Navigating the Resource Maze
A simulation of resource finding for families of children with special needs

Sharon E. Rosenkoetter
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# Navigating the Resource Maze

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Families of young children with special needs face many challenges

One of the most persistent is finding and coordinating the resources available to support the family and the child with a disability.

Many families with a seriously ill or disabled infant or young child have other children to nurture, an extended family to support, and jobs and community responsibilities to maintain. Thus, navigating the maze becomes part of a juggling act to which participants bring different experiences and varying communication skills.

This simulation will help preservice and inservice professionals and family advocates better understand the experiences of these families and, thereby, become better equipped to meet the families’ needs. Experience with the simulation may help participants discover new community resources, rethink service approaches, use improved communication modes, or form more realistic expectations in interactions with client family members. It also may help them assist families to use informal supports as well as contact the myriad agencies that may be helpful.

Up to 75 participants can increase their understanding during a realistic, 3-hour set of exercises and debriefings. Each attendee joins a “family” for two 30-minute “weeks.”

Family members work with representatives of service agencies: health and mental health, social services, financial planning, insurance, early intervention, special education, Head Start, housing, transportation, public assistance, employment services, religious groups, and advocacy.

Family members explore options and make decisions to locate and access needed support, both formal and informal.

Objectives
- Participants will gain information about available services and how to access them.
• Participants will explore the financial demands of disabilities or serious health issues.
• Participants will increase their empathy for the families by discussing their feelings about the multiple challenges they face.
• Participants will analyze the contribution of family service coordinators to helping their family navigate the resource maze.
• Participants will share their insights and conclusions and take their insights home to improve their professional practice.

Continuing Education Units
Sponsors may choose to offer a certificate of attendance for 3 hours of inservice training to participants who attend the entire session (see page 10).

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Overview for Facilitators

This simulation works with family advocates, undergraduate or graduate students, para-professionals, and practicing professionals from a variety of human service disciplines. It is effective with direct service personnel as well as with policymakers. Local interagency groups may choose to present it to foster discussion of family-responsive practices. The simulation can be adapted for a variety of communities and audiences. Cultural similarities and differences may be emphasized by the participants or stressed by the simulation's organizers.

How the Simulation Works

The simulation, from 25 to 75 people enact the lives of family members according to scenarios presented to them. There are three different family configurations (the J's, the S's, and the W's), and each configuration has both a limited-income and a middle-income profile. In the S family configuration, for example, the Smiths have lower income and the Scotts have higher income.

Within each letter pair (e.g., the Scotts and the Smiths), the one first in alphabetical order is the middle-income family. Participants don't know this as the simulation begins, but it may be useful to discuss during the debriefing.

The six families' profiles are on pages 5–10.

Each family has three adults plus at least two children; some of the latter are represented by cutout dolls. Two of the six families have an infant with a disability, two have a toddler, and two have a preschool-age child. The special needs present a variety of physical, mental, and psychosocial barriers to children's development, though of course each family's experience with special needs, as well as with other life events, is unique.

All six families also have children without special needs. A variety of parenting patterns is represented in the six scenarios.

Family members spend the entire session with the other members of their own family.
within the single scenario given them. More than one family has the same profile, but participants do not realize that because they do not talk with one other until a reflection time at the end of the simulation, after each family has dealt individually with its dilemmas.

Additional participants in the simulation are representatives of community agencies (or volunteers playing their roles) whom families consult as they attempt to navigate the resource maze. This guide calls these individuals “agency representatives” even though some of the professionals (e.g., a pastor, a physician) work for other types of organizations.

When families consult an agency representative during the simulation, the representatives explain how a family can access particular supports to meet goals the family members have identified.

These agency representatives are very important to the success of the simulation because they represent the possibilities and the challenges in the resource maze. Of course, every agency has constraints of time, money, and personnel. The simulation attempts neither to show agencies negatively nor to present an overly optimistic view, but rather to convey some of the typical issues that families encounter even when agency personnel are doing their best to be helpful. See page 13 for ways to recruit agency representatives.

Parents say that informal supports, such as friends, extended family, and voluntary associations in the community, often are very helpful when they are dealing with a crisis. Informal supports are represented in this simulation by offers of help that each family receives during the session, offers that families can choose or decline to accept.

Similarly, worries about family or friends, on top of parenting concerns, can alter the impact of childhood disability on a family’s life. Additional challenges are presented on challenge cards that come to families as they work through their dilemmas.
Family Profiles

Jackson Family

- Grandmother, Margaret, 76, has had an active life but now is in poor health.
- Mother, Kendra, 24, is a recent college graduate and works at an insurance company as an actuary.
- Father, Aaron, 29, is a sheet metal worker. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pays child support, and takes the children out for activities at least weekly. His new wife, Mindy, supports this relationship.
- Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a special diet, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. This week the family was referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
- Todd is 8 months old, “thriving,” and a very energetic baby who sleeps very little.

Assets and income

- Kendra and the boys live with Margaret in a home that Margaret owns.
- Grandma Margaret receives a monthly Social Security payment of $400 and has additional retirement income of $1,000 per month.
- Kendra earns $24,000 per year ($1,700 per month take-home).
- Grandma has provided child care so that Kendra can work, but Grandma feels she cannot continue to do this because of poor health and the energy demands of two little boys.
- Aaron and Mindy contribute $600 monthly in child support, help with occasional expenses, and bring “little gifts” of clothes and toys for the boys.
- Kendra has health insurance paid by her employer. Aaron has no health insurance. Trey and Todd have no health insurance because family premiums under Kendra’s plan would cost an additional $600 per month, which she says she cannot afford.
- Margaret has Medicare and a Medicare Supplemental Insurance policy.
- Margaret owns a 1997 Chevrolet that is paid for. Kendra uses it freely.

Monthly expenses

- No mortgage payment.
- Insurance and property taxes for the home: $150.
- Utilities: $300.
• Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
• Medical: $12,000 in bills outstanding; others for Trey’s recent hospitalization have not yet arrived. Many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
• Food: $250–$350.

Johnson Family
• Grandmother, Margaret, 76, has had an active life but now is in poor health.
• Mother, Kendra, 24, is a high school graduate and works at a local manufacturing plant (nonunion).
• Father, Aaron, 29, is a self-employed appliance repairman and handyman. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pay child support, and take the children out at least weekly. His new wife, Mindy, supports this relationship.
• Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed with diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a special diet, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. The family has been referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
• Todd is 8 months old, “thriving,” and a very energetic baby who sleeps little.

Assets and income
• Kendra and the boys live together in a small apartment with Grandma Margaret.
• Grandma Margaret receives a monthly Social Security payment of $200; she has been babysitting for neighborhood children (in addition to Trey and Todd) for about $100 per week but believes she can no longer do this.
• Kendra’s pay is $11 per hour, $680 take-home pay every two weeks, $21,120 per year before taxes.
• Grandma has provided child care so that Kendra can work, but she feels that she cannot continue to do this because of poor health and the energy demands of caring for the young children.
• Aaron and Mindy contribute $230 monthly in child support; this is very dependable.
• Kendra has health insurance paid by her employer. Trey and Todd have no health insurance because family premiums on Kendra’s plan would cost an extra $600 per month. Aaron has no health insurance.
• Margaret has Medicare.
• Margaret owns a 1982 Chevrolet that is paid for. Kendra uses it freely.

Monthly expenses
• Rent: $350.
• Utilities: $300.
• Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
• Medical: $12,000 in bills outstanding, but some from Trey’s recent hospitalization have not yet arrived; many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
• Food: $200–$300.

Scott Family
• Mother, Miranda, 45, is a homemaker and artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues; the two of them spend very little time together as a couple but would like to change this.
• Father, Robert, 49, is an attorney who works long hours. He is rather detached from the children and extremely critical about his son’s behavior. He wishes that things with his wife were as they used to be.
• Megan, 16, is from Miranda’s first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.
• Brady is 4½ with severe behavior problems involving impulse control and aggression. Brady attends a community preschool five mornings a week; the preschool has just told Miranda that Brady won’t be welcome after next week.
• Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income
• The family lives in a comfortable 3-bedroom home that they are buying. Robert’s income is $65,000 per year ($5,418 per month take-home).
• They have a stock portfolio and additional real estate worth $20,000.
• Miranda’s income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.
• They have three cars, one boat, and a small motor home.

Monthly expenses
• Mortgage: $1,000.
• Vehicle loan payments: $1,300.
• Food: $600.
• Health insurance: $750; no major medical challenges at this time.
• Other insurance: $400.
• Property taxes: $192.
• Utilities: $200.
Smith Family

- Mother, Miranda, 45, is a homemaker and an artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues. The two of them spend very little time together as a couple. They want to change this.
- Father, Robert, 49, is a non-union truck driver who works long hours. He is rather detached from the children and extremely critical about his son’s behaviors. He wishes that things with his wife were as they used to be.
- Megan, 16, is from Miranda’s first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.
- Brady is 4½ with severe behavior problems involving impulse control and aggression. Brady attends a church playgroup three mornings a week. The director has just told Miranda that due to Brady’s behavior, he is not welcome after next week.
- Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income

- The family lives in a crowded, three-bedroom home that they are renting.
- Robert’s income is $18,000 per year ($1,350 a month take-home).
- Miranda’s income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since. The family has one, older car.

Monthly expenses

- Rent: $450.
- Car payment: $100.
- Food: $400.
- No health insurance; uneven medical costs.
- Other insurance: $60.
- Utilities: $200.

Washington Family

- Mother, Jayne, 31, is a teacher employed at a school district 30 miles from home. She is now on maternity leave but has only 3 weeks remaining.
- Father, John, 45, is the assistant manager of a small department store 20 miles from home.
- Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds), and high-level bilirubin (jaundice). She will be followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week at 1 week corrected age. Caitlin will be on an apnea monitor and oxygen system when she comes home.
- Rachel is 5 and in kindergarten; she loves school.
- Ben, a son from John’s first marriage, is 19. He attends
the community college near where his dad works. He lives at home but is gone a great deal.

**Assets and income**
- The family lives together in a new four-bedroom home that they are buying; their equity in the home is $25,000.
- John’s income is $40,000 a year. Jayne’s income is $25,000 a year. They bring home a total of $4,158 a month. Both parents’ incomes are needed to pay monthly bills.
- The family has three cars, including Ben’s “old clunker.”

**Monthly expenses**
- Mortgage: $750.
- Car payments: $650.

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**Wilson Family**
- Mother, Jayne, 31, is a receptionist at a small business 30 miles from home; she is on maternity leave but has only 3 weeks remaining.
- Father, John, 45, is employed by a grocery store 20 miles from home.
- Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds) and high-level bilirubin (jaundice). She is being followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week, at 1 week corrected age, but will be on an apnea monitor and an oxygen system when she comes home.
- Rachel is 5 and in kindergarten; she loves school.
- Ben, a son from John’s first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

**Assets and income**
- The family lives together in a small three-bedroom home that they rent.
- John’s income is $15,000 a year. Jayne’s income is $13,520 a year. Together, they bring home about $2,027 a month.
- The family has two old cars.
Monthly expenses

- Rent: $350.
- Car payments: $250.
- Food: $400-$500.
- Health insurance: John has health insurance provided by his employer, but Jayne and the children are not covered.
- Other insurance: $100.
- Utilities: $300 both winter and summer.
- Medical: The family is still untangling costs of the NICU and physicians for Caitlin’s care, but these are expected to be very high. They have no health insurance for Caitlin or Jayne. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby’s hospitalization.

First Steps

Sponsorship

Organizers must first determine who will sponsor the simulation. Multiple sponsors and interagency support often are helpful in attracting the endorsements that lead to broader participation in the event and, ultimately, more family-supportive practices throughout the community after the simulation (Table 1). Within a college or university, sponsorship by multiple departments and training programs underscores the value of interdisciplinary support for families of infants, toddlers, and young children with special needs.

Sponsorship provides linkages to the target participants: service providers from a program like Early Intervention or Healthy Start or Head Start; child care providers; cross-agency leaders; students; administrators; caseworkers; policymakers; family advocates; new professionals; or, best of all, a diversity of people representing various agencies, disciplines, levels of education, ages, and interests. Simulation planners need to publicize the event early enough to attract the target participants and agency representatives.

Other Programming

The simulation may be a stand-alone activity, may lead into a meal featuring informal discussions, or may serve as a prelude to day-long collective reflection and planning of new directions for a community or an agency. Organizers need to decide on the purpose and target audience of the simulation. Some sponsors will be attracted by the objective of increasing resource awareness. Others will focus more on affective outcomes.

Continuing Education Credits

Offering continuing education credits requires lead time to meet the requirements of the different professional organizations. Some professional organizations require a representative of their discipline to be on the planning committee of an event (continued on page 12)
Potential Partners to Sponsor *Navigating the Resource Maze.*

**Community**
- Interagency council
- Commission on Children and Families
- School district
- Special education parents
- Health department
- Mental health agency
- Social service agency
- Early Head Start/Head Start
- Early Intervention
- Healthy Start
- Parents as Teachers, or similar program
- Hospital
- Child care resource and referral
- Community college
- Mayor’s office
- Civic groups

**University departments**
- Extension Service
- Human Development and Family Sciences
- Special Education
- Early Childhood Education
- Social Work
- Public Health
- Women’s Studies
- Rehabilitation Studies
- Adapted Physical Education
- Office of Career Planning
- Counseling
- Psychology

**State entities**
- Commission on Children and Families
- Health
- Education
- Social Services
- Developmental Disabilities
- State Interagency Coordinating Council
- Division for Early Childhood, Council for Exceptional Children
- Association for the Education of Young Children
- Head Start Collaboration Project or Head Start Quality Improvement Center—Disabilities Services
for which they will award continuing education units (CEUs). Other organizations require submitting course objectives in advance, résumés of presenters, and documentation of instruction hours.

All organizations that grant CEUs are likely to need signed evidence of participation and assurance of attendance during the entire session, as presented by the simulation’s sponsors. The latter is also true for undergraduate or graduate academic credit to which this experience may contribute contact hours.

Many simulation organizers choose to provide documentation of attendance for participants to use in pursuing their own CEUs.

**Summary**

The first steps are:

- Define purpose clearly
- Target participants
- Arrange shared sponsorship
- Plan course credit or CEUs
- Choose date and time
- Select location
- Establish time line and responsibilities
- Design publicity to attract desired attendees

Registration materials should stress that, due to the interactive nature of the simulation, participants should plan to arrive at least 15 minutes before the session begins.

Choose the location carefully. A big room such as a gymnasium or large fellowship hall works best. Participants taking the role of family members (25 to 75 persons) will sit in chairs, clustered by individual families in the center of the room. Persons representing service agencies will sit behind tables arranged around the walls of the room (see sample floor plan, page 20). During the simulation, family members will move freely around the room to converse with agency representatives and other family members. If the room is too small to allow easy movement, participants will be uncomfortable.

Similarly, acoustics are important. Most of the time, many participants and agency representatives will be conversing, and a facility that minimizes reverberating sound creates a more pleasant experience.

At the outset, it is important to define the time line and responsibilities for Navigating the Resource Maze. The following sections will list tasks to be accomplished. They can be adjusted to fit into the time a community has to plan and conduct the simulation.

**Date, Time, and Location**

Date, time, and location for the simulation are best established early. The event can be scheduled for any day of the week and any time of day, though 3 hours is the minimum needed to complete it successfully. A sample schedule for 9 a.m. to noon is:

- 8:45 Registration and seating
- 9:00 Introduction
- 9:15 Family study and planning in individual family groups
- 10:10 Second experience
- 10:45 Family discussion and planning
- 11:00 Small-group discussion
- 11:25 Whole-group processing
- 11:55 Evaluation and closing
Next Steps

Plan Publicity
The planning committee decides how to publicize the simulation. Preregistration is strongly recommended to avoid the problem of having too many or too few participants for the family roles. Encourage those who register to follow through and actually attend the simulation, but at the same time be prepared for drop-ins and no-shows.

