221-6827
e-mail: nessinfo@seals.com
Web site: http://www.seals.com/

Spina Bifida Association of America
4590 MacArthur Boulevard, Suite 250
Washington, DC 20007
(202) 944-3285; (800) 621-3141
e-mail: sbaa@sbaa.org
Web site: http://www.sbaa.org/home.htm

# Appendix D

## Autism and Pervasive Developmental Disorder Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

Autism and Pervasive Developmental Disorder (PDD) are neurological disorders that affect a child's ability to communicate, understand language, play, and relate to others. The causes of autism and PDD are unknown.

According to the Individuals with Disabilities Education Act (IDEA), autism is "a developmental disability significantly affecting verbal and nonverbal communication and social interaction, usually evident before age three, that adversely affects a child's educational performance." When children display "autistic" behaviors, but do not meet all of the criteria for autistic disorder, they may receive a diagnosis of PDD (Diagnostic and Statistical Manual of Mental Disorders-IV, American Psychiatric Association, 1994).

Due to the similarity of behaviors associated with autism and PDD, use of the terms has caused some confusion among parents and professionals. However, the treatment and educational needs of children with these diagnoses are often similar.

### Characteristics

Some or all of the following characteristics may be observed in mild to significant forms:

- communication problems (using and understanding language)
- difficulty relating to people, objects, and events
- unusual play with toys and other objects
- difficulty with changes in routine or familiar surroundings
- repetitive body movements or behavior patterns

Children with autism or PDD vary widely in abilities, intelligence, and behaviors. Some children do not speak; others have limited language that often includes repeated phrases or conversations. Those with more advanced language skills tend to use a small range of topics, and have difficulty with abstract concepts. Repetitive play skills, a limited range of interests, and impaired social skills are generally evident as well. Unusual responses to sensory information—for example, loud noises, lights, certain textures of food or fabrics—are also common.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 1 (FS1): General Information about Autism and Pervasive Developmental Disorder. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# *Appendix D*

## Educational Implications

Children with autism and PDD are eligible for special education and related services under IDEA. Educational programs for children with autism or PDD focus on improving communication, social, academic, behavioral, and daily living skills. Behavior and communication problems that interfere with learning sometimes require the assistance of a knowledgeable professional in the autism field who develops and helps implement a plan that can be carried out at home and school.

The classroom environment should be structured so that the program is consistent and predictable. Children with autism or PDD learn better and are less confused when information is presented visually as well as verbally.

> While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about autism, contact:

Autism Hotline
Autism Services Center
P.O. Box 507
Huntington, WV 25710-0507
(304) 525-8014

Autism Society of America
7910 Woodmont Avenue, Suite 650
Bethesda, MD 20814-3015
Telephone: (301) 657-0881
For information and referral, call (800) 328-8476.
Web site: http://www.autism-society.org/asa_home.html

Institute for the Study of Developmental Disabilities
The University Affiliated Program of Indiana
2853 East 10th Street
Bloomington, IN 47408-2601
(812) 855-6508; (812) 855-9396 (TT)
e-mail: foshaj@isdd.isdd.indiana.edu
Web site: http://www.isdd.indiana.edu/

## Deafness and Hearing Loss Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

The Individuals with Disabilities Education Act (IDEA) includes "hearing impairment" and "deafness" as two of the categories under which children with disabilities may be eligible for special education and related service programming. While the term "hearing impairment" is often used generically to describe a wide range of hearing losses, including deafness, the regulations for IDEA define hearing loss and deafness separately.

IDEA defines a **hearing impairment** as "an impairment in hearing, whether permanent or fluctuating, that adversely affects a child's educational performance." Hearing loss can range from mild to severe. **Deafness** is defined as "a hearing impairment that is so severe that the child is impaired in processing linguistic information through hearing, with or without amplification."

### Educational Implications

Hearing loss or deafness does not affect a person's intellectual capacity or ability to learn. However, children who have a hearing loss or are deaf generally require some form of special education services in order to receive an adequate education. Such services may include:

- regular speech, language, and auditory training from a specialist
- amplification systems
- services of an interpreter for those children who use manual communication
- instruction for the teacher and peers in alternate communication methods, such as sign language

Children who are hard of hearing will find it much more difficult than children who have normal hearing to learn vocabulary, word order, and other aspects of verbal communication. For children who are deaf or have severe hearing losses, early and consistent use of visible communication modes (such as sign language, fingerspelling, and Cued Speech) and/or amplification and aural/oral training can help reduce this language delay.