Targeted publicity, by mail or listserv, is useful for recruiting a manageable number of participants. Experience shows that “teasers” — short announcements of an upcoming worthwhile event and “save the date”—up to 6 months before the simulation build anticipation and help participants prioritize the activity on their personal and agency calendars. Some employees need several months’ notice to secure permission to attend the event on salaried time.

Registrants should know that their presence at the simulation is expected and that fellow “family members” are depending on them. They should be asked to inform the sponsors as early as possible if they can’t attend.

A waiting list may be used to fill vacated slots. In addition, materials should be prepared for several additional families in case more participants attend than were expected.

Customize Content
After simulation leaders familiarize themselves with the event’s content, they may wish to adapt materials for local use.

Organizers may wish to change agency names to fit state and local practice; for example, “Child and Family Services” or “State Social Service,” instead of what this guide calls “public assistance” and “Families Together” or “COPE” instead of the “parent training and information center.”

This guide uses common surnames for the six family profiles. You may wish to change names and/or provide additional ethnic or religious information to fit the local community.

Recruit Others
At least 2 months before the simulation, the planning committee determines the agency representative slots to be filled and the individuals best suited to filling them, and then recruits those individuals (Table 2, page 14). Some of the representatives relate to families with all three profiles, some to two, and some to just one. Several agency representatives are essential resources for families with limited incomes, some for families with middle income, and some for all families.

A number of representatives are optional resources; others are essential. Some agencies are so important for many families (e.g., the public assistance agency) that more than one representative would be necessary in a simulation with 30 or...
### Table 2. 
#### Agency Representatives’ Roles in the Simulation.

<table>
<thead>
<tr>
<th>Agency</th>
<th>Needed?</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public assistance agency</td>
<td>Essential</td>
<td>Need 2 or more workers; most families will need to consult</td>
</tr>
<tr>
<td>Child care resource and referral</td>
<td>Essential</td>
<td>Essential for 2 of 6 family profiles</td>
</tr>
<tr>
<td>Counselors in private practice</td>
<td>See next column</td>
<td>Need this and/or mental health center for 2 of 6 family profiles</td>
</tr>
<tr>
<td>Mental health center</td>
<td>See next column</td>
<td>Need this and/or counselors for 2 of 6 family profiles</td>
</tr>
<tr>
<td>House of worship</td>
<td>Highly recommended</td>
<td>Some will use family choice</td>
</tr>
<tr>
<td>Parent support group for emotional disturbance</td>
<td>Essential</td>
<td>Essential for 2 of 6 family profiles</td>
</tr>
<tr>
<td>Parent support group for disabilities</td>
<td>Highly recommended</td>
<td>Some will use family choice</td>
</tr>
<tr>
<td>Community developmental disabilities organization</td>
<td>Highly recommended</td>
<td>Needed by 2 of 6 family profiles</td>
</tr>
<tr>
<td>Early Intervention</td>
<td>Essential</td>
<td>Needed by 4 of 6 family profiles; 1 family service coordinator for every 2 families recommended</td>
</tr>
<tr>
<td>Special education cooperative</td>
<td>Essential</td>
<td>Needed by 2 of 6 family profiles and useful for some others</td>
</tr>
<tr>
<td>Early Head Start/Head Start</td>
<td>Essential</td>
<td>Needed by 3-4 of 6 family profiles; may need more than 1 representative, including family advocate</td>
</tr>
<tr>
<td>Parent education center</td>
<td>Highly recommended</td>
<td>Needed by 2 of 6 family profiles</td>
</tr>
<tr>
<td>Services for children with special health care needs</td>
<td>Essential</td>
<td>Needed for 4 of 6 family profiles</td>
</tr>
<tr>
<td>Health department</td>
<td>Essential</td>
<td>To broker services for many families</td>
</tr>
<tr>
<td>Physician/nurse practitioner</td>
<td>Highly recommended</td>
<td>Traditionally talks at length with a small number of families, as a kind of medical case manager</td>
</tr>
<tr>
<td>State insurance for uninsured children CHIP (Children’s Health Insurance Program)</td>
<td>Essential</td>
<td>Needed for at least 4 of 6 family profiles</td>
</tr>
<tr>
<td>Private health insurance</td>
<td>Optional</td>
<td>Might be used by 2 of 6 family profiles</td>
</tr>
<tr>
<td>Consumer Credit Counseling</td>
<td>Essential</td>
<td>Needed by nearly all families, though often families fail to use it</td>
</tr>
</tbody>
</table>
more participants. Finally, some resources may be located within different agencies in various states and communities; for example, the child care resource and referral agency may be a stand-alone agency in some places, operate within a community college or a health department in another area, and be attached to a child care center or to the Extension Service in a third. The task here is to involve an agency representative who has the function required by the simulation, regardless of the function’s sponsoring entity.

Telephone or personal contacts seem to work best in obtaining commitment to participate. State agency personnel (e.g., health department, child care bureau, developmental disabilities council) often are eager to fill roles because it puts them in touch with people who actually use the policies their offices develop.

Follow up an agency representative’s oral agreement to participate with a letter that confirms the schedule and briefly describes Navigating the Resource Maze. (The template is in Sleeve 1, “Materials for Facilitators” at the back of the manual.)

It’s helpful to have a 30- to 60-minute meeting with agency representatives before the simulation. However, if that isn’t practical, send information about the families to be served along with the confirmation letter.

Make follow-up contacts 1 month and 1 week before the simulation to ensure that key agency representatives will appear on the day of the event and that they feel comfortable in the roles they are going to play.

In the experience of the authors, agency representatives appreciate the opportunity to participate in Navigating the Resource Maze because involvement:

- Provides an opportunity to share information about their agencies’ services with people who will use the information to help families.
- Helps their staff learn more about early childhood intervention and the families who may benefit from it.
- Helps their leadership and personnel develop greater sensitivity to family resources, priorities, and concerns in order to become more responsive in routine interactions.
- Increases awareness of certain family issues that agencies may not be addressing adequately.

The session includes time for agency representatives to discuss their simulation experiences with one another and then to share comments with the family members.

Ask agency personnel to bring multiple copies of the forms they typically use to counsel families; for example, Temporary Assistance to Needy Families (TANF) applications for the state and intake forms for Early Head Start or Early Intervention. Brochures explaining services are also distributed to families as they would be in the

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real world. Organizers might want to assemble packets of information or resources that participants can take home with them. Participants learn more about agency resources if a contact list for participating agencies and brochures can be shared after the simulation ends.

If the simulation is to be held frequently in the same locality—for example, in a university class—it may be difficult to attract agency representatives again and again. It may be possible for volunteers with relevant expertise to play certain roles; for example, a nurse playing a family practice physician. Such volunteers should gather materials from their real-life counterparts and likely will need more help from the organizers in advance than agency personnel representing themselves.

The affective objectives of the simulation may be obtained readily with volunteers in the agency slots, but, in such cases, less specific information about the agencies' services may be shared than when actual agency representatives enact their own roles.

The involvement of three important agencies needs further explanation.

Public Assistance Agency
Half the families will have good reason to consult the public assistance agency, perhaps early in the simulation. It is important to have at least two workers from this agency, perhaps one who is more experienced and one less experienced, to simulate real life. If there are many participants, three public assistance workers may be helpful. It is acceptable to have family members wait in line to see a caseworker because that reflects reality, but it is not desirable to have families spend their entire simulation time waiting in line.

Parent-run Family Support Agencies
It is essential to have one or more parent-run family support agencies represented. These groups vary greatly in size, scope, and title from state to state. Support groups for families of children with disabilities often "specialize" in certain conditions. Some children in the simulation have physical/developmental disabilities, while others have social/emotional/behavioral challenges.

Family Service Coordinators
Four of the six family profiles in the simulation have children who qualify for early intervention services under Part C of the Individuals with Disabilities Education Act (IDEA). Thus, if the parents choose to participate in early intervention, by law they are entitled to have a family service coordinator to assist them.

Any families among the six profiles who are accepted into Early Head Start or Head Start also are assigned to a family advocate. In most states, children in preschool special education services are not assigned family advocates. This may become a topic to include in the follow-up discussions.
Using actual family service coordinators during the simulation (with their routine materials and procedures) is recommended. Each of the early intervention personnel carries a caseload of two families and makes “home visits” to explain available services and offer assistance. If fewer family service coordinators are available, families will need to wait their turn, a situation that may simulate staffing shortages in real life. If families choose to contact Early Head Start or Head Start and are eligible to participate, a family advocate is assigned, but the family does not receive automatic home visits without initially contacting program staff. Given the constraints of time and varying priorities, during the simulation some families receive family service coordination while others do not. Participants of past simulations have consistently noted how helpful it is for families to receive this service at a time of crisis.

Finally, the planning committee needs to assign responsibility for many small tasks related to equipment, materials preparation, facilitation, and custodial work.

Summary
The “next steps” include:

- Plan publicity to help participants “save the date” well in advance.
- Establish registration procedures and deadlines.
- Become familiar with the content of the simulation.
- Adapt simulation names to fit state and local practice.
- (Optional) Vary family stories or family names to fit local ethnic patterns.
- Decide which agencies from the recommended list will be represented in your simulation and suggest possible agency contacts.
- Determine whether the project can attract persons who actually work for the agencies to play their own roles in the simulation or whether organizers will need volunteers to play some roles.
- Invite agency representatives (or volunteers) to attend an orientation meeting 1 hour before the simulation begins. Send additional information to help them feel comfortable in their roles. Send reminders 1 month and 1 week prior to the event.
- Determine responsibilities for photocopying, sign making, assembling packets, furniture set-up and take-down, custodial work, microphones, ordering refreshments for the orientation meeting, and facilitating the session’s welcome and group discussions.

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Two Weeks Before the Simulation

Ensure that all the parts are in place to make the simulation flow smoothly. Remind agency representatives of their important contributions to the session, verify the schedule for the participants, and answer questions. Inform family service coordinators about how they will make “home visits” to families. Plan how participants will be assigned to families. Provide a floor plan; see sample, page 20, which you will need to customize to include the names of participating agencies. The floor plan will help move family members quickly and easily into place for the simulation. Make a preview visit to the simulation site, if possible, to ensure that the physical setting will be ready.

Prepare printed materials and assemble them into packets. Color coding printed materials and signs helps organizers arrange materials and helps attendees find their appropriate locations. (Other color groups can be substituted for the ones below.)

Jackson – light pink
Johnson – deep pink (rose)
Scott – peach
Smith – salmon
Washington – light yellow
Wilson – deep yellow (goldenrod)
Service providers – white
Publicity – buff
Entry directions and floor plan – lavender
Evaluation – green

If family packets are in clear plastic envelopes, then the paper color can show through and help organizers distinguish them from one another.

If large manila envelopes are used, tape to the front of the envelope the colored sheet with the family name on it.

The same colors are used on signs for the individual family units as well as for their background materials and directions.

The colors also are used on large signs at the locations where families of the same name and agency representatives will gather to process the simulation experiences.

At the end of the simulation, if participants reassemble the materials they’ve used, organizers can reassemble the simulation kit more easily.

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Summary

Two weeks before the simulation:

- Remind agency representatives of their roles and the times for the orientation meeting and the simulation. Answer their questions, paying special attention to the family service coordinators. Replace agency representatives if there are last-minute schedule conflicts. It is helpful to have a couple of flexible volunteers who can step into any agency representative’s role at the last minute.
- Plan refreshments for the orientation meeting (for example, rolls and coffee for morning, pizza before an evening session).
- Summarize registration data, make check-off lists for the simulation, and assign registrants to families.
- Draw a floor plan to help registrants see where to go for the simulation. See sample, page 20.
- Prepare general materials with objectives and the day’s schedule, which will be presented upon arrival to all who attend.
- Prepare packets of resource brochures to pick up at the end of the session.
- Prepare name tags with family or agency names—not actual names—and put them in appropriate packets.
- Prepare color-coded packets for individual families. Assign registrants to family units, separating co-workers from the same organization or agency.
- Prepare information for agency representatives.
- Prepare sheets and procedures to award CEUs.
- Prepare signs for welcome, registration, CEUs, packets of resource brochures, family units, agency representatives’ tables, and small-group locations.
- Check on arrangements at the site for custodial work, microphones, and furniture set-up according to the simulation floor plan.
- On the script on pages 22–24 (or alternate scripts you prepare), note who will facilitate each part of the session.
- Use a bell, timer, or whistle to call the simulation group back together periodically to receive more directions or to debrief.

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Sample Floor Plan for Simulation

Customize as needed to reflect the number of family units participating in your simulation and the names of the agencies participating.

- Parent support group for emotional disturbance
- Early Intervention
- State Interagency Coordinating Council
- School District/ Special Ed Cooperative
- Early Head Start/ Head Start
- Parent Education Center
- Public Assistance Agency
- Child Care Resource & Referral Agency
- Counselors in private practice
- Mental Health Center
- House of worship
- Johnson #1
- Wilson #2
- Scott #1
- Smith #1
- Jackson #2
- Washington #3
- Wilson #1
- Scott #2
- Jackson #1
- Washington #2
- Smith #3
- Johnson #3
- Smith #2
- Wilson #3
- Jackson #3

Approximate number of family groups needed (sets of 4 chairs each)

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The Day of the Simulation

If you’ve never set up this simulation before, and you’re including an orientation for agency representatives, the authors recommend that you transport materials to the site at least 3 hours before the session is to start. Experienced simulation facilitators probably will need less time for set-up.

At the site:

- Post signs, registration materials, and CEU materials where they will be needed.
- Arrange packets in appropriate places in family groups.
- Check microphones.
- Arrange food for orientation meeting 1 hour before the session.
- Conduct the orientation meeting and answer all questions.
- Be ready to welcome attendees half an hour before the event. Expect the biggest rush about 15 minutes before you plan to start. Because this is an interactive, highly structured session, it is important to begin on time.
- Help family members find their family unit, put on their name tags, look at the lavender information sheet you gave them as they entered, and read over their family profile. Participants who are co-workers should, if possible, be assigned to different family units for the simulation.
- Have several people available to meet unexpected needs or to troubleshoot.
- Position the bell, timer, or whistle to be used to call groups back together for additional directions.

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Conducting the Simulation

It is important to follow the schedule closely to keep the simulation on track. One or more persons may lead various portions of the event. The following clarifies expectations and gives directions.

Welcome and Orientation
(Starting, for example, at 9 a.m.)

Introduce yourself and give the name of the event: Navigating the Resource Maze—A Simulation of Resource Finding for Families of Young Children with Special Needs.

Acknowledge the sponsors by name.

Mention housekeeping details:

- CEU-related materials will be available at the end of the session at table ___.
- After the simulation, you may pick up a packet of brochures about services in our community and our state that you may use to assist families of young children with special needs.
- Restrooms are located _____________. We won't take a formal break during the simulation. Leave and return as you need to.
- Please remember to evaluate today's session on the green form you received when you entered the hall. We will appreciate any comments you can share to help us improve this simulation.

Present orientation. A sample script follows.

Sample Script

Families of young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support the family and the child with special needs.

The goal of this event is to help participants better understand families' experiences in finding resources for their young child with special needs. We also will learn a great deal more about the services that are available to support families in various circumstances. The objectives for today's session are on your lavender information sheet.

We hope you will enter into this activity seriously and participate actively in your family's dilemmas. Many people from area agencies are here to serve us, and we appreciate their time.

Today we will be role-playing the experiences of ___ families [number of units at this session] of young children with disabilities or serious illnesses. Please use your imagination and creativity and really get into this. If your family is a whiz and solves everything immediately, please put some more human dynamics into the discussion. It will be more meaningful and more fun if you can do that. We hope that today's activities will be worthwhile and will help you improve your practice after you leave.

In the first 15 minutes, please become familiar with your family and your environment.
1. Read your family’s description.
2. Within your family grouping, decide who will play which role. Children under age 15 are represented by doll cutouts.
3. Put on your name tag, and try consistently to be that person for the next 2 hours.
4. Notice the variety of resources around the room to help you solve your family’s most pressing issues. Pamphlets are available from each agency for each participant during or at the end of the session. Feel free to consult an agency that you don’t know about. The people who work there will help you figure out what is best for your children and family.

After this 15-minute orientation period, you will have two 30-minute “experiences” [or 25 or 35 minutes, depending on the schedule] during which you and your family members work together with service providers to meet your ongoing family needs as well as to locate assistance for your child. You will be given dilemmas to stimulate your need to explore resources. These dilemmas are in envelopes in your packet. You also will receive a special challenge or support about halfway through your experience. It may add to your concern or relieve it.

A signal will sound each time your family should regroup for discussion. After each experience, your family will have time to touch bases with one another and discuss your next steps.

Then we will have small- and large-group reflection times to learn from the experiences of other families. We plan to conclude at or before noon. If you have questions, please ask _____ or _______ as we move among the families.

**After 10 minutes (9:25 a.m.)**
(Ring bell) Do you all know your part to play? You will have 30 minutes to try to solve your family’s dilemmas. (Proceed with Experience #1.)

**After 10 minutes (10 a.m.)**
(Ring bell) Please look at the questions in your Experience #1 envelope and spend 10 minutes discussing them with other members of your family.

**After 10 minutes (10:10 a.m.)**
(Ring bell) Surely everything is not yet resolved, but please now look at the items in your Experience #2 envelope and decide how your family will proceed next. Begin to talk with agency representatives as soon as you are ready. Proceed with Experience #2.

**After 15 minutes (10:55 a.m.)**
(Ring bell) Now it is time to reflect on what we have gained from the situations of our......
families. At the signal, please pick up your chair and quickly move to the color that is on the family description in your packet. Agency representatives, please meet by the white sign. Family service coordinators, please meet with the family groups that you served during the simulation.

(Wait for participants to regroup, then continue.)

In today's activities, there were really just three profiles of families. Within each profile, some families had middle incomes and the rest had limited incomes. The families with whom you will now meet are exactly like your own family and had the same dilemmas; the only difference was in the informal supports and challenges each family received. Questions to guide your discussion are on sheets under your color-coded sign. Please quickly appoint a facilitator and a recorder and begin discussion. When your group reports, you will be asked to sketch your family profile and to summarize your group discussion.

After 25 minutes (11:25)
(Ring bell. Leave chairs and participants where they are. The facilitator should guide the following discussions.)

There were three basic family profiles in today's simulation. Within each family type, one set of families was economically comfortable while the other set faced economic challenges. Let's start with the Scott family. (Report)

The Smith family has similar characteristics but a significantly lower income. (Report)

Next, let's have the Washington family. (Report)

Let's hear from the Wilson family, in a similar situation except significantly lower income. (Report)

Now, let's have the Jackson family. (Report)

Finally, let's hear from the Jefferson family, similar to the Jacksons except significantly lower income. (Report)

Many people helped today to interpret their agencies for the rest of us. Let's hear a summary of their reactions. (Report from the agency representatives)

Are there other comments anyone would like to share? What is the most significant message you gained from today's experience? (Discuss)

30 minutes later (11:55)

Thank you for sharing your thoughts and your energies with the simulation today. We wish you well in taking this experience back to the work place. Don't forget to pick up your CEU-related materials and resource packets at the tables on the way out.

Two more things:

- First, before you leave, please remember to complete the green evaluation form. If you've misplaced yours, please pick up another at the registration desk.
- Second, please put all your simulation materials back into the packet they came in, so they can be reused.

Thank you for coming!
After the Simulation

A few follow-up activities are suggested.

- Thank the sponsors, facility providers, agency representatives, and facilitators for their contributions to the event.
- Tabulate the simulation evaluations and report them to the sponsors.
- Plan follow-up activities as suggested by the evaluations and the planning committee.

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Chapter 2. The Families: An Overview of Materials and Preparations

Materials for each family's packet are listed below. We recommend color coding most materials (other color groups can be substituted for the ones below):

Jackson – light pink
Smith – salmon
Washington – light yellow
Johnson – deep pink (rose)
Scott – peach
Wilson – dark yellow (goldenrod)

Using clear plastic packet covers allows the family name and color to show through. However, you can use paper envelopes instead if you attach the family's name (on an appropriately colored sheet) to the outside of the envelope.

There are six family profiles. That means your simulation will have multiple Washington families, multiple Scott families, etc. Arrange the floor plan so that families with the same profile are not sitting next to each other (see page 20 for a sample floor plan).

During the simulation, each family has two “Experiences.” Half the units of a given family start with one Experience and half start with another. This stretches the capacity of the agency representatives to see as many families as possible; it also reflects reality, because families' crises do not happen in the same sequence.

During their Experiences, each family receives “challenge” and “support” cards. The cards, which differ among families, introduce the unexpected, informal benefits and challenges that families experience when they are coping with crises. These can help or hinder the family in reaching its goals.

Place one Family Packet at each cluster of four chairs. The family's dolls will occupy one or two chairs; participants will occupy the other chairs.

If the total number of simulation participants is not divisible by three, the families can function most easily with only two participants.

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Family Packets
Each packet contains the following, which you make using the templates and masters in the “Materials for Family Packets” sleeves (sleeves 4–9) at the back of the manual. (This list of contents also appears at the front of each “Materials for Family Packets” sleeve.)

A Family profile (three copies of the appropriate profile)
  • Jackson
  • Johnson
  • Scott
  • Smith
  • Washington
  • Wilson

B Introduction and schedule of the simulation (one copy)

C Name tags (three, one for each member of the family to be played by a participant)

D A copy of the first and second Experiences for that family

E Two pairs of “challenge” and “support” cards, each pair in its own small, sealable envelope. Clip one Experience sheet (see D, above) to each envelope as directed on masters.

F Two dolls for each family

Preparation Steps
Items A, B, and D — Photocopy on color-coded paper (see page 27) if possible. Copies of the family profile may be on both sides of the sheet.

Item C — Consider placing name tags in pendant or stick-on name tag holders, to be reused when the simulation is repeated.

Item E — Photocopy on white paper. Cut apart. Proceed as above.

Item F — Photocopy on plain paper, card stock, or construction paper and cut out. Laminating plain paper and construction paper before you cut out the doll greatly increases durability.
Family Service Coordinators: An Overview of Materials and Preparations

It is best to have one Family Service Coordinator (FSC) for each two J and S families. (Brady W is 4\(\frac{1}{2}\) and thus not entitled to an FSC in most states. However, if your state would give him one, your simulation should also.) If there is a shortage of FSCs, families will have to wait, and FSCs will have to stretch— a real-world situation.

All the families an FSC serves (up to four, or two during each Experiences) should have the same profile. It’s a good idea to give each FSC a copy of the family’s profile and the Experiences the family will have at least a week before the simulation so that the FSC can bring along appropriate forms, brochures, and other resources to share with the family.

If each FSC has just two families, the FSC will see one family in the first Experience and the other family in the second Experience.

During each segment of the simulation, the FSC makes a “home visit” to the family, listens to their concerns, and helps them find resources. The FSC plays himself or herself and acts just as the role would unfold in real life.

Most Head Start and Early Head Start programs call the family service coordinator by the title of Family Advocate. Any families in Early Head Start or Head Start also may be assigned an FSC at the time they enroll in the program. If the family also has an FSC from Early Intervention, these FSCs will need to work together. Some of the W families may be entitled to a Family Advocate from Head Start. Special Education also will try to help them find resources, and public assistance may provide a case manager. This overabundance of coordination represents a situation that occurs in real life.

Materials for Family Service Coordinators
The FSCs should bring materials from the programs where they work. Or, simulation facilitators can assemble materials from local early intervention programs. Materials an FSC ordinarily uses in counseling

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families with special needs might include program bro-
chures, intake forms, and explanations of local or state
family support services.

Following are materials that facilitators will need to provide
to the FSCs before, during, and after the simulation.

Before
• Confirmation letter sent 4 to 6 weeks before the simula-
tion. (Template is in Sleeve 1, “Materials for Facilitators,” at
the back of the manual.)
• Reminder letter sent 8 days before the simulation. (Tem-
plate is in Sleeve 1, “Materials for Facilitators,” at the back of
the manual.)
• Profile of families to be served, sent before the simula-
tion with the confirmation letter and with the reminder
letter. (Master is in Sleeve 2, “Materials for Family Service
Coordinators,” at the back of the manual.)

During
• Introduction to and schedule of the simulation—one copy
for each FSC. (Template is in Sleeve 2, “Materials for Family
Service Coordinators,” at the back of the manual.)
• Name tag
• Extra copy of the family profile

After
• Thank-you letter, sent to all agency representatives within
1 week after the simulation. (Template is in Sleeve 1,
“Materials for Facilitators,” at the back of the manual.)

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Agency Representatives: An Overview of Materials and Preparations

Some agency representatives (e.g., the Family Service Coordinators, the Consumer Credit Counseling representative) will need an advance look at the family profiles in order to plan how to carry out their functions. The simulation planning committee should use its judgment about when to distribute these profiles (by mail ahead of time or at the orientation meeting just before the simulation) and which agency representatives need more or less information. This depends somewhat on the experience of the persons playing these roles.

Materials for Agency Representatives

These are materials you'll give to agency representatives before, during, and after the simulation.

Before
• Confirmation letter sent 4 to 6 weeks before the simulation. (Template is in Sleeve 1, “Materials for Facilitators,” at the back of the manual.)
• Reminder letter sent 8 days before the simulation. (Template is in Sleeve 1, “Materials for Facilitators,” at the back of the manual.) Profiles of families to be served, sent with the confirmation letter and with the reminder letter before the simulation. (Masters are in Sleeve 3, “Materials for Agency Representatives,” at the back of the manual.)

During
• Introduction to and schedule of the simulation—one copy. (Template is in Sleeve 3, “Materials for Agency Representatives,” at the end of the manual.)
• Name tag

The agency representatives should bring to the simulation any materials they ordinarily would use in counseling families who have children with special needs. Materials might include intake forms, service plans, brochures, and financial
tables. Agency representatives also could be invited to bring posters, logos, and other materials that would enhance their “offices” and convey information about their services.

After
• Thank-you letter, sent within 1 week after the simulation. (Template is in Sleeve 1, “Materials for Facilitators,” at the back of the manual.)

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Facilitators: 
An Overview of Materials and Preparations

Masters and templates for the materials described here are in Sleeve 1, “Materials for Facilitators,” toward the back of the manual.

- Sample letters to Family Service Coordinators, agency representatives, and the provider of the facility used for the simulation. Customize these as desired, duplicate, and distribute; a distribution time is recommended at the top of each template.
- Needs profiles of the J, S, and W families: the services they will use and a summary of the Experiences the families will work on. Duplicate these profiles as required for other facilitators’ reference and use. (Versions of these materials for the families’ own use are in the “Family Packets” sleeves.)
- Template for handout (“lavender sheet”) and for the floor plan to be stapled to it, for distribution to all participants as they enter the facility for the simulation.
- Questions for each family unit to discuss after they have finished working on both Experiences.
- Questions for discussions that the J, S, and W families will have in small groups later in the simulation.
- Six signs (8.5 by 11 inches), each with one of the family names in large letters. Copy on appropriately colored paper or card stock, and post in six different places to tell families where to gather for small-group discussions toward the end of the session.
- Evaluation forms to distribute to participants as they enter the simulation.
- Two doll cutouts for each family unit participating.

In Addition Facilitators will need to make a sign for each agency representative’s “office” (table). The sign, which identifies the agency at that table, should be large enough and positioned so that participants can see it easily from some distance.
Navigating the Resource Maze

Sleeve 1.

Materials for Facilitators

In This Sleeve
Sample letters, for the facilitators to send to:
• Family Service Coordinators
• Agency Representatives
• Facility providers

Template for handout ("lavender sheet") to give simulation participants as they enter the facility for the simulation.

Template for floor plan. Customize to reflect the number of participating family units and the names of the agencies that will be represented at the simulation. Copy on lavender paper and staple to the handout described above. Give one set to every participant as he or she enters the facility for the simulation.

Masters for needs profiles of the J, S, and W families. Make one copy of each, on plain paper, for each of the facilitators. Masters include:
• Experiences of the J, S, and W families, for the facilitators’ information
• Questions for family-group discussions, for the facilitators’ information

Masters for signs for the J, S, and W families. Make one copy of each master on appropriately colored paper. Post the signs to indicate where each group of J, S, and W families should gather later in the simulation to discuss their Experiences.

Master for questions ("Directions for Small-group Discussions") that the J, S, and W families will discuss in small groups later in the simulation. Make one copy, on appropriately colored paper, for the Jackson family, one copy for the Johnson family, and so on.

Master for dolls that represent children under age 15 in each family. Make two copies for each family unit participating. You can print on plain paper, construction paper, card stock, or cardboard. Laminating—especially on plain paper and construction paper—greatly improves durability.

Template for evaluation forms.

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

(Inside address)

Dear ________.

A persistent challenge in promoting the development of infants, toddlers, and young children with special needs is to locate resources to support them and their families. The goal of the simulation in which you will participate is to help family advocates and preservice and inservice professionals better understand families’ experiences in resource finding when their child has special needs.

Your role in the simulation is to represent your agency in advising people about the services you provide, especially with regard to the enclosed “experiences.” You will help families deal with the issues described on the enclosed sheets. Two groups of families—one with middle income and one with lower income—will ask whether you can help them with their experiences.

Please bring along any forms or brochures that you ordinarily might use in advising families. Other families may ask additional questions. Those questions could be about anything related to your services, so if you have a basic information sheet you might want to bring it along.

Please read the enclosed schedule for the simulation and the descriptions of the families before you come.

See you on [date] at [time] at [location] for refreshments and orientation. The simulation follows at [time].

Thanks again. If you have any questions, please call [name] at [telephone number].

Sincerely,

Enclosures
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

(Inside address)

Dear ________,

Thank you for agreeing to contribute your skills to a simulation to help family advocates and preservice and inservice professionals better understand families’ experiences in resource finding when their child has special needs. As you well know, a persistent challenge in promoting the development of infants, toddlers, and young children with special needs is to locate resources to support them and their families. The session we are planning has been well received in several other states.

Your role in the simulation is to work with two or more families who fit the profile that is enclosed. You will make a “home visit” to each family and work with them to meet the challenges they are facing. During your interactions, please function just as you do in your everyday work. Please bring along any forms or brochures that you might use for such assistance. Feel free to improvise on your role!

Please read the enclosed schedule for the simulation and the descriptions of the families before you come. We are counting on you at the simulation to support each of “your” families, so your attendance is important. Please let us know as soon as possible if you cannot attend.

See you on [date] at [time] at [location] for refreshments and orientation. The simulation follows at [time].

Thanks again. If you have any questions, please call [name] at [telephone number].

Sincerely,

Enclosures
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

(Inside address)

Dear ________,

We are looking forward to welcoming you next week as a key participant in the simulation *Navigating the Resource Maze*.

A persistent challenge in promoting the development of infants, toddlers, and young children with special needs is locating resources to support them and their families. The goal of this simulation is to help family advocates and preservice and inservice professionals better understand families’ experiences in resource finding when their child has special needs.

The orientation meeting for service providers begins at [time and date] in [location]. Refreshments will be served. The simulation itself begins at [time] and ends at [time].

Your primary role in the simulation is as a representative of ________ agency for the [name] families. You are also likely to have questions from other families. My letter of [date] included descriptions of the families you are most likely to meet. I am enclosing another copy here for your reference. Also, please bring forms or brochures that you would use in your professional interactions with these families. You also might want to bring agency-related posters or logos to display in your “office” (i.e., at your table) during the simulation.

Thanks again for your participation. If you have any questions, please call [name] at [telephone number].

Sincerely,

Enclosures

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Letter to *Agency Representatives*.

Customize as desired and send **8 days** before the simulation. Include copies of appropriate family profiles.