Individuals with hearing loss, including those who are deaf, now have many helpful devices available to them. Text telephones (known as TTs, TTYs, or TDDs) enable people to type phone messages over the telephone network. The Telecommunications Relay Service (TRS), now required by law, makes it possible for TT users to communicate with virtually anyone (and vice versa) via telephone. The National Institute on Deafness and Other Communication Disorders Information Clearinghouse (telephone: (800) 241-1044, voice; (800) 241-1055, TT) makes available lists of TRS numbers by state.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 3 (FS3): General Information about Deafness and Hearing Loss. 1996. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# Appendix E

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about deafness and hearing loss, contact:

Alexander Graham Bell Association for the Deaf, Inc.
3417 Volta Place, N.W.
Washington, DC 20007
(202) 337-5220 (Voice/TT)
e-mail: agbell2@aol.com
Web site: http://www.agbell.org/

American Society for Deaf Children
2848 Arden Way, Suite 210
Sacramento, CA 95825-1373
(800) 942-2723 (Voice/TT)
e-mail: asdc1@aol.com
Web site: http://www.educ.kent.edu/deafed/asdchome.htm

American Speech-Language-Hearing Association
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700 (Voice/TT); (800) 498-2071
Web site: http://www.asha.org/

National Information Center on Deafness
Gallaudet University
800 Florida Avenue, N.E.
Washington, DC 20002-3695
(202) 651-5051 (Voice); (202) 651-5052 (TT)
e-mail: nicd@gallux.gallaudet.edu
Web site: http://www.gallaudet.edu/~nicd

National Institute on Deafness and Other Communication Disorders Clearinghouse
1 Communication Avenue
Bethesda, MD 20892-3456
(800) 241-1044 (Voice); (800) 241-1055 (TT)
e-mail: nidcd@aerie.com
Web site: http://www.nih.gov/nidcd/

Self Help for Hard of Hearing People (SHHH)
7910 Woodmont Avenue, Suite 1200
Bethesda, MD 20814
(301) 657-2248 (Voice); (301) 657-2249 (TT)
e-mail: shhh.nancy@genie.com
Web site: http://www.shhh.org/

# Appendix F

## Down Syndrome Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

Down syndrome is the most common and readily identifiable chromosomal condition associated with mental retardation. It is caused by a chromosomal abnormality: for some unexplained reason, an accident in cell development results in 47 instead of the usual 46 chromosomes. In most cases, the diagnosis of Down syndrome is made according to results from a chromosome test administered shortly after birth. Although parents of any age may have a child with Down syndrome, the incidence is higher for women over 35.

### Characteristics

Individuals with Down syndrome are usually smaller than their peers, and their physical as well as intellectual development is slower. Besides having a distinct physical appearance, children with Down syndrome also frequently have specific health-related problems. A lowered resistance to infection makes these children more prone to respiratory problems. Visual problems such as crossed eyes and far- or nearsightedness are more frequent in those with Down syndrome, as are mild to moderate hearing loss and speech difficulty.

Approximately one-third of babies born with Down syndrome have heart defects, most of which are now correctable. Some individuals are born with gastrointestinal tract problems that can be surgically corrected.

Some people with Down syndrome also may have a condition known as Atlantoaxial Instability, a misalignment of the top two vertebrae of the neck. This condition makes individuals more prone to injury if they participate in activities that overextend or flex the neck. Parents are urged to have their child examined by a physician to determine whether or not their child should be restricted from activities that place stress on the neck. Although this misalignment is a potentially serious condition, proper diagnosis can help prevent serious injury.