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(Inside address)

Dear __________.

Thank you for contributing your time and talents to *Navigating the Resource Maze*. Evaluations show that we were successful in our goal of sensitizing family advocates and preservice and inservice professionals to family resources and family dilemmas.

Your contribution to the event was significant. Without the service providers, the simulation could not have occurred. We hope that the simulation also aided you in reflecting on your own services to families with infants, toddlers, and young children with special needs.

Best wishes.

Sincerely,
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

(Inside address)

Dear ________,

Thank you for contributing use of your facility for our simulation Navigating the Resource Maze. As you know, our goal was to sensitize family advocates and preservice and inservice professionals to family resources and dilemmas when young children have special needs. Evaluations show that we were successful in reaching our goal. The event was extremely informative for those who participated.

Your contribution to the event was significant. Your staff was most helpful. They took all the requests for special arrangements in stride and seemed to enjoy seeing the simulation unfold.

Again, thank you for your assistance. Best wishes.

Sincerely,
Families of infants, toddlers, and young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support them and their child with a disability.

This simulation will help preservice and inservice professionals and family advocates better understand the experiences of these families and thereby become better equipped to meet the families' needs.

Each attendee joins a “family” for two 30-minute “weeks.” Family members work with representatives of service agencies: health and mental health, social services, financial planning, insurance, early intervention, special education, Head Start, housing, transportation, public assistance, employment services, religious groups, and advocacy. Family members explore options and make decisions to locate and access needed support, both formal and informal.

Objectives for Navigating the Resource Maze include the following.

1) Participants will gain information about available services and how to access them.
2) Participants will explore the financial demands of disabilities or serious health issues.
3) Participants will increase their empathy for the families by discussing their feelings about the multiple challenges they face.
4) Participants will analyze the contribution of family service coordinators to helping their family navigate the resource maze.
5) Participants will share their insights and conclusions and take their insights home to improve their professional practice.

Schedule
[adapt for your local plan]

8:45 Registration and seating
9:00 Introduction
9:15 Family study and planning in individual family groups
9:25 Experience #1
10:00 Family discussion and planning
10:10 Experience #2
10:40 Family discussion and planning
10:55 Small-group discussion
11:25 Whole-group processing
11:55 Evaluation and closing

(over)
Procedures
1. You will be part of a family for the next several hours. Find where your family group is to gather (ask facilitators for help if you need it). At your family’s location, you will find a packet of information and materials, which include name tags.

2. Read the profile of your family that is in the packet. Given your new family and its situation, imagine how you would process new information, use your time, and communicate with other family members and the larger community.

3. Within your family grouping, take one role. Put on your name tag and try consistently to “be” that person. You may envision your family to be of whatever ethnicity, race, religion, or geographic location you choose. Descriptions are intended to allow for personalization. Children under age 15 are represented by doll cutouts.

4. Around the room you will see resources to help you solve your family’s dilemmas. Pamphlets will be available from each service agency during the session or after it ends.

5. After the introductory comments from the organizers, open the small envelope for Experience #1 and begin to work on it with your family.

6. At the end of the session, please
   • Return all materials to the family packet in which you received them
   • Complete the evaluation form

Thank you for participating!

The sponsors of Navigating the Resource Maze affirm that every family is unique and that no simulation can fully convey the issues of parenting or family decision making with a child with special needs. Nevertheless, we urge participants to enter into their roles without reservation to attain maximum benefit from the experience.

For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Sample Floor Plan

Customize as needed to reflect the number of family units participating in your simulation and the names of the agencies participating. Print on lavender paper, attach to the introduction and schedule (also printed on lavender paper), and give to all simulation participants as they enter the facility.

Parent support group for emotional disturbance
Early Intervention
State Interagency Coordinating Council
School District/Special Ed Cooperative
Early Head Start/Head Start

Public Assistance Agency

Child Care Resource & Referral Agency

Counselors in private practice

Mental Health Center

House of worship

Johnson #1  Wilson #2  Scott #3
Smith #1  Jackson #2  Washington #3

Wilson #1  Scott #3  Johnson #3
Smith #3

Jackson #1  Approximate number of family groups needed (sets of 4 chairs each)

Smith #1  Smith #2  Wilson #3

Johnson #2

Washington #1  Jackson #3

Services for Children with Special Health Care Needs

Health Department

Physician/nurse practitioner

Children’s Health Insurance Program

Consumer Credit Counseling

Private health insurance

For most current information: http://extension.oregonstate.edu/catalog

THIS PUBLICATION IS OUT OF DATE.
Family Needs Profile — J Families
Three family members—mother Kendra, grandmother Margaret, father Aaron—plus two dolls for each J family unit participating.

Services the Families Will Use
Family Service Coordinator from Early Intervention for the Transportation/Work Dilemma—one FSC for every two J families in the simulation (brochures and forms helpful)
State children’s health plan, Services for Children with Special Health Care Needs—general planning for both dilemmas (brochures helpful). Will they help with transportation if the family is eligible?
Community developmental disabilities organization for the Transportation/Work Dilemma—can they help with respite care?
Consumer Credit Counseling for the Transportation/Work Dilemma—assistance with financial planning
Child care resource and referral for the Child Care Dilemma—finding care for both boys, including Trey with multiple special needs
Public assistance agency for child care assistance and Temporary Assistance for Needy Families (TANF) for both dilemmas

Early Head Start, if the community has one, for both dilemmas. How does Early Head Start work with Early Intervention? (Brochures and forms helpful)

Experiences
Each family faces two different Experiences during the simulation. Each Experience is posed as a dilemma.

The Child Care Dilemma Since Grandma Margaret’s health is declining, she will not be able to care for both children. What options will the parents consider for child care? How much will each cost? How will they pay for it? The family will need to think about what additional questions they have as they prepare a child care provider for this totally new experience. Who might help them with this?

The Transportation/Work Dilemma The parents need to consult the pediatric diabetes physician and other specialists at the medical center as well as doctors in town; they also need to travel frequently to the medical center for various appointments. How can Kendra continue to work to support the family and still take Trey for medical care? What informal and formal resources will they use? What other questions do they have?

Concluding Family Discussion
Families will be encouraged to plan their activities and work with agency personnel and informal community contacts during the next week to move their family forward in coping with its challenges. Families will be asked to discuss what they have learned that might make a difference for their family.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Family Needs Profile — S Families
Three family members—mother Miranda, father Robert, Miranda’s daughter Megan—plus two dolls for each S family unit participating

Services the Families Will Use
Clergy person (for the Family Dilemma)
Early Childhood Special Education (for the Brady Dilemma)
Head Start (for the Brady Dilemma)
State’s health insurance for children with low income (for the Brady Dilemma)
Parenting education center (for both dilemmas)
State or local parent support group for families with children with behavior disorders (for the Brady Dilemma)
Mental health center (for the Family Dilemma and perhaps for the Brady Dilemma)
Community counselors (for the Family Dilemma)
Primary care physician (for the Brady Dilemma)

Experiences
Each family faces two different Experiences during the simulation. Each Experience is posed as a dilemma.

The Brady Dilemma: What supports can help Brady learn and have friends and participate more in the life of the community? What will be the parents’ next steps in helping Brady? How will they pay for them? What additional questions do they have? What else would be useful to them?

The Family Dilemma: What resources can help this family remain intact and become the family they want to be? What will be their next steps in improving their family relationships? How will they pay for them? What additional questions do they have?

Concluding Family Discussion
How did the addition of informal supports (family, neighbors, community groups) or additional challenges help or hurt the family’s problem solving? How might formal services help? What else would be useful to them?

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Family Needs Profile — W Families
Three family members—mother Jayne, father John, and son Ben—plus two dolls for each W family unit participating.

Services the Families Will Use
Family Service Coordinator (for the Caitlin Dilemma)—one FSC for every two W families in the simulation (brochures and forms helpful)
Public assistance agency for SSI (the Financial Dilemma)
State health insurance for children with low income (the Financial Dilemma)—Wilsons definitely will need, and Washingtons should check
Insurance agent (the Financial Dilemma)—for the Washingtons
Maternal and Infant Services at Health Department—for the Washingtons
Consumer Credit Counseling

Experiences
Each family faces two different Experiences during the simulation. Each Experience is posed as a dilemma.

The Caitlin Dilemma What is most important for the family right now in helping Caitlin and the other children? What resources will they call upon first? The family should think about what additional questions they have as they get into this totally new experience.

The Financial Dilemma How will the family approach its financial situation? How will the family pay for the high costs of Caitlin's birth and first months of life as well as her ongoing medical costs? Should Jayne go back to work after her maternity leave expires? If so, how will the family pay for child care? What resources will they use? What additional questions do they have?

Concluding Family Discussion
Many people and agencies are available to help the family with the dilemmas they face. Encourage families to plan their activities and work with agency personnel and informal community contacts during the next week or two to move the family forward in coping with its challenges. Families will be asked to discuss what they have learned that might make a difference for their family.
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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Directions for Small-group Discussions

Appoint a recorder to take notes and to give a 3-minute report to the larger group about your families’ answers to the following questions.

1. Please begin your report with a short profile of your family.

2. What resources did you use during your experiences?

3. What additional support or resources would have helped you during this challenging time?

4. What insights or conclusions have you formed about the resources for families of infants or young children with disabilities?
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**Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs**

**Evaluation**

Date __________________________

Your role in the simulation: family member _____ service provider _____

Which of the following best describes your occupation or family role in real life?

- ___ Family of a child with a disability
- ___ Early interventionist
- ___ Special educator
- ___ Home visitor
- ___ Preschool teacher
- ___ Elementary teacher
- ___ Elected/governmental official
- ___ Other (please explain) __________________________________________________

What is your reaction to the simulation?

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Please list your favorite part(s) of this experience.

Please suggest ways to improve this simulation.

What from this experience will help you do your job better?

Other comments or questions?
In This Sleeve

**Masters for profiles** of the J, S, and W families. Reproduce on plain paper and send a copy of the appropriate family profile to each Family Service Coordinator with the confirmation letter and with the reminder letter. Make an extra copy for each FSC for the day of the simulation, as backup.

**Masters for the Experiences of the J, S, and W families** (i.e., the dilemmas the families face). Reproduce on plain paper and send to each Family Service Coordinator with the confirmation letter and with the reminder letter. Make an extra copy for each FSC for the day of the simulation, as backup.

**Template for overview** of the simulation and sample schedule of activities. Customize, reproduce on plain paper, and send a copy with the confirmation letter and with the reminder letter. Make an extra copy for each FSC for the day of the simulation, as backup.

**In Addition**

Facilitators also will need to provide a **name tag** for each Family Service Coordinator.

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For most current information: [http://extension.oregonstate.edu/catalog](http://extension.oregonstate.edu/catalog)
Jackson Family Profile

- Grandmother, Margaret, 76, has had an active life but now is in poor health.
- Mother, Kendra, 24, is a recent college graduate and works at an insurance company as an actuary.
- Father, Aaron, 29, is a sheet metal worker. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pays child support, and takes the children out for activities at least weekly. His new wife, Mindy, supports this relationship.
- Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a specialist, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. This week the family was referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
- Todd is 8 months old, "thriving," and a very energetic baby who sleeps very little.

Assets and income

- Kendra and the boys live with Margaret in a home that Margaret owns.
- Grandma Margaret receives a monthly Social Security payment of $400 and has additional retirement income of $1,000 per month.
- Kendra earns $24,000 per year ($1,700 per month take-home).
- Grandma has provided child care so that Kendra can work, but Grandma feels she cannot continue to do this because of poor health and the energy demands of two little boys.
- Aaron and Mindy contribute $600 monthly in child support, help with other occasional expenses, and bring "little gifts" of clothes and toys for the boys.
- Kendra has health insurance paid by her employer. Aaron has no health insurance. Trey and Todd have no health insurance because family premiums under Kendra’s plan would cost an additional $600 per month, which she says she cannot afford.
- Margaret owns a 1997 Chevrolet that is paid for. Kendra uses it freely.

Monthly expenses

- No mortgage payment.
- Insurance and property taxes for the home: $150.
- Utilities: $300.
- Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
- Medical: $12,000 in bills outstanding; others for Trey’s recent hospitalization have not yet arrived. Many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Johnson Family Profile

- Grandmother, Margaret, 76, has had an active life but now is in poor health.
- Mother, Kendra, 24, is a high school graduate and works at a local manufacturing plant (nonunion).
- Father, Aaron, 29, is a self-employed appliance repairman and handyman. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pay child support, and take the children out at least weekly. His new wife, Mindy, supports this relationship.
- Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a special diet, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. The family has been referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
- Todd is 8 months old, “thriving,” and a very energetic baby who sleeps little.

Assets and income

- Kendra and the boys live together in a small apartment with Grandma Margaret.
- Grandma Margaret receives a monthly Social Security payment of $200; she has been babysitting for neighborhood children (in addition to Trey and Todd) for about $100 per week but believes she can no longer do this.
- Kendra’s pay is $11 per hour ($680 take-home every two weeks, $21,120 per year before taxes).
- Grandma has provided child care so that Kendra can work, but she feels that she cannot continue to do this because of poor health and the energy demands of caring for the young children.
- Aaron and Mindy contribute $230 monthly in child support; this is very dependable.
- Kendra has health insurance paid by her employer. Trey and Todd have no health insurance because family premiums on Kendra’s plan would cost an extra $600 per month. Aaron has no health insurance:
  - Margaret has Medicare.
  - Margaret owns a 1982 Chevrolet that is paid for. Kendra uses it freely.

Monthly expenses

- Rent: $350.
- Utilities: $300.
- Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
- Medical: $12,000 in bills outstanding, but some from Trey’s recent hospitalization have not yet arrived; many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
- Food: $200–$300.
Scott Family Profile

- Mother, Miranda, 45, is a homemaker and artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues; the two of them spend very little time together as a couple but would like to change this.

- Father, Robert, 49, is an attorney who works long hours. He is rather detached from the children and extremely critical about his son's behaviors; he wishes that things with his wife were as they used to be.

- Megan, 16, is from Miranda's first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.

- Brady is 4½ with severe behavior problems involving impulse control and aggression. Brady attends a community preschool five mornings a week; the preschool has just told Miranda that Brady won't be welcome after next week.

- Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income

- The family lives in a comfortable 5-bedroom home that they are buying.
- Robert's income is $65,000 per year ($4,158 per month take-home).
- They have a stock portfolio and additional real estate worth $20,000.
- Miranda's income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.
- They have three cars, one boat, and one small motor home.

Monthly expenses

- Mortgage: $1,000.
- Vehicle loan payments: $1,300.
- Food: $600.
- Health insurance: $750; no major medical challenges at this time.
- Other insurance: $400.
- Property taxes: $192.
- Utilities: $200.
Navigating the Resource Maze: A Simulation of Resource Finding
for Families of Young Children with Special Needs

Smith Family Profile
• Mother, Miranda, 45, is a homemaker and an artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues. The two of them spend very little time together as a couple. They would like to change this.
• Father, Robert, 49, is a nonunion truck driver who works long hours. He is rather detached from the children and extremely critical about his son’s behaviors. He wishes that things with his wife were as they used to be.
• Megan, 16, is from Miranda’s first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.
• Brady is 4½ with severe behavior problems involving impulse control and aggression. Brady attends a church playgroup three mornings a week. The director has just told Miranda that due to Brady’s behavior, he is not welcome after next week.
• Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income
• The family lives in a crowded, three-bedroom home that they are renting.
• Robert’s income is $18,000 per year ($1,500 a month take-home).
• Miranda’s income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.
• The family has one, older car.

Monthly expenses
• Rent: $450.
• Car payment: $100.
• Food: $400.
• No health insurance; uneven medical costs.
• Other insurance: $60.
• Utilities: $200.

For most current information:
http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Washington Family Profile

• Mother, Jayne, 31, is a teacher employed at a school district 30 miles from home. She is now on maternity leave but has only 3 weeks remaining.
• Father, John, 45, is the assistant manager of a small department store 20 miles from home.
• Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds), and high-level bilirubin (jaundice). She will be followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week at 1 week corrected age. Caitlin will be on an apnea monitor and oxygen system when she comes home.
• Rachel is 5 and in kindergarten; she loves school.
• Ben, a son from John’s first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

Assets and income

• The family lives together in a new four-bedroom home that they are buying; their equity in the home is $25,000.
• John’s income is $40,000 a year. Jayne’s income is $25,000 a year. They bring home a total of $4,158 a month. Both parents’ incomes are needed to pay monthly bills.
• The family has three cars, including Ben’s “clunker.”

Monthly expenses

• Mortgage: $750.
• Car payments: $650.
• Food: $400–500.
• Health insurance: $500.
• Other insurance: $325.
• Property taxes: $158.
• Utilities: $400 both winter and summer.
• Credit cards: $200.
• Medical: The Washingtons are still untangling costs of the NICU and physicians for Caitlin’s care, but these are expected to be very high. Health insurance will not cover it all. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby’s hospitalization.

THIS PUBLICATION IS OUT OF DATE. For most current information: http://extension.oregonstate.edu/catalog
Wilson Family Profile

- Mother, Jayne, 31, is a receptionist at a small business 30 miles from home. She is on maternity leave but has only 3 weeks remaining.
- Father, John, 45, is employed by a grocery store 20 miles from home.
- Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds) and high-level bilirubin (jaundice). She is being followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week, at 1 week corrected age, but will be on an apnea monitor and an oxygen system when she comes home.
- Rachel is 5 and in kindergarten; she loves school.
- Ben, a son from John's first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

Assets and Income

- The family lives together in a small three-bedroom home that they rent.
- John's income is $15,000 a year. Jayne's income is $13,520 a year. Together, they bring home about $2,027 a month.
- The family has two old cars.

Monthly Expenses

- Rent: $350.
- Car payments: $250.
- Food: $400–$500.
- Health insurance: John has health insurance provided by his employer, but Jayne and the children are not covered.
- Other insurance: $100.
- Utilities: $300 both winter and summer.
- Medical: The family is still untangling costs of the NICU and physicians for Caitlin's care, but these are expected to be very high. They have no health insurance for Caitlin or Jayne. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby's hospitalization.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Experiences of the J, S, and W Families
Each family faces two different Experiences during the simulation. Each Experience is posed as a dilemma.

The J Families
The Child Care Dilemma Since Grandma Margaret's health is declining, she will not be able to care for both children. What options will the parents consider for child care? How much will each cost? How will they pay for it? The family will need to think about what additional questions they have as they prepare a child care provider for this totally new experience. Who might help them with this?

The Transportation/Work Dilemma The parents need to consult the pediatric diabetes physician and other specialists at the medical center as well as doctors in town; they also need to travel frequently to the medical center for various appointments. How can Kendra continue to work to support the family and still take Trey for medical care? What informal and formal resources will they use? What other questions do they have?

The S Families
The Brady Dilemma What supports can help Brady learn and have friends and participate more in the life of the community? What will be the parents' next steps in helping Brady? How will they pay for them? What additional questions do they have? What else would be useful to them?

The Family Dilemma What resources can help this family remain intact and become the family it wants to be? What will be their next steps in improving their family relationships? How will they pay for them? What additional questions do they have?

The W Families
The Caitlin Dilemma What is most important for the family right now in helping Caitlin and the other children? What resources will they call upon first? The family should think about what additional questions they have as they get into this totally new experience.

The Financial Dilemma How will the family approach its financial situation? How will the family pay for the high costs of Caitlin's birth and first months of life as well as her ongoing medical costs? Should Jayne go back to work after her maternity leave expires? If so, how will the family pay for child care? What resources will they use? What additional questions do they have?
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Each attendee joins a “family” for two 30-minute “weeks.” Family members work with representatives of service agencies: health and mental health, social services, financial planning, insurance, early intervention, special education, Head Start, housing, transportation, public assistance, employment services, religious groups, and advocacy. Family members explore options and make decisions to locate and access needed support, both formal and informal.

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4) Participants will analyze the contribution of family service coordinators to helping their family navigate the resource maze.
5) Participants will share their insights and conclusions and take their insights home to improve their professional practice.

Schedule
[adapt for your local plan]

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10:00 Family discussion and planning
10:10 Experience #2
10:40 Family discussion and planning
10:55 Small-group discussion
11:25 Whole-group processing
11:55 Evaluation and closing

Overview and schedule of activities for Family Service Coordinators.
Customize as needed.

For most current information:
http://extension.oregonstate.edu/catalog
In This Sleeve
Masters for profiles of the J, S, and W families. Reproduce on plain paper and send to each Agency Representative with the confirmation letter and with the reminder letter. Make an extra copy for each Agency Representative for the day of the simulation, as backup.

Masters for the Experiences of the J, S, and W families (i.e., the dilemmas the families face). Reproduce on plain paper and send to each Agency Representative with the confirmation letter and with the reminder letter. Make an extra copy for each Agency Representative for the day of the simulation, as backup.

Template for overview of the simulation and sample schedule of activities. Customize, reproduce on plain paper, and send a copy with the confirmation letter and with the reminder letter.

In Addition
Facilitators also will need to provide a name tag for each Agency Representative.
Jackson Family Profile

- Grandmother, Margaret, 76, has had an active life but now is in poor health.
- Mother, Kendra, 24, is a recent college graduate, and works at an insurance company as an actuary.
- Father, Aaron, 29, is a sheet metal worker. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pays child support, and takes the children out for activities at least weekly. His new wife, Mindy, supports this relationship.
- Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a specialist, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. This week the family was referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
- Todd is 8 months old, “thriving,” and a very energetic baby who sleeps very little.

Assets and income

- Kendra and the boys live with Margaret in a home that Margaret owns.
- Grandma Margaret receives a monthly Social Security payment of $400 and has additional retirement income of $1,000 per month.
- Kendra earns $24,000 per year ($1,700 per month take-home).
- Grandma has provided child care so that Kendra can work, but Grandma feels she cannot continue to do this because of poor health and the energy demands of two little boys.
- Aaron and Mindy contribute $600 monthly in child support, help with other occasional expenses, and bring “little gifts” of clothes and toys for the boys.
- Kendra has health insurance paid by her employer. Aaron has no health insurance. Trey and Todd have no health insurance because family premiums under Kendra’s plan would cost an additional $600 per month, which she says she cannot afford.
- Margaret owns a 1997 Chevrolet that is paid for. Kendra uses it freely.

Monthly expenses

- No mortgage payment.
- Insurance and property taxes for the home: $150.
- Utilities: $300.
- Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
- Medical: $12,000 in bills outstanding; others for Trey’s recent hospitalization have not yet arrived. Many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Johnson Family Profile
• Grandmother, Margaret, 76, has had an active life but now is in poor health.
• Mother, Kendra, 24, is a high school graduate and works at a local manufacturing plant (nonunion).
• Father, Aaron, 29, is a self-employed appliance repairman and handyman. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pay child support, and take the children out at least weekly. His new wife, Mindy, supports this relationship.
• Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a special diet, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. The family has been referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
• Todd is 8 months old, “thriving,” and a very energetic baby who sleeps little.

Assets and Income
• Kendra and the boys live together in a small apartment with Grandma Margaret.
• Grandma Margaret receives a monthly Social Security payment of $200; she has been babysitting for neighborhood children (in addition to Trey and Todd) for about $100 per week but believes she can no longer do this.
• Kendra’s pay is $11 per hour ($680 take-home every two weeks, $21,120 per year before taxes).
• Grandma has provided child care so that Kendra can work, but she feels that she cannot continue to do this because of poor health and the energy demands of caring for the young children.
• Aaron and Mindy contribute $230 monthly in child support; this is very dependable.
• Kendra has health insurance paid by her employer. Trey and Todd have no health insurance because family premiums on Kendra’s plan would cost an extra $600 per month. Aaron has no health insurance.
• Margaret has Medicare.
• Margaret owns a 1982 Chevrolet that is paid for. Kendra uses it freely.

Monthly Expenses
• Rent: $300.
• Utilities: $300.
• Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
• Medical: $12,000 in bills outstanding, but some from Trey’s recent hospitalization have not yet arrived; many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
• Food: $200–$300.
Scott Family Profile

- Mother, Miranda, 45, is a homemaker and artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues; the two of them spend very little time together as a couple but would like to change this.

- Father, Robert, 49, is an attorney who works long hours. He is rather detached from the children and extremely critical about his son’s behaviors; he wishes that things with his wife were as they used to be.

- Megan, 16, is from Miranda’s first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.

- Brady is 4½ with severe behavior problems involving impulse control and aggression. Brady attends a community preschool five mornings a week; the preschool has just told Miranda that Brady won’t be welcome after next week.

- Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income

- The family lives in a comfortable 5-bedroom home that they are buying.

- Robert’s income is $65,000 per year ($4,158 per month take-home).

- They have a stock portfolio and additional real estate worth $20,000.

- Miranda’s income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.

- They have three cars, one boat, and one small motor home.

Monthly expenses

- Mortgage: $1,000.

- Vehicle loan payments: $1,300.

- Food: $600.

- Health insurance: $750; no major medical challenges at this time.

- Other insurance: $400.

- Property taxes: $192.

- Utilities: $205.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Smith Family Profile

• Mother, Miranda, 45, is a homemaker and an artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues. The two of them spend very little time together as a couple. They would like to change this.

• Father, Robert, 49, is a nonunion truck driver who works long hours. He is rather detached from the children and extremely critical about his son's behaviors. He wishes that things with his wife were as they used to be.

• Megan, 16, is from Miranda's first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.

• Brady is 4½ with severe behavior problems involving impulse control and aggression. Brady attends a church playgroup three mornings a week. The director has just told Miranda that due to Brady's behavior, he is not welcome after next week.

• Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income

• The family lives in a crowded, three-bedroom home that they are renting.

• Robert's income is $18,000 per year ($1,500 a month take-home).

• Miranda's income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.

• The family has one, older car.

Monthly expenses

• Rent: $450.

• Car payment: $100.

• Food: $400.

• No health insurance; uneven medical costs.

• Other insurance: $60.

• Utilities: $200.

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Washington Family Profile

• Mother, Jayne, 31, is a teacher employed at a school district 30 miles from home. She is now on maternity leave but has only 3 weeks remaining.
• Father, John, 45, is the assistant manager of a small department store 20 miles from home.
• Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds), and high-level bilirubin (jaundice). She will be followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week at 1 week corrected age. Caitlin will be on an apnea monitor and oxygen system when she comes home.
• Rachel is 5 and in kindergarten; she loves school.
• Ben, a son from John’s first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

Assets and income

• The family lives together in a new four-bedroom home that they are buying; their equity in the home is $25,000.
• John’s income is $40,000 a year. Jayne’s income is $25,000 a year. They bring home a total of $4,158 a month. Both parents’ incomes are needed to pay monthly bills.
• The family has three cars, including Ben’s “ol’ clunker.”

Monthly expenses

• Mortgage: $750.
• Car payments: $650.
• Food: $400–$500.
• Health insurance: $500.
• Other insurance: $325.
• Property taxes: $158.
• Utilities: $400 both winter and summer.
• Credit cards: $200.
• Medical: The Washingtons are still untangling costs of the NICU and physicians for Caitlin’s care, but these are expected to be very high. Health insurance will not cover it all. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby’s hospitalization.
Navigating the Resource Maze: A Simulation of Resource Finding
for Families of Young Children with Special Needs

Wilson Family Profile

• Mother, Jayne, 31, is a receptionist at a small business 30 miles from home. She is on maternity leave but has only 3 weeks remaining.

• Father, John, 45, is employed by a grocery store 20 miles from home.

• Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds) and high-level bilirubin (jaundice). She is being followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week, at 1 week corrected age, but will be on an apnea monitor and an oxygen system when she comes home.

• Rachel is 5 and in kindergarten; she loves school.

• Ben, a son from John's first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

Assets and income

• The family lives together in a small three-bedroom home that they rent.

• John's income is $15,000 a year. Jayne's income is $13,520 a year. Together, they bring home about $2,027 a month.

• The family has two old cars.

Monthly expenses

• Rent: $350.

• Car payments: $250.

• Food: $400–$500.

• Health insurance: John has health insurance provided by his employer, but Jayne and the children are not covered.

• Other insurance: $100.

• Utilities: $300 both winter and summer.

Medical: The family is still untangling costs of the NICU and physicians for Caitlin's care, but these are expected to be very high. They have no health insurance for Caitlin or Jayne. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby's hospitalization.

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Experiences of the J, S, and W Families

Each family faces two different Experiences during the simulation. Each Experience is posed as a dilemma.

The J Families

**The Child Care Dilemma** Since Grandma Margaret’s health is declining, she will not be able to care for both children. What options will the parents consider for child care? How much will each cost? How will they pay for it? The family will need to think about what additional questions they have as they prepare a child care provider for this totally new experience. Who might help them with this?

**The Transportation/Work Dilemma** The parents need to consult the pediatric diabetes physician and other specialists at the medical center as well as doctors in town; they also need to travel frequently to the medical center for various appointments. How can Kendra continue to work to support the family and still take Trey for medical care? What informal and formal resources will they use? What other questions do they have?

The S Families

**The Brady Dilemma** What supports can help Brady learn and have friends and participate more in the life of the community? What will be the parents’ next steps in helping Brady? How will they pay for them? What additional questions do they have? What else would be useful to them?

**The Family Dilemma** What resources can help this family remain intact and become the family it wants to be? What will be their next steps in improving their family relationships? How will they pay for them? What additional questions do they have?

The W Families

**The Caitlin Dilemma** What is most important for the family right now in helping Caitlin and the other children? What resources will they call upon first? The family should think about what additional questions they have as they get into this totally new experience.

**The Financial Dilemma** How will the family approach its financial situation? How will the family pay for the high costs of Caitlin’s birth and first months of life as well as her ongoing medical costs? Should Jayne go back to work after her maternity leave expires? If so, how will the family pay for child care? What resources will they use? What additional questions do they have?
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Families of infants, toddlers, and young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support them and their child with a disability.

This simulation will help preservice and inservice professionals and family advocates better understand the experiences of these families and thereby become better equipped to meet the families' needs.

Each attendee joins a “family” for two 30-minute “weeks.” Family members work with representatives of service agencies: health and mental health, social services, financial planning, insurance, early intervention, special education, Head Start, housing, transportation, public assistance, employment services, religious groups, and advocacy. Family members explore options and make decisions to locate and access needed support, both formal and informal.

Objectives for Navigating the Resource Maze include the following:

1) Participants will gain information about available services and how to access them.
2) Participants will explore the financial demands of disabilities or serious health issues.
3) Participants will increase their empathy for the families by discussing their feelings about the multiple challenges they face.
4) Participants will analyze the contribution of family service coordinators to helping their family navigate the resource maze.
5) Participants will share their insights and conclusions and take their insights home to improve their professional practice.

Schedule
(adapt for your local plan)

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:45</td>
<td>Registration and seating</td>
</tr>
<tr>
<td>9:00</td>
<td>Introduction</td>
</tr>
<tr>
<td>9:15</td>
<td>Family study and planning</td>
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<td></td>
<td>in individual family groups</td>
</tr>
<tr>
<td>9:25</td>
<td>Experience #1</td>
</tr>
<tr>
<td>10:00</td>
<td>Family discussion and planning</td>
</tr>
<tr>
<td>10:10</td>
<td>Experience #2</td>
</tr>
<tr>
<td>10:40</td>
<td>Family discussion and planning</td>
</tr>
<tr>
<td>10:55</td>
<td>Small-group discussion</td>
</tr>
<tr>
<td>11:25</td>
<td>Whole-group processing</td>
</tr>
<tr>
<td>11:55</td>
<td>Evaluation and closing</td>
</tr>
</tbody>
</table>

Overview and schedule of activities for Agency Representatives. Customize as needed.
Navigating the Resource Maze

Sleeve 4.