### Educational Implications

Individuals with Down syndrome vary widely in their mental abilities, behavior, and developmental progress. Because of the range of ability in children with Down syndrome, it is important for families and all members of the school's education team to place few limitations on potential capabilities. Teaching tasks in a step-by-step manner with frequent reinforcement and consistent feedback has been proven successful.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 4 (FS4): General Information about Down Syndrome. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# Appendix F

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about Down syndrome, contact:

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003; (800) 433-5255
e-mail: thearc@metronet.com
Web site: http://thearc.org/welcome.html

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(404) 633-1555; (800) 232-6372
e-mail: ndsc@charitiesusa.com
Web site: http://www.carol.net/~ndsc

National Down Syndrome Society
666 Broadway, 8th Floor
New York, NY 10012
(212) 460-9330; (800) 221-4602
Web site: http://ndss.org/

# Appendix G

## Mental Retardation Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

People with mental retardation develop cognitively at a below-average rate and experience difficulty in learning and social adjustment. The regulations for the Individuals with Disabilities Education Act (IDEA) defines mental retardation as "significantly subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period, that adversely affects a child's educational performance."

"General intellectual functioning" is typically measured by an intelligence test. Persons with mental retardation usually score 70 or below on such tests. "Adaptive behavior" refers to a person's adjustment to everyday life. Difficulties may occur in learning, communication, social, academic, vocational, and independent living skills.

Probably the greatest number of children with mental retardation have chromosome abnormalities. Other biological causes may include: asphyxia (lack of oxygen); blood incompatibilities between the mother and fetus; and maternal infections, such as rubella or herpes.

### Characteristics

Mental retardation is not a disease, nor should it be confused with mental illness. Many authorities agree that people with mental retardation develop in the same way as people without mental retardation, but at a slower rate. Others suggest that persons with mental retardation have difficulties in particular areas of basic thinking and learning such as attention, perception, or memory. Depending on the extent of the impairment—mild, moderate, severe, or profound—individuals with mental retardation will develop differently in academic, social, and vocational skills.

### Educational Implications

Persons with mental retardation have the capacity to learn, to develop, and to grow. Appropriate educational services that begin in infancy and continue throughout the developmental period and beyond will enable children with mental retardation to develop to their fullest potential. As with all education, modifying instruction to meet individual needs is the starting point for successful learning. Throughout their child's education, parents should be an integral part of the planning and teaching team.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 8 (FS8): General Information about Mental Retardation. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# *Appendix G*

In teaching persons with mental retardation, it is important to:

- use concrete materials that are interesting, age-appropriate, and relevant to the children
- present information in small, sequential steps and review each step frequently
- provide prompt and consistent feedback
- teach children with mental retardation, whenever possible, in the same school they would attend if they did not have mental retardation

Many persons with mental retardation require specialized services for special needs. Such services include diagnostic and evaluation services; special early education opportunities, beginning with infant stimulation programs and continuing through preschool; and educational programs that include age-appropriate activities, functional academics, transition training, and opportunities for independent living and employment to the maximum extent possible.

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about mental retardation, contact:

American Association on Mental Retardation (AAMR)
444 N. Capitol Street, N.W., Suite 846
Washington, DC 20001
(202) 387-1968; (800) 424-3688
Web site: http://www.aamr.org

The Arc (formerly the Association for Retarded Citizens of the United States)
500 East Border Street, Suite 300
Arlington, TX 76010
(817) 261-6003; (800) 433-5255
Web site: http://thearc.org/welcome.html

National Down Syndrome Congress
1605 Chantilly Drive, Suite 250
Atlanta, GA 30324
(404) 633-1555; (800) 232-6372
Web site: http://www.carol.net/~ndsc

National Down Syndrome Society
666 Broadway, Suite 810
New York, NY 10012
(212) 460-9330; (800) 221-4602
Web site: http://ndss.org

# Cerebral Palsy Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

Cerebral palsy is a condition caused by damage to the brain, usually occurring before, during, or shortly after birth. "Cerebral" refers to the brain, and "palsy" to a disorder of movement or posture. It is neither progressive nor communicable. It is also not "curable," although education, therapy, and applied technology can help persons with cerebral palsy lead productive lives. It is not a disease and should never be referred to as such. It can range from mild to significant.

The causes of cerebral palsy may include illness during pregnancy, premature delivery, or lack of oxygen supply to the baby. It may also occur early in life as a result of an accident, lead poisoning, or viral infection.

## Characteristics

There are three main types of cerebral palsy: **spastic**—stiff and difficult movement; **athetoid**—involuntary and uncontrolled movement; and **ataxic**—disturbed sense of balance and depth perception. Individuals may also have a combination of these three types.