Materials for Jackson Family Packets

In This Sleeve

Family Name
Make one copy for each Jackson family packet, to serve as the “front page” for their packet.

Family Profile
Make three copies for each Jackson family packet.

Sample Introduction and Schedule of the Simulation
Customize this information for your community and make one copy for each Jackson family packet.

Name Tags
Make three tags—one each for Kendra, Margaret, and Aaron—for each Jackson family packet.

Experiences 1 and 2: the Child Care Dilemma and the Transportation/Work Dilemma
Make one copy of each Experience for each Jackson family packet.

On half the copies of the Child Care Dilemma, write “Do this first”; on the other half, write “Do this second.”

On half the copies of the Transportation/Work Dilemma, write “Do this first”; on the other half, write “Do this second.”

Clip each sheet to the outside of a small, sealable envelope.

(“Challenge” and “support” cards will go inside the envelopes; see below.)

In assembling packets for Jackson families, make sure to pair a “Do this first” Dilemma with a “Do this second” Dilemma. For example, if the Child Care Dilemma says “Do this first,” be sure the Transportation/Work Dilemma says “Do this second.”

“Challenge” and “Support” Cards
For each Jackson family packet, randomly choose one “challenge” and one “support” card for Child Care Dilemma and one “challenge” and one “support” card for the Transportation/Work Dilemma from

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among those on the masters. Put each pair of cards in a separate, small envelope and seal it. To each envelope, clip the appropriate “Experience” sheet (above) and include in the family’s packet.

**Follow-up Questions about the Experiences**

Make one copy for each Jackson family packet.

**In Addition**

Each Jackson family packet also should contain two doll cutouts. The master for the doll cutout is in Sleeve 1, “Materials for Facilitators.”

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Jackson Family Profile

- Grandmother, Margaret, 76, has had an active life but now is in poor health.
- Mother, Kendra, 24, is a recent college graduate, and works at an insurance company as an actuary.
- Father, Aaron, 29, is a sheet metal worker. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pays child support, and takes the children out for activities at least weekly. His new wife, Mindy, supports this relationship.
- Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a special diet, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. This week the family was referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
- Todd is 8 months old, “thriving,” and a very energetic baby who sleeps very little.

Assets and income

- Kendra and the boys live with Margaret in a home that Margaret owns.
- Grandma Margaret receives a monthly Social Security payment of $400 and has additional retirement income of $1,000 per month.
- Kendra earns $24,000 per year ($1,700 per month take-home).
- Grandma has provided child care so that Kendra can work, but Grandma feels she cannot continue to do this because of poor health and the energy demands of two little boys.
- Aaron and Mindy contribute $600 monthly in child support, help with other occasional expenses, and bring “little gifts” of clothes and toys for the boys.
- Kendra has health insurance paid by her employer. Aaron has no health insurance. Trey and Todd have no health insurance because family premiums under Kendra’s plan would cost an additional $600 per month, which she says she cannot afford.
- Margaret has Medicare and a Medicare Supplemental Insurance policy.
- Margaret owns a 1997 Chevrolet that is paid for. Kendra uses it freely.

Monthly expenses

- No mortgage payment.
- Insurance and property taxes for the home: $150.
- Utilities: $300.
- Gas and insurance for automobile: $150 prior to Trey’s illness; at least $250 now.
- Medical: $12,000 in bills outstanding; others for Trey’s recent hospitalization have not yet arrived. Many new major costs are anticipated to treat Trey’s diabetes and other potential problems.
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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Families of young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support the family and their child with special needs.

The goal of this event is to help participants better understand families’ experiences in finding resources for their young child with special needs. We also will learn a great deal more about the services that are available to support families in various circumstances. The objectives for today’s session are printed on your lavender information sheet.

We hope you will enter into this activity seriously and participate actively in your family’s dilemmas. Many people from area agencies are here to serve us, and we appreciate their time.

Today you will be role-playing the experiences of a family with a young child who has a disability or serious illness. Please use your imagination and creativity and really get into this. If your family is a whiz and solves everything immediately, please put in some more human dynamics into the discussion. It will be more meaningful and more fun if you can do that. We hope that today’s activities will be worthwhile while you are doing them and will help you to improve your practice after you leave.

In the first 15 minutes, please become familiar with your family and your environment.

1. Read your family’s description.
2. Within your family grouping, choose among described roles. Children under age 15 are represented by doll cutouts.
3. Put on your name tag, and try consistently to be that person for the next 2 hours.
4. Notice the variety of resources around the room to assist you in solving your family’s most pressing issues. Pamphlets are available from each agency for each participant during or at the end of the session. Feel free to consult an agency you don’t know about. The people who work there will help you figure out what is best for your children and family.

After that 15-minute orientation period, you will have two 30-minute periods [or 25 or 35 minutes, depending on the schedule] during which you and your family members work together with service providers to meet your ongoing family needs as well as locate assistance for your child. You will be given two dilemmas—one about Child Care and the other about Transportation/Work—to stimulate your need to explore resources. These dilemmas are in envelopes in your packet.

A signal will sound each time your family should regroup for discussion. After each experience, your family will have time to touch bases with one another and discuss your next steps. Then we will have small- and large-group reflection times to learn from the experiences of other families. We plan to conclude at or before noon [or, the hour you have set]. If you have questions, please ask the facilitators who are moving among the families.

(over)
**Schedule**
[adapt for your local plan]

- **8:45** Registration and seating
- **9:00** Introduction
- **9:15** Family study and planning in individual family groups
- **9:25** Experience #1
- **10:00** Family discussion and planning
- **10:10** Experience #2
- **10:40** Family discussion and planning
- **10:55** Small-group discussion
- **11:25** Whole-group processing
- **11:55** Evaluation and closing

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Jackson Family Experience: The Child Care Dilemma

Since Grandma Margaret’s health is declining, she will not be able to care for the two active children in the family or for the neighborhood children. What options will you consider for child care for Trey and Todd? How much will each cost? How will you pay for it? Think about questions you have as you prepare a new child care provider to take care of Trey and Todd. Who might help you with these preparations?

You also will look for financial resources to help you pay for the child care. Perhaps Kendra or Aaron should quit work to take Trey to his appointments. Is that feasible?

Visit the following resources, not necessarily in this order:
• Consumer Credit Counseling, to figure out your financial situation
• The public assistance agency, to check on child care assistance and Temporary Assistance to Needy Families (TANF)
• The Resource and Referral Center for child care referrals
• The Community Developmental Disabilities Organization (CDDO) to learn about respite care, since Trey has a developmental disability

After you have made sense of the information that you receive, then and only then look at the cards inside this envelope.

During your family discussion time after visiting agency representatives, talk together and choose child care for Trey and Todd and decide how you will pay for it.
Jackson Family Experience: The Transportation/Work Dilemma

Given the need to consult the pediatric diabetes physician, the pediatric vision specialist, the pediatric cardioligist, and perhaps other specialists at the medical center as well as doctors in town, how can Kendra continue to work to support the family and still take Trey to needed medical care? What informal and formal resources will you use? What additional questions do you have related to this dilemma?

Start by defining your situation and writing down what questions you have. Your Family Service Coordinator will help you work through this dilemma. Talk among the three of you and with your family's service coordinator from Early Intervention or Early Head Start and try to figure out how to approach this problem. Your child's health and your family's well-being come first, but you all must eat, too.

Can Services for Children with Special Health Care Needs help you? What about your state's health insurance plan for children? Is any money available from public assistance? Would Consumer Credit Counseling help you figure out the best course of action?

After you have made sense of the information that you receive, then and only then look at the cards inside this envelope.

Then plan your activities and work with agency personnel and informal community contacts during the next week to move your family forward in coping with its challenges. What have you learned that might make a difference for your family?
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Jackson Family Challenge and Support Cards — Child Care Dilemma

Aaron and Mindy are willing to watch the boys 2 days a week. How can you fill the child care needs the other 3 days?

The “Happy Helpers” Club offers to set up a community fund-raiser to help your family with all its expenses. They think they could raise about $2,000. You have never taken “charity” from others. Should you accept their offer?

The Martha Circle at the neighborhood church is willing to provide a babysitter 1 day a week until Trey’s “doctoring” is finished. Would that help any way?

Your sister works in the same town and lives nearby. Her two children are cared for by her neighbor in an unlicensed home that seems dirty and chaotic. Your sister would like you to take Trey and Todd to the same place. What will you do?

Your neighbor’s 16-year-old daughter enjoys Trey and Todd and has babysat for them occasionally in the evenings or on weekends. How can you use her help?

Your church has a weekly “mother’s morning out” program on Friday mornings. Is there any way that this program could help?

You have called all 12 places on the child care list you received from the health department. One has openings for a toddler, but the provider is reluctant to care for a child with Down syndrome and diabetes (even though neither condition is “catching”). Isn’t this discrimination? Where can you get information? What resources might be available to train this provider?
Jackson Family Challenge and Support Cards — Transportation/Work Dilemma

Kendra, you are really tired after Todd’s birth and Trey’s hospitalization, and you wonder about just quitting your job and staying home. Could you do this?

Aaron, your boss offers to let you move to evening or night shift if you will continue working. Would this be a good solution? How?

Members of your place of worship have offered to drive you to scheduled appointments.

Kendra’s employer has agreed to allow Kendra to work a 4-day week, 10 hours per day.

Kendra, you have used all your sick leave and vacation time and can no longer take days off without losing pay. Your employer is frowning on your absences.

Kendra, you have used all your sick leave and vacation time and can no longer take days off without losing pay, but your co-workers have taken up a collection of their days and have donated them to you.

Aaron, you have scheduled your work so that you can be at home 1 day each week.

Aaron, you feel terrible about what is happening to Trey. You offer to schedule your jobs so that you can spend full time taking Trey to appointments.

You find out that a sorority of retired teachers might assist you with transportation to appointments. Grandma Margaret is a retired teacher.

Your neighbors might help if you asked them. The president of the Lions Club, an old friend of Grandma Margaret, has repeatedly said, “Let us know if we can help with anything.”
Jackson Family Follow-up Questions to Discuss

After completing work on both Experiences—the Child Care Dilemma and the Transportation/Work Dilemma—review your Experiences and note what you learned. Questions to answer:

How did the addition of informal supports (family, neighbors, community groups) on the “challenge” and “support” cards help or hinder your finding solutions to your dilemmas?

What formal services did you choose to use? Why? Why did you avoid others?

How did the presence or absence of a Family Service Coordinator affect your decision making?

What additional questions do you have about these issues?

What have you learned that might make a difference for your family in the future?
In This Sleeve
Family Name
Make one copy for each
Johnson family packet, to serve
as the “front page” for their
packet.

Family Profile
Make three copies for each
Johnson family packet.

Sample Introduction and
Schedule of the Simulation
Customize this information for
your community and make one
copy for each Johnson family
packet.

Name Tags
Make three tags—one each for
Kendra, Margaret, and Aaron—
for each Johnson family packet.

Experiences 1 and 2: the Child
Care Dilemma and the Trans-
portation/Work Dilemma
Make one copy of each Experi-
ence for each Johnson family
packet.

On half the copies of the Trans-
portation/Work Dilemma, write
“Do this first”; on the other half,
write “Do this second.”

Clip each sheet to the outside of
a small, sealable envelope.
(“Challenge” and “support”
cards will go inside the enve-
lopes; see below.)

In assembling packets for
Johnson families, make sure to
pair a “Do this first” Dilemma
with a “Do this second”
Dilemma. For example, if the
Child Care Dilemma says “Do
this first,” be sure the Transpor-
tation/Work Dilemma says “Do
this second.”

“Challenge” and
“Support” Cards
For each Johnson family packet,
randomly choose one
“challenge” and one “support”
card for the Child Care Dilemma
and one “challenge” and one
“support” card for the Transpor-
tation/Work Dilemma from
among those on the masters. Put each pair of cards in a separate, small envelope and seal it. To each envelope, clip the appropriate “Experience” sheet (above) and include in the family’s packet.

**In Addition**
Each Johnson family packet also should contain two doll cutouts. The master for the doll cutout is in Sleeve 1, “Materials for Facilitators.”

**Follow-up Questions about the Experiences**
Make one copy for each Johnson family packet.

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For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding
for Families of Young Children with Special Needs

Johnson Family Profile

- Grandmother, Margaret, 76, has had an active life but now is in poor health.
- Mother, Kendra, 24, is a high school graduate and works at a local manufacturing plant (nonunion).
- Father, Aaron, 29, is a self-employed appliance repairman and handyman. He does not live with the rest of the family due to divorce but continues to be friends with Kendra and Margaret, pay child support, and take the children out for activities at least weekly. His new wife, Mindy, supports this relationship.
- Trey is 2 years old, a charming little boy. He has Down syndrome and was recently diagnosed as having diabetes. He was hospitalized for a short time in a metropolitan area but is now back home in his rural area 50 miles away. Trey needs a special diet, blood tests several times a day, and insulin injections twice a day. During this transition period, he needs to see his primary care physician in town weekly and his pediatric diabetes specialist in the metropolitan area at least twice a month. The family has been referred to specialists for a likely vision problem and a possible heart arrhythmia; the specialists are also in the metropolitan area. Trey also has developmental needs related to his Down syndrome.
- Todd is 8 months old, “thriving,” and a very energetic little guy who sleeps little.

Assets and Income

- Kendra and the boys live together in a small apartment with Grandma Margaret.
- Grandma Margaret receives a monthly Social Security payment of $200; she has been babysitting for neighborhood children (in addition to Trey and Todd) for about $100 per week but believes she can no longer do this.
- Kendra's pay is $11 per hour ($680 take-home pay every 2 weeks; $21,120 per year before taxes).
- Grandmas has provided child care so Kendra can work, but she feels that she cannot continue to do this because of poor health and the energy demands of caring for the young children.
- Aaron and Mindy contribute $230 monthly in child support; this is very dependable.
- Kendra has health insurance paid by her employer. Trey and Todd have no health insurance because family premiums on Kendra’s plan would cost an extra $600 per month. Aaron has no health insurance.
- Margaret has Medicare.
- Margaret owns a 1982 Chevrolet that is paid for. Kendra uses it freely.

Monthly Expenses

- Rent: $350.
- Utilities: $300.
- Gas and insurance for automobile: $150 prior to Trey's illness, at least $250 now.
- Medical: $12,000 in bills outstanding, but some from Trey's recent hospitalization have not yet arrived; many new major costs are anticipated to treat Trey's diabetes and other potential problems.
- Food: $200–$300.
Families of young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support the family and their child with special needs.

The goal of this event is to help participants better understand families’ experiences in finding resources for their young child with special needs. We also will learn a great deal more about the services that are available to support families in various circumstances. The objectives for today’s session are printed on your lavender information sheet.

We hope you will enter into this activity seriously and participate actively in your family’s dilemmas. Many people from area agencies are here to serve us, and we appreciate their time.

Today you will be role-playing the experiences of a family with a young child who has a disability or serious illness. Please use your imagination and creativity and really get into this. If your family is a whiz and solves everything immediately, please put some more human dynamics into the discussion. It will be more meaningful and more fun if you can do that. We hope that today’s activities will be worthwhile while you are doing them and will help you to improve your practice after you leave.

In the first 15 minutes, please become familiar with your family and your environment.

1. Read your family’s description.
2. Within your family grouping, choose among described roles. Children under age 15 are represented by doll cutouts.
3. Put on your name tag, and try consistently to be that person for the next 2 hours.
4. Notice the variety of resources around the room to assist you in solving your family’s most pressing issues. Pamphlets are available from each agency for each participant during or at the end of the session. Feel free to consult an agency that you don’t know about. The people who work there will help you figure out what is best for your children and family.

After that 15-minute orientation period, you will have two 30-minute periods [or 25 or 35 minutes, depending on the schedule] during which you and your family members work together with service providers to meet your ongoing family needs as well as locate assistance for your child. You will be given two dilemmas—one about Child Care and the other about Transportation/Work—to stimulate your need to explore resources. These dilemmas are in envelopes in your packet.

A signal will sound each time your family should regroup for discussion. After each experience, your family will have time to touch bases with one another and discuss your next steps. Then we will have small- and large-group reflection times to learn from the experiences of other families. We plan to conclude at or before noon [or, the hour you have set]. If you have questions, please ask the facilitators who are moving among the families.

(over)
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>8:45</td>
<td>Registration and seating</td>
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<tr>
<td>9:00</td>
<td>Introduction</td>
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<tr>
<td>9:15</td>
<td>Family study and planning in individual family groups</td>
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<tr>
<td>9:25</td>
<td>Experience #1</td>
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<td>10:00</td>
<td>Family discussion and planning</td>
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<td>10:10</td>
<td>Experience #2</td>
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<td>10:40</td>
<td>Family discussion and planning</td>
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<td>10:55</td>
<td>Small-group discussion</td>
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<tr>
<td>11:25</td>
<td>Whole-group processing</td>
</tr>
<tr>
<td>11:55</td>
<td>Evaluation and closing</td>
</tr>
</tbody>
</table>

Schedule
[adapt for your local plan]

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Johnson Family Experience: The Child Care Dilemma

Since Grandma Margaret’s health is declining, she will not be able to care for the two active children in the family or for the neighborhood children. What options will you consider for child care for Trey and Todd? How much will each cost? How will you pay for it? Think about questions you want to ask as you prepare a new child care provider to take care of Trey and Todd. Who might help you with these preparations?

You also will look for financial resources to help you pay for the child care. Perhaps Kendra or Aaron should quit work to take Trey to his appointments. Is that feasible?

Visit the following resources, not necessarily in this order:
- Consumer Credit Counseling, to figure out your financial situation
- The public assistance agency, to check on child care assistance and Temporary Assistance to Needy Families (TANF)
- The Resource and Referral Center for child care referrals
- The Community Developmental Disabilities Organization (CDDO) to learn about respite care, since Trey has a developmental disability

After you have made sense of the information that you receive, then and only then look at the cards inside this envelope.

During your family discussion time after visiting the agency representatives, talk together and choose child care for Trey and Todd and decide how you will pay for it.
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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Johnson Family Experience: The Transportation/Work Dilemma

Given the need to consult the pediatric diabetes physician, the pediatric vision specialist, the pediatric cardiologist, and perhaps other specialists at the medical center as well as doctors in town, how can Kendra continue to work to support the family and still take Trey to needed medical care? What informal and formal resources will you use? What additional questions do you have related to this dilemma?

Start by defining your situation and writing down what questions you have. Your Family Service Coordinator will help you work through this dilemma. Talk among the three of you and with your family’s service coordinator from Early Intervention or Early Head Start and try to figure out how to approach this problem. Your child’s health and your family’s well-being come first, but you all must eat, too.

Can Services for Children with Special Health Care Needs help you? What about your state’s health insurance plan for children? Is any money available from public assistance? Would Consumer Credit Counseling help you figure out the best course of action?

After you have made sense of the information that you receive, then and only then look at the cards inside this envelope.

Then plan your activities and work with agency personnel and informal community contacts during the next week to move your family forward in coping with its challenges. What have you learned that might make a difference for your family?

For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Johnson Family Challenge and Support Cards — Child Care Dilemma

Aaron and Mindy are willing to watch the boys 2 days a week. How can you fill the child care needs the 3 other days?

The “Happy Helpers” Club offers to set up a community fund raiser to help your family with all its expenses. They think they could raise about $2,000. You have never taken “charity” from others. Should you accept their offer?

The Martha Circle at the neighborhood church is willing to provide a babysitter 1 day a week until Trey’s “doctoring” is finished. Would that help in any way?

Your sister works in the same town and lives nearby. Her two children are cared for by her neighbor in an unlicensed home that seems dirty and chaotic. Your sister would like you to take Trey and Todd to the same place. What will you do?

Your neighbor’s 16-year-old daughter enjoys Trey and Todd and has babysat for them occasionally in the evening or on weekends. How can you use her help?

Your house of worship has a weekly “mother’s morning out” program on Friday mornings. Is there any way that this program could help?

You have called all 12 places on the child care list you received from the health department. One has openings for a toddler, but the provider is reluctant to care for a child with Down syndrome and diabetes (even though neither condition is “catching”). Isn’t this discrimination? Where can you get information? What resources might be available to train this provider?
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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Johnson Family Challenge and Support Cards — Transportation/Work Dilemma

Kendra, you are really tired after Todd’s birth and Trey’s hospitalization, and you wonder about just quitting your job and staying home. Could you do this?

Members of your place of worship have offered to drive you to scheduled appointments.

Kendra’s employer has agreed to allow Kendra to work a 4-day week, 10 hours per day.

Kendra, you have used all your sick leave and vacation time and can no longer take days off without losing pay. Your employer is frowning on your absences.

Kendra, you have used all your sick leave and vacation time and can no longer take days off without losing pay, but your co-workers have taken up a collection of their days and have donated them to you.

Aaron, you have scheduled your work so that you can be gone 1 day each week.

Aaron, you feel terrible about what is happening to Trey. You offer to schedule your jobs so that you can spend all time taking Trey to appointments.

You find out that a sorority of retired teachers might assist you with transportation to appointments. Grandma Margaret is a retired teacher.

Your neighbors might help if you asked them. The president of the Lions Club, an old friend of Grandma Margaret, has repeatedly said, “Let us know if we can help with anything.”
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Johnson Family Follow-up Questions to Discuss

After completing work on both experiences—the Child Care Dilemma and the Transportation/Work Dilemma—review your experiences and note what you learned. Questions to answer:

How did the addition of informal supports (family, neighbors, community groups) on the “challenge” and “support” cards help or hinder your finding solutions to your dilemmas?

What formal services did you choose to use? Why? Why did you avoid others?

How did the presence or absence of a Family Service Coordinator affect your decision making?

What additional questions do you have about these issues?

What have you learned that might make a difference for your family in the future?

For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze

Sleeve 6.

Materials for Scott Family Packets

In This Sleeve
Family Name
Make one copy for each Scott family packet, to serve as the “front page” for their packet.

Family Profile
Make three copies for each Scott family packet.

Sample Introduction and Schedule of the Simulation
Customize this information for your community and make one copy for each Scott family packet.

Name Tags
Make three tags—one each for Miranda, Robert, and Megan—for each Scott family packet.

Experiences 1 and 2:
the Brady Dilemma and the Family Dilemma
Make one copy of each Experience for each Scott family packet.

On half the copies of the Brady Dilemma, write “Do this first”; on the other half, write “Do this second.”

On half the copies of the Family Dilemma, write “Do this first”; on the other half, write “Do this second.”

Clip each sheet to the outside of a small, sealable envelope. (“Challenge” and “support” cards will go inside the envelopes; see below.)

In assembling packets for Scott families, make sure to pair a “Do this first” Dilemma with a “Do this second” Dilemma. For example, if the Brady Dilemma says “Do this first,” be sure the Family Dilemma says “Do this second.”

“Challenge” and “Support” Cards
For each Scott family packet, randomly choose one “challenge” and one “support” card for the Brady Dilemma and one “challenge” and one “support” card for the Family Dilemma from among those on the masters. Put each pair of cards
in a separate, small envelope and seal it. To each envelope, clip the appropriate “Experience” sheet (above) and include in the family’s packet.

**Letter about Brady from L’il Angels Preschool**
Make one copy for each Scott family packet.

**Follow-up Questions about the Experiences**
Make one copy for each Scott family packet.

**In Addition**
Each Scott family packet also should contain two doll cutouts. The master for the doll cutout is in Sleeve 1, “Materials for Facilitators.”

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Scott Family Profile
• Mother, Miranda, 45, is a homemaker and an artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues; the two of them spend very little time together as a couple. They would like to change this.
• Father, Robert, 49, is an attorney who works long hours. He is rather detached from the children and extremely critical about his son’s behaviors; he wishes that things with his wife were as they used to be.
• Megan, 16, is from Miranda’s first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.
• Brady is age 4½ with severe behavior problems involving impulse control and aggression. Brady attends a community preschool five mornings a week; the preschool has just told Miranda that Brady will not be welcome after next week.
• Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income
• The family lives in a comfortable 5-bedroom home that they are buying.
• Robert’s income is $65,000 per year ($4,158 per month take-home).
• They have a stock portfolio and additional real estate worth $20,000.
• Miranda’s income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.
• They have three cars, one boat, and one small motor home.

Monthly expenses
• Mortgage: $1,000.
• Vehicle loan payments: $1,300.
• Food: $600.
• Health insurance: $750; no major medical challenges at this time.
• Other insurance: $400.
• Property taxes: $192.
• Utilities: $200.

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Families of young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support the family and their child with special needs.

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Today you will be role-playing the experiences of a family with a young child who has a disability or serious illness. Please use your imagination and creativity and really get into this. If your family is a whiz and solves everything immediately, please put some more human dynamics into the discussion. It will be more meaningful and more fulfilling if you can do that. We hope that today's activities will be worthwhile while you are doing them and will help you to improve your practice after you leave.

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1. Read your family's description.
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After that 15-minute orientation period, you will have two 30-minute periods [or 25 or 35 minutes, depending on the schedule] during which you and your family members work together with service providers to meet your ongoing family needs as well as locate assistance for your child. You will be given two dilemmas—one about Child Care and the other about Transportation/Work—to stimulate your need to explore resources. These dilemmas are in envelopes in your packet.

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(over)
Schedule
[adapt for your local plan]

8:45  Registration and seating
9:00  Introduction
9:15  Family study and planning
      in individual family groups
9:25  Experience #1
10:00 Family discussion and planning
10:10 Experience #2
10:40 Family discussion and planning
10:55 Small-group discussion
11:25 Whole-group processing
11:55 Evaluation and closing

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For most current information:
http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs
Name Tags — Scott Family

- Miranda Scott (mother)
- Megan Scott (teenage daughter)
- Robert Scott (father)

This publication is out of date. For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Scott Family Experience: The Brady Dilemma

During this experience, you will try to find resources to help your son, Brady. Visit the resources that the teacher suggested and learn how they might assist you and what steps you might take next.

What supports can help Brady learn, have friends, and participate more in the life of the community? What will be your next steps in helping Brady? How will you pay for them?

Early childhood special education might be helpful. Some Head Starts have behavior specialists. The community mental health center and our community's private counselors might be useful to your family. It is always wise to check with a physician to see whether there could be medical causes for some of Brady's difficulties. We have a very good parent support group in our area for families of children with behavior problems, and they are a great resource for many families.

There is a lot of evidence that if children like Brady do not get help early, their problems can escalate. But members of your family are kind of embarrassed about this. Who ever heard of a 4-year-old being kicked out of school? (see enclosed letter)

After you have made sense of some of the information from the resource agencies, then and only then look at the "challenge" and "support" cards inside this envelope.

What additional questions do you have? How will you work together to resolve this dilemma?

For most current information: http://extension.oregonstate.edu/catalog
Scott Family Experience: The Family Dilemma

Brady has problems at preschool: he has just been asked to withdraw due to aggressive and noncompliant behavior (see enclosed letter). He also has problems at home: constant activity, irritability, aggression against animals and people, and noncompliance. His problems have compounded difficulties in family dynamics that have been present for years.

Miranda, you are exhausted and frantic. You feel guilty because no matter what you do, the situation just seems to get worse. Your greatest concern is about the quality of your marriage. Sometimes, you feel very alone in dealing with Brady's problems. They haven't gone away, and Brady will be starting kindergarten soon.

Robert, you have agreed to try to find some help in dealing with Brady's effects on the family. However, you are very focused on Brady rather than on any other family dynamics. You hope there is someone who can shape this kid up before he starts kindergarten. And you hope it won't cost too much. Some months, it's hard to pay all the bills, and Megan will start college soon. You are a “private” person who doesn't usually confide personal information to others.

Megan, you are scared and worried about what might happen because your mom and stepdad don't talk to each other very much anymore. It is hard to know what gets into Brady. He's a good kid, but sometimes he is really violent; for example, one time he really hurt your baby sister. Another time, he killed the neighbor's kittens. You feel quite alone right now. Surely none of your friends would understand these kinds of problems.

These community resources have been recommended:

- Your pastor, priest, or rabbi
- The community mental health center
- Parenting classes and marriage counseling from counselors in private practice here or in a neighboring city,
- The local parenting education center
- The parent support group for families with children with behavior disorders
- If the bills get too high, the Consumer Credit Counseling service to help you figure out how to pay for these things.

Visit the resources suggested and learn how they might assist you and what steps you might take next to help your family remain intact and become the family you want it to be.

After you have made sense of some of this information, then and only then read the “challenge and support” cards inside this envelope.

Dealing with a “hidden” disability like behavior disorder can be more difficult than dealing with an obvious disability. Even family members don't always recognize the need for help. How was the addition of informal supports (family, neighbors, community groups) to your problem-solving beneficial or detrimental? Might formal services have helped more? What else would be useful to you?
Dear Mr. and Mrs. Scott,

I’ve been hoping that we could find a way for Brady to be successful in our classroom. As we have discussed a number of times, Brady is having lots of difficulty in our preschool classroom. He sweeps toys off shelves, hurts other children (bites, hits, kicks, spits), and resists teacher’s directions (refuses, runs, shouts “no”). We are increasingly concerned about the safety of other children in the classroom and about Brady’s readiness for kindergarten in a few months.

We feel that we are no longer beneficial to Brady’s needs and will not be able to have Brady continue in our Center. Since Brady’s behavior is keeping him from learning and having friends, we strongly recommend that you locate assistance for dealing with those behaviors.

Some resources that you might find helpful would be the School District’s early childhood special education director, Head Start, your physician, and Keys for Networking (the parent support group for families with children with challenging behavior).

I am sorry that this preschool did not work out for Brady, but we have done all that we can do. We would be glad to provide information to anyone with whom you choose to work.

Sincerely,

Miss Mary
Director
L’il Angels Preschool

For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Scott Family Challenge and Support Cards — Brady Dilemma

Brady needs friends. A neighbor with a 4-year-old son is willing to help you form a play group. What difference will this make in your planning and actions?

Your best friend from college has just moved back to town. What difference will this make in your planning and actions?

A family nearby has a 16-year-old daughter who is willing to babysit. She is a very capable young woman, and Brady is crazy about her.

Your house of worship has an active Parents’ Club, which you have never attended. What difference might this make in your planning and actions?

You really haven't made friends here. All your friends live in other states. What difference has this made in your planning and actions?

Brady likes to swim. The Y has just started a preschool swim class. You would like to enroll Brady, but you are worried about whether he can handle this. What difference would this make in your planning and actions?

The Sunday school teacher has asked Miranda and Robert to take turns coming to Sunday school with Brady because the teacher needs help in controlling his behavior. You really haven’t made friends here. You don't know what to think about this.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Scott Family Challenge and Support Cards — Family Dilemma

You have a close relationship with your sister, who lives in the same neighborhood, has always been there when you need her, and usually has great advice. What difference does this make in your planning and actions?

Last week when your sister from Florida visited, Brady bit her baby, and your sister says that he should be put in an institution! What difference do these negative comments make in your planning and actions?

Your parents live in town, love your children, and are available to take them on outings. What difference can this make in your planning and actions?

Both sets of grandparents are very critical of Brady, as well as of Miranda’s and Robert’s parenting. They don’t like to spend time with any of the children. What difference does this make in your planning and actions?

Both Miranda’s and Robert’s families are large, emotionally close, and willing to help each other. What difference does this make in your planning and actions?

The only surviving extended family member is Robert’s father, who is working with an oil company in Argentina. What difference does this make in your planning and actions?

Miranda’s mother is a widow in frail health and incapable of managing her household or limited finances. Miranda is an only child. What difference does this make in your planning and actions?