Cerebral palsy is characterized by an inability to fully control motor function. Depending on which part of the brain has been damaged and the degree of involvement of the central nervous system, one or more of the following may occur: spasms; involuntary movement; disturbance in gait and mobility; seizures; abnormal sensation and perception; impairment of sight, hearing, or speech; or mental retardation.

## Educational Implications

Early identification of cerebral palsy may help prevent developmental problems and lead to appropriate intervention. Activities for children with cerebral palsy may include:

- speech and language therapy
- occupational therapy
- physical therapy
- medical intervention
- family support services

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 2 (FS2): General Information about Cerebral Palsy. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

- early education
- assistive technology

The intensity of services provided will of course vary from individual to individual. Persons with cerebral palsy are usually able to attain a substantial degree of independence but, in some cases, may need considerable assistance.

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about cerebral palsy, contact:

United Cerebral Palsy Association
1660 L Street, N.W., Suite 700
Washington, DC 20036-5602
(202) 776-0406; (202) 973-7197 (TT); (800) 872-5827 (Voice/TT)
e-mail: ucpanatl@ucpa.org
Web site: http://www.ucpa.org

National Easter Seal Society
230 West Monroe Street, Suite 1800
Chicago, IL 60606
(312) 726-6200; (312) 726-4258 (TT); (800) 221-6827
e-mail: nessinfo@seals.con
Web site: http://www.seals.com

National Rehabilitation Information Center (NARIC)
8455 Colesville Road, Suite 935
Silver Spring, MD 20910-3319
(301) 588-9284 (Voice/TT); (800) 346-2742
Web site: http://www.naric.com/naric

# Appendix I

## Epilepsy Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

According to the Epilepsy Foundation of America (EFA), epilepsy is a physical condition that occurs when there is a sudden, brief change in how the brain works. When brain cells are not working properly, a person's consciousness, movement, or actions may be altered for a short time. These physical changes are called epileptic seizures. Epilepsy is therefore sometimes called a seizure disorder. Epilepsy affects people in all nations and of all races.

Some people can experience a seizure and not have epilepsy. For example, many young children have convulsions from fevers. These febrile convulsions are one type of seizure. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. A single seizure does not mean that a person has epilepsy.

### Characteristics

The symptoms below may be indicators of epilepsy:

- "blackouts" or periods of confused memory
- episodes of staring or unexplained periods of unresponsiveness
- involuntary movement of arms and legs
- "fainting spells" with incontinence or followed by excessive fatigue
- odd sounds, distorted perceptions, episodic feelings of fear that cannot be explained

Seizures can be generalized, meaning that all brain cells are involved. One type of generalized seizure consists of a convulsion with a complete loss of consciousness. Another type looks like a brief period of fixed staring.

Seizures are partial when those brain cells not working properly are limited to one part of the brain. Such partial seizures may cause periods of "automatic behavior" and altered consciousness. This is typified by purposeful-looking behavior, such as buttoning or unbuttoning a shirt. Such behavior, however, is unconscious, may be repetitive, and is usually not recalled.

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* Adapted with permission from National Information Center for Children and Youth with Disabilities (NICHCY)'s Fact Sheet Number 6 (FS6): General Information about Epilepsy. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# Appendix I

### Educational Implications

Children with epilepsy or seizure disorders are eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA), formerly the Education of the Handicapped Act (Public Law 94-142).

It is important that the teachers and school staff be informed about the child's condition, possible effects of medication, and what to do in case a seizure occurs at school. School personnel and the family should work together to monitor the effectiveness of medication as well as any side effects.

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about epilepsy, contact:

Epilepsy Foundation of America (EFA)
4351 Garden City Drive, Suite 406
Landover, MD 20785
(301) 459-3700; (800) EFA-1000 (toll free)
(301) 577-0100 for publications
e-mail: postmaster@efa.org
Web site: http://www.efa.org

National Institute of Neurological Disorders and Stroke (NINDS)
National Institutes of Health
Building 31, Room 8A06
9000 Rockville Pike
Bethesda, MD 20892
(301) 496-5751; (800) 352-9424

# Emotional Disturbance Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

The Individuals with Disabilities Education Act (IDEA) defines a "serious emotional disturbance" as a condition exhibiting one or more of the following characteristics over a long period of time and to a marked degree that adversely affects educational performance:

- an inability to learn that cannot be explained by intellectual, sensory, or health factors
- an inability to build or maintain satisfactory interpersonal relationships with peers and teachers
- inappropriate types of behavior or feelings under normal circumstances
- a general pervasive mood of unhappiness or depression
- a tendency to develop physical symptoms or fears associated with personal or school problems" [Code of Federal Regulations, Title 34, Section 300.7(b)(9)].

It is important to note that many children with problem behaviors do not qualify for special education and related services according to IDEA's criteria for "serious emotional disturbance." This diagnosis, which only covers the far end of the spectrum of behavior disorders, comprises just one percent of the child population. Currently, the Federal government is reviewing the way in which serious emotional disturbance is defined.

### Characteristics

The causes of emotional disturbance have not yet been adequately determined. Although a number of factors, such as heredity, brain disorder, diet, stress, and family functioning have been suggested as possible causes, research has not shown any of these factors to be the direct cause. Some of the characteristics and behaviors seen in children who have emotional disturbances include:

- serious and chronic aggression/victimization of others
- self-injurious behavior
- withdrawal (failure to initiate interaction with others; retreat from exchanges of social interaction)
- distorted thinking, excessive anxiety, bizarre motor acts, and abnormal mood swings

Many children who do not have emotional disturbances may display some of these same behaviors at various times during their development. However, when children have serious emotional disturbances, there is a marked increase in the frequency, intensity, and duration of these behaviors.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 5 (FS5): General Information about Emotional Disturbance. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

### Educational Implications

Educational programs for children with a serious emotional disturbance should include attention to developing social skills and increasing self-awareness, self-esteem, and self-control.

Children eligible for special education services under the category of serious emotional disturbance may have Individualized Education Programs (IEPs) that include psychiatric, psychological, or counseling services as a related service. This is an important related service that is available under the law, and is to be provided by a qualified social worker, psychologist, psychiatrist, guidance counselor, or other qualified professional.

There is a growing recognition that families, as well as their children, need support, respite care, intensive case management services, and a multi-agency treatment plan. Many communities are working toward providing these wrap-around services, and there are a growing number of agencies and organizations actively involved in establishing support services in the community. Parent support groups are also important, and organizations such as the Federation of Families for Children's Mental Health and the National Alliance for the Mentally Ill have parent representatives and groups in every state. Both of these organizations are listed under the resource section of this fact sheet.

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about emotional disturbance, contact:

American Academy of Child and Adolescent Psychiatry
Public Information Office
3615 Wisconsin Avenue, N.W.
Washington, DC 20016-3007
(202) 966-7300; (800) 333-7636
e-mail: mbel@cap.org
Web site: http://www.aacap.org/web/aacap/

ERIC Clearinghouse on Disabilities and Gifted Education
Council for Exceptional Children
1920 Association Drive
Reston, VA 20191-1589
(800) 328-0272; (703) 264-9449 (TTY)
e-mail: eric@cec.sped.org
Web site: http://www.cec.sped.org/ericec.htm

Federation of Families for Children's Mental Health
1021 Prince Street
Alexandria, VA 22314-2971
(703) 684-7710
e-mail: ffcmh@crosslink.com

National Alliance for the Mentally Ill
200 N. Glebe Road, Suite 1015
Arlington, VA 22203-3754
(703) 524-7600; (800) 950-NAMI
e-mail: namiofc@aol.com
Web site: http://www.nami.org

National Clearinghouse on Family Support and Children's Mental Health
Portland State University
P.O. Box 751
Portland, OR 97207-0751
(503) 725-4040; (800) 628-1696

National Mental Health Association
1021 Prince Street
Alexandria, VA 22314-2971
(703) 684-7722; (800) 969-6642
e-mail: nmhainfo@aol.com
Web site: http://www.nmha.org

For your state CASSP (Children and Adolescent Service System Program) office, or state mental health representative for children, call NICHCY (800-695-0285) and ask for a State Resource Sheet for your state.

## Learning Disabilities Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

The Individuals with Disabilities Education Act (IDEA) defines a learning disability as "a disorder in one or more of the basic psychological processes involved in understanding or in using spoken or written language, which may manifest itself in an imperfect ability to listen, think, speak, read, write, spell, or do mathematical calculations."

The IDEA definition further states that learning disabilities include "such conditions as perceptual disabilities, brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia." According to the law, learning disabilities do not include learning problems that are primarily the result of visual, hearing, or motor disabilities; mental retardation; or environmental, cultural, or economic disadvantage. Definitions of learning disabilities also vary among states.

### Characteristics

Learning disabilities are characterized by a significant difference in the child's achievement in some areas, as compared to her overall intelligence. Children who have learning disabilities may exhibit a wide range of traits, including problems with reading comprehension, spoken language, writing, or reasoning ability. Hyperactivity, inattention, and perceptual coordination problems may also be associated with learning disabilities. Other traits that may be present include a variety of symptoms, such as perceptual impairments, motor disorders, and behaviors such as impulsiveness, low tolerance for frustration, and problems in handling day-to-day social interactions and situations.

Learning disabilities may occur in the following academic areas:

- spoken language: delays or disorders in listening and speaking
- written language: difficulties with reading, writing, and spelling
- reasoning: difficulty in organizing and integrating thoughts
- organization skills: difficulty in organizing all facets of learning
- arithmetic: difficulty in performing arithmetic functions or comprehending basic concepts

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 7 (FS7): General Information about Learning Disabilities. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# Appendix K

## Educational Implications

Some teachers report that the following strategies have been effective with some children who have learning disabilities:

- Capitalize on the child's strengths.
- Provide a structured environment and clear expectations.
- Use short sentences and a simple vocabulary.
- Provide opportunities for success in a supportive atmosphere to help build self-esteem.
- Provide immediate feedback.
- Provide positive reinforcement of appropriate social skills at school and home.
- Recognize that children with learning disabilities can greatly benefit from the gift of time to grow and mature.

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about learning disabilities, contact:

Division of Learning Disabilities
Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 20191-1589
(703) 620-3660; (703) 264-9446 (TTY)
Web site: http://www.cec.sped.org

International Dyslexia Society
Chester Building, Suite 382
8600 LaSalle Road
Baltimore, MD 21286-2044
(410) 296-0232; (800) 222-3123
e-mail: info@ods.org
Web site: http://www.interdys.org/

Learning Disabilities Association of America (LDA)
4156 Library Road
Pittsburgh, PA 15234-1349
(412) 341-1515; (412) 341-8077
e-mail: ldanatl@usaor.net
Web site: http://www.ldanatl.org

National Center for Learning Disabilities
381 Park Avenue South, Suite 1401
New York, NY 10016
(212) 545-7510; (888) 575-7373
Web site: http://www.ncld.org

## Speech and Language Disorders Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

Speech and language disorders refer to problems in communication and related areas, such as the ability to control mouth muscles to make sounds. These delays and disorders range from simple sound substitutions to the inability to understand or use language. Some causes of speech and language disorders include hearing loss, oral muscle problems, neurological disorders, brain injury, mental retardation, and physical impairments such as cleft lip or palate.

### Characteristics

A child's communication is considered delayed when the child is noticeably behind his peers in the acquisition of speech and/or language skills. Sometimes a child will have greater receptive (understanding) than expressive (speaking) language skills, but this is not always the case.

**Speech disorders** are difficulties producing speech sounds, or problems with voice quality. People with speech disorders have trouble using some speech sounds, which can also be a symptom of a delay. They may say "see" when they mean "ski" or they may have trouble using other sounds, like "l" or "r." Listeners may have trouble understanding what someone with a speech disorder is trying to say.

A **language disorder** is an impairment in a person's ability to understand and/or use words in context, both verbally and nonverbally. Some characteristics of language disorders include improper use of words and their meanings; inability to express ideas; and inability to follow directions. One or a combination of these characteristics may occur in children who are affected by language learning disabilities or developmental language delay. Children may hear or see a word, but not be able to understand its meaning. They may have trouble getting others to understand what they are trying to communicate.

### Educational Implications

The ability to communicate allows people to learn about the world, use knowledge and skills, and interact with family and friends. Because the ability to communicate is so essential, children with speech and language disorders need appropriate, timely intervention. While many speech and language patterns can be called "baby talk" and are part of any young child's normal development, they can become problematic if the child does not "outgrow" them as expected. In this way, an initial delay in speech and language or an initial speech pattern can become a disorder which can cause difficulties in learning.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 11 (FS11): General Information about Speech and Language Disorders. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# Appendix L

Speech-language pathologists assist children who have communication disorders in various ways. They provide individual therapy for the child, and consult with the child's teacher and family about effective ways to facilitate the child's communication both in class and at home. Technology can also help children whose physical disabilities make communication difficult. The use of electronic communication systems allow nonspeaking people and people with significant physical disabilities to engage in the give and take of shared thought.

> While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about speech and language disorders, contact:

Alliance for Technology Access
2175 E. Francisco Boulevard, Suite L
San Rafael, CA 94939
(415) 455-4575
e-mail: atainfo@ataccess.org
Web site: http://www.ataccess.org

American Speech-Language-Hearing Association (ASHA)
10801 Rockville Pike
Rockville, MD 20852
(301) 897-5700 (Voice or TDD); (800) 498-2071
e-mail: webmaster@asha.org
Web site: http://www.asha.org

Learning Disabilities Association of America (LDA)
4156 Library Road
Pittsburgh, PA 15234-1349
(412) 341-1515; (412) 341-8077
e-mail: ldanatl@usaor.net
Web site: http://ldanatl.org

Division for Children with Communication Disorders
c/o Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 20191-1589
(703) 620-3660; (703) 264-9446 (TTY)
Web site: http://www.cec.sped.org

# Traumatic Brain Injury Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

Note: Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

The regulations of the Individuals with Disabilities Education Act (IDEA) now include Traumatic Brain Injury (TBI) as a separate disability category. While children with TBI have always been eligible for special education and related services, it should be easier for them under this new category to receive the services to which they are entitled.

IDEA defines TBI as "an acquired injury to the brain caused by an external physical force, resulting in total or partial functional disability or psychosocial impairment, or both, that adversely affects a child's educational performance." The term applies to open and closed head injuries resulting in impairments in one or more areas, including cognition; language; memory; attention; reasoning; abstract thinking; judgment; problem-solving; sensory, perceptual, and motor abilities; psychosocial behavior; physical functions; information processing; and speech. The term does not apply to brain injuries that are congenital or degenerative, or brain injuries induced by birth trauma.

### Characteristics

Children who sustain TBI may experience a complex array of problems, including:

- **Physical impairments**: speech, vision, hearing, and other sensory impairment; headaches; lack of fine motor coordination; spasticity of muscles; paralysis of one or both sides; seizure disorders; balance problems; and other gait impairments.
- **Cognitive impairments**: short- and long-term memory deficits; impaired concentration; slowness of thinking; limited attention span; perception impairments; communication, reading, and writing impairments; planning problems; sequencing difficulties; and impaired judgment.
- **Psychosocial, behavioral, or emotional impairments**: fatigue; mood swings; denial; self-centeredness; anxiety; depression; lowered self-esteem; restlessness; lack of motivation; inability to self-monitor; difficulty with emotional control; inability to cope; agitation; excessive laughing or crying; and difficulty relating to others.

Any or all of these impairments may occur to different degrees, from mild to severe.

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* Adapted with permission from the National Information Center for Children and Youth with Disabilities (NICHCY) Fact Sheet Number 4 (FS4): General Information about Traumatic Brain Injury. 1997. Other fact sheets are available from NICHCY, P.O. Box 1492, Washington, DC 20013.

### Educational Implications

Although children with TBI may seem to function much like children born with other handicapping conditions, it is important to recognize that the sudden onset of a significant disability resulting from trauma is very different. Children with brain injuries can often remember how they were before the trauma, which can result in a constellation of emotional and psychosocial problems not usually present in children with congenital disabilities. Further, the trauma impacts family, friends, and professionals who, recalling what the child was like prior to the injury, may have difficulty in subsequently adjusting goals and expectations for the child.

Careful planning for school re-entry (including establishing linkages between the trauma center/rehabilitation hospital and the special education team at the school) is extremely important to meet the child's needs. Teachers should be aware that, because the child's short-term memory may be impaired, she may forget what she appeared to learn earlier in the day. To work effectively with children with TBI, educators may need to:

- provide repetition and consistency
- demonstrate new tasks, state instructions, and provide examples to illustrate concepts
- avoid figurative language
- reinforce lengthening periods of attention to appropriate tasks
- probe skill acquisition frequently and provide repeated practice
- teach compensatory strategies for increasing memory
- prepare for children's reduced stamina, and provide rest breaks as needed
- keep the environment as distraction free as possible

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about traumatic brain injuries, contact:

Brain Injury Association (formerly the National Head Injury Foundation)
105 North Alfred Street
Alexandria, VA 22314
(703) 236-6000
Web site: http://www.biausa.org

Epilepsy Foundation of America
4351 Garden City Drive, Suite 406
Landover, MD 20785-2267
(301) 459-3700; (800) 332-1000; (800) 332-2070 (TTY)
e-mail: postmaster@efa.org
Web site: http://www.efa.org

## Visual Impairments Fact Sheet*

This fact sheet is not about a specific child; it is about a *condition*. Remember, reading this fact sheet is only the beginning of caring for children with disabilities. Just as with any child, it is of primary importance to know about the child's interests, strengths, and needs.

**Note:** Written materials about specific disabilities are available from a number of organizations. For names and addresses of these organizations, see the list that appears at the end of this fact sheet, and consult the Resources section of this guide.

The terms "partially sighted," "low vision," "legally blind," and "totally blind" are used in the educational context to describe children with visual impairments. They are defined as follows:

- "**Partially sighted**" indicates some type of visual problem that has resulted in a need for special education.

- "**Low vision**" generally refers to a significant visual impairment. Low vision applies to all individuals with sight who are unable to read the newspaper at a normal viewing distance, even with the aid of eyeglasses or contact lenses. They use a combination of vision and other senses to learn, although they may require adaptations in lighting or the size of print, and, sometimes, Braille (a system of writing that uses characters made up of raised dots).

- "**Legally blind**" means that a person has less than 20/200 vision in the better eye, or a very limited field of vision.

### Characteristics

The effect of visual problems on a child's development depends on the severity, type of loss, age at which the condition appears, and overall functioning level of the child. Many children who have multiple disabilities may also have visual impairments resulting in motor, cognitive, and/or social-developmental delays.

A young child with visual impairments has little reason to explore interesting objects in the environment and, thus, may miss opportunities to have experiences and to learn. Because the child cannot see parents or peers, he or she maybe unable to imitate social behavior or pick up on nonverbal cues. Visual handicaps can create obstacles to a growing child's independence.

### Educational Implications

Children with visual impairments should be assessed early if they are to benefit from early intervention programs. Assistive technology, such as computers and low-vision optical and video aids, enables many partially sighted, low-vision, and blind children to participate in regular class activities. Large-print materials, books on tape, and Braille books are available as well. In addition, children with visual impairments may need special equipment and modifications in the regular curriculum to emphasize listening skills, communication, mobility, and self-help skills.

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* Adapted with permission from National Information Center for Children and Youth with Disabilities (NICHCY)'s Fact Sheet Number 13 (FS13): General Information about Visual Impairments. 1997. Other fact sheets are available in English and Spanish from NICHCY, P.O. Box 1492, Washington, DC 20013.

# Appendix N

While many children who share the same diagnosis may have similar needs, it is important to remember that each child is always unique. The Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP) provide the road map for supports and services to meet the specific needs of individual children.

For more information about visual impairments, contact:

American Council of the Blind, Parents Division
c/o American Council of the Blind
1155 15th Street, N.W., Suite 720
Washington, DC 20005
(202) 467-5081; (800) 424-8666
e-mail: ncrabb@acces.digex
Web site: http://www.acb.org

American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
(800) AFBLIND (Toll free hotline)
To order publications, call: (800) 232-3044
e-mail: afbinfo@afb.org
Web site: http://www.afb.org/afb

Division for the Visually Handicapped
c/o Council for Exceptional Children
1920 Association Drive
Reston, VA 22091-1589
(703) 620-3660

National Association for Parents of the Visually Impaired, Inc.
P.O. Box 317
Watertown, MA 02272
(817) 972-7441; (800) 562-6265

National Association for Visually Handicapped
22 West 21st Street, 6th Floor
New York, NY 10010
(212) 889-3141
Web site: http://www.navh.org

National Braille Association, Inc. (NBA)
3 Townline Circle
Rochester, NY 14623
(716) 427-8260

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