Robert’s mother lives in town and helps her son’s family in many ways, including with finances as needed. What difference does this make in your planning and actions?

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Scott Family Follow-up Questions to Discuss

After completing work on both Experiences—the Brady Dilemma and the Family Dilemma—review your experiences and note what you learned. Questions to answer:

How did the addition of informal supports (family, neighbors, community groups) on the “challenge and support” cards help or hinder your finding solutions to your dilemmas?

What formal services did you choose to use? Why? Why did you avoid others?

What additional questions do you have about these issues?

What have you learned that might make a difference for your family in the future?

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For most current information: http://extension.oregonstate.edu/catalog
Navigating the Resource Maze
Sleeve 7.

Materials for Smith Family Packets

In This Sleeve
Family Name
Make one copy for each Smith family packet, to serve as the “front page” for their packet.

Family Profile
Make three copies for each Smith family packet.

Sample Introduction and Schedule of the Simulation
Customize this information for your community and make one copy for each Smith family packet.

Name Tags
Make three tags—one each for Miranda, Robert, and Megan—for each Smith family packet.

Experiences 1 and 2: the Brady Dilemma and the Family Dilemma
Make one copy of each Experience for each Smith family packet.

On half the copies of the Brady Dilemma, write “Do this first”; on the other half, write “Do this second.”

On half the copies of the Family Dilemma, write “Do this first”; on the other half, write “Do this second.”

Clip each sheet to the outside of a small, sealable envelope. (“Challenge” and “support” cards will go inside the envelopes; see below.)

In assembling packets for Smith families, make sure to pair a “Do this first” Dilemma with a “Do this second” Dilemma. For example, if the Brady Dilemma says “Do this first,” be sure the Family Dilemma says “Do this second.”

“Challenge” and “Support” Cards
For each Smith family packet, randomly choose one “challenge” and one “support” card for the Brady Dilemma and one “challenge” and one “support” card for the Family Dilemma from among those on the masters. Put each pair of cards...
in a separate, small envelope and seal it. To each envelope, clip the appropriate “Experience” sheet (above) and include in the family’s packet.

**In Addition**

Each Smith family packet also should contain two doll cutouts. The master for the doll cutout is in Sleeve 1, “Materials for Facilitators.”

**Letter about Brady from L’il Angels Preschool**

Make one copy for each Smith family packet.

**Follow-up Questions about the Experiences**

Make one copy for each Smith family packet.
Navigating the Resource Maze: A Simulation of Resource Finding
for Families of Young Children with Special Needs

Smith Family Profile
• Mother, Miranda, 45, is a homemaker and an artist. She is tired from constant child care and very protective and concerned about her son Brady. She and her husband quarrel frequently about Brady and other issues. The two of them spend very little time together as a couple. They would like to change this.
• Father, Robert, 49, is a nonunion truck driver who works long hours. He is rather detached from the children and extremely critical about his son’s behaviors. He wishes that things with his wife were as they used to be.
• Megan, 16, is from Miranda’s first marriage. She is very close to her mother, and she loves her brother and sister very much. Her stepdad has always been nice to her.
• Brady is age 4½ with severe behavior problems involving impulse control and aggression. Brady attends a church playgroup three mornings a week. The director has just told Miranda that due to Brady’s behavior, he is not welcome after next week.
• Keisha, age 2, has been an easy baby and provides great delight for her family.

Assets and income
• The family lives in a crowded, three-bedroom home that they are renting.
• Robert’s income is $18,000 per year ($1,350 a month take-home).
• Miranda’s income was $10,000 per year before her child care responsibilities escalated, but it has dwindled to nothing since.
• The family has one, older car.

Monthly expenses
• Rent: $450.
• Car payment: $100.
• Food: $400.
• No health insurance; uneven medical costs.
• Other insurance: $60.
• Utilities: $200.

For most current information: http://extension.oregonstate.edu/catalog
Overview and schedule of activities for the Smith family. Customize as needed.

Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Families of young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support the family and their child with special needs.

The goal of this event is to help participants better understand families’ experiences in finding resources for their young child with special needs. We also will learn a great deal more about the services that are available to support families in various circumstances. The objectives for today’s session are printed on your lavender information sheet.

We hope you will enter into this activity seriously and participate actively in your family’s dilemmas. Many people from area agencies are here to serve us, and we appreciate their time.

Today you will be role-playing the experiences of a family with a young child who has a disability or serious illness. Please use your imagination and creativity and really get into this. If your family is a whiz and solves everything immediately, please put some more human dynamics into the discussion. It will be more meaningful and more fulfills you can do that. We hope that today’s activities will be worthwhile while you are doing them and will help you to improve your practice after you leave.

In the first 15 minutes, please become familiar with your family and your environment.

1. Read your family’s description.
2. Within your family grouping, choose among described roles. Children under age 15 are represented by doll cutouts.
3. Put on your name tag, and try consistently to be that person for the next 2 hours.
4. Notice the variety of resources around the room to assist you in solving your family’s most pressing issues. Pamphlets are available from each agency for each participant during or at the end of the session. Feel free to consult an agency that you don’t know about. The people who work there will help you figure out what is best for your children and family.

After that 15-minute orientation period, you will have two 30-minute periods [or 25 or 35 minutes, depending on the schedule] during which you and your family members work together with service providers to meet your ongoing family needs as well as locate assistance for your child. You will be given two dilemmas—one is about Brady and the other about the Family—to stimulate your need to explore resources. These dilemmas are in envelopes in your packet.

A signal will sound each time your family should regroup for discussion. After each experience, your family will have time to touch bases with one another and discuss your next steps. Then we will have small- and large-group reflection times to learn from the experiences of other families. We plan to conclude at or before noon [or, the hour you have set]. If you have questions, please ask the facilitators who are moving among the families.

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Name Tags — Smith Family

Miranda Smith (mother)

Robert Smith (father)

Megan Smith (teenage daughter)

Miranda Smith (mother)

Robert Smith (father)

Megan Smith (teenage daughter)

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Smith Family Experience: The Brady Dilemma

During this experience, you will try to find resources to help your son, Brady. Visit the resources that the teacher suggested and learn how they might assist you and what steps you might take next.

What other supports can help Brady to learn, have friends, and participate more in the life of the community? How will you pay for them?

Early childhood special education might be helpful. Some Head Start programs have behavior specialists. The community mental health center and our community’s private counselors might be useful to your family. It is always wise to check with a physician to see whether there could be medical causes for some of Brady’s difficulties. We have a very good parent support group in our area for families of children with behavior problems, and they are a great resource for many families.

There is a lot of evidence that if children like Brady do not get help early, their problems can escalate. But members of your family are kind of embarrassed about this. Who ever heard of a 4-year-old being kicked out of school (see enclosed letter)?

After you have made sense of some of the information from the resource agencies, then and only then look at the “challenge” and “support” cards inside this envelope.

What additional questions do you have? How will you work together to resolve this dilemma?

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Smith Family Experience: The Family Dilemma

Brady has problems at preschool: he has just been asked to withdraw due to aggressive and noncompliant behavior (see enclosed letter). He also has problems at home: constant activity, irritability, aggression against animals and people, and noncompliance. His problems have compounded difficulties in family dynamics that have been present for years.

Miranda, you are exhausted and frantic. You feel guilty because no matter what you do, the situation just seems to get worse. Your greatest concern is about the quality of your marriage. Sometimes, you feel very alone in dealing with Brady's problems. They haven't gone away, and Brady will be starting kindergarten soon.

Robert, you have agreed to try to find some help in dealing with Brady's effects on the family. However, you are very focused on Brady rather than on any other family dynamics. You hope there is someone who can shape this kid up before he starts kindergarten. You hope it won't cost too much. Some months, it's hard to pay all the bills, and Megan will start college soon. You are a “private” person who doesn't usually confide personal information to others.

Megan, you are scared and worried about what might happen because your mom and stepdad don't talk to each other very much anymore. It's hard to know what gets into Brady. He's a good kid, but sometimes he is really violent; for example, one time he really hurt your baby sister. Another time, he killed the neighbor's kittens. You feel quite alone right now. Surely none of your friends would understand these kinds of problems.

These community resources have been recommended:

- Your pastor, priest, or rabbi
- The community mental health center
- Counselors in private practice here or in a neighboring city, which has parenting classes and marriage counseling
- The local parenting education center
- The parent support group for families with children with behavior disorders
- If the bills get too high, the Consumer Credit Counseling service to help you figure out how to pay for these things.

Visit the resources suggested and learn how they might assist you and what steps you might take next to help your family remain intact and become the family you want it to be.

After you have made sense of some of this information, then and only then read the “challenge and support” cards inside this envelope.

Dealing with a “hidden” disability like behavior disorder can be more difficult than dealing with an obvious disability. Even family members don't always recognize the need for help. How was the addition of informal supports (family, neighbors, community groups) to your problem-solving beneficial or detrimental? Might formal services have helped more? What else would be useful to you?
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Dear Mr. and Mrs. Smith,

I’ve been hoping that we could find a way for Brady to be successful in our classroom. As we have discussed a number of times, Brady is having lots of difficulty in our preschool classroom. He sweeps toys off shelves, hurts other children (bites, hits, kicks, spits), and resists teacher’s directions (refuses, runs, shouts “no”). We are increasingly concerned about the safety of other children in the classroom and about Brady’s readiness for kindergarten in a few months.

We feel that we are no longer beneficial to Brady’s needs and will not be able to have Brady continue in our Center. Since Brady’s behavior is keeping him from learning and having fun, we strongly recommend that you locate assistance for dealing with those behaviors.

Some resources that you might find helpful would be the School District’s early childhood special education director, Head Start, your physician, and Keys for Networking (the parent support group for families with children with challenging behavior).

I am sorry that this preschool did not work out for Brady, but we have done all that we can do. We would be glad to provide information to anyone with whom you choose to work.

Sincerely,

Miss Mary
Director,
L’il Angels Preschool
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Smith Family Challenge and Support Cards — Brady Dilemma

Brady needs friends. A neighbor with a 4-year-old son is willing to help you form a play group. What difference will this make in your planning and actions?

Your best friend from college has just moved back to town. What difference will this make in your planning and actions?

A family nearby has a 16-year-old daughter who is willing to babysit. She is a very capable young woman, and Brady is crazy about her.

Your house of worship has an active Parents’ Club, which you have never attended. What difference might this make in your planning and actions?

You really haven’t made friends here. All your friends live in other states. What difference has this made in your planning and actions?

Brady likes to swim. The Y has just started a preschool swim class. You would like to enroll Brady, but you are worried about whether he can handle this. What difference would this make in your planning and actions?

The Sunday school teacher has asked Miranda and Robert to take turns coming to Sunday school with Brady because the teacher needs help in controlling his behavior. You really haven’t made friends here. You don’t know what to think about this.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Smith Family Challenge and Support Cards — Family Dilemma

You have a close relationship with your sister, who lives in the same neighborhood, has always been there when you need her, and usually has great advice. What difference does this make in your planning and actions?

Last week when your sister from Florida visited, Brady bit her baby, and your sister says that he should be put in an institution! What difference do these negative comments make in your planning and actions?

Your parents live in town, love your children, and are available to take them on outings. What difference can this make in your planning and actions?

Both sets of grandparents are very critical of Brady, as well as of Miranda’s and Robert’s parenting. They don’t like to spend time with any of the children. What difference does this make in your planning and actions?

Both Miranda’s and Robert’s families are large, emotionally close, and willing to help each other. What difference does this make in your planning and actions?

The only surviving extended family member is Robert’s father, who is working with an oil company in Argentina. What difference does this make in your planning and actions?

Miranda’s mother is a widow in frail health and incapable of managing her household or limited finances. Miranda is an only child. What difference does this make in your planning and actions?

Robert’s mother lives in town and helps her son’s family in many ways, including with finances as needed. What difference does this make in your planning and actions?

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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Smith Family Follow-up Questions to Discuss

After completing work on both Experiences—the Brady Dilemma and the Family Dilemma—review your experiences and note what you learned. Questions to answer:

How did the addition of informal supports (family, neighbors, community groups) on the “challenge” and “support” cards help or hinder your finding solutions to your dilemmas?

What formal services did you choose to use? Why? Why did you avoid others?

What additional questions do you have about these issues?

What have you learned that might make a difference for your family in the future?
In This Sleeve
Family Name
Make one copy for each Washington family packet, to serve as the “front page” for their packet.

Family Profile
Make three copies for each Washington family packet.

Sample Introduction and Schedule of the Simulation
Customize this information for your community and make one copy for each Washington family packet.

Name Tags
Make three tags—one each for Jayne, John, and Ben—for each Washington family packet.

Experiences 1 and 2: the Caitlin Dilemma and the Financial Dilemma
Make one copy of each Experience for each Washington family packet.

On half the copies of the Caitlin Dilemma, write “Do this first”; on the other half, write “Do this second.”

On half the copies of the Financial Dilemma, write “Do this first”; on the other half, write “Do this second.”

Clip each sheet to the outside of a small, sealable envelope. (“Support” cards will go inside the envelopes; see below.)

In assembling packets for Washington families, make sure to pair a “Do this first” Dilemma with a “Do this second” Dilemma. For example, if the Caitlin Dilemma says “Do this first,” be sure the Financial Dilemma says “Do this second.”

“Support” Cards
For each Washington family packet, randomly choose two “support” cards for the Caitlin Dilemma and two “support” cards for the Financial Dilemma from among those on the masters. Put each pair of cards in a separate, small envelope and seal it. To each envelope,
clip the appropriate “Experience” sheet (above) and include in the family’s packet.

Follow-up Questions about the Experiences
Make one copy for each Washington family packet.

In Addition
Each Washington family packet also should contain two doll cutouts. The master for the doll cutout is in Sleeve 1, “Materials for Facilitators.”
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Washington Family Profile

- Mother, Jayne, 31, is a teacher employed at a school district 30 miles from home. She is now on maternity leave but has only 3 weeks remaining.
- Father, John, 45, is the assistant manager of a small department store 20 miles from home.
- Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds), and high level bilirubin (jaundice). She will be followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. She will be released from the hospital next week at 1 week corrected age. Caitlin will be on an apnea monitor and oxygen system when she comes home.
- Rachel is 5 and in kindergarten; she loves school.
- Ben, a son from John's first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

Assets and income

- The family lives together in a new four-bedroom home that they are buying; their equity in the home is $25,000.
- John's income is $40,000 a year. Jayne's income is $25,000 a year. They bring home a total of $4,158 a month. Both parents' incomes are needed to pay monthly bills.
- The family has three cars, including Ben's old clunker.

Monthly expenses

- Mortgage: $750.
- Car payments: $650.
- Food: $400–$500.
- Health insurance: $500.
- Other insurance: $325.
- Property taxes: $158.
- Utilities: $400 both winter and summer.
- Credit cards: $200.
- Medical: The Washingtons are still untangling costs of the NICU and physicians for Caitlin's care, but these are expected to be very high. Health insurance will not cover it all. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby's hospitalization.

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Name Tags — Washington Family

Jayne Washington (mother)

John Washington (father)

Ben Washington (teenage son)

Jayne Washington (mother)

John Washington (father)

Ben Washington (teenage son)

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Washington Family Experience: The Caitlin Dilemma

Your dear little baby, Caitlin, is finally coming home from the hospital. She has had a tough start in life, and it appears there will be many more hurdles to jump for her and for the rest of the family. You want to do the very best you can to help her learn and grow.

The time since Caitlin’s birth has been difficult for the whole family. Jayne tried to be at the hospital as much as possible, even sleeping there many nights. John has always worked long hours, and he showed up at the hospital at very unexpected times, whenever he could snatch a few moments away from work and sleep. Ben helped out a lot, especially in caring for Rachel. He even cut back his courses at college so he could assist at home. Ben is already really fond of Caitlin. Jayne and John feel guilty about the way they have slighted Rachel during this time, but she seems pretty resilient. She is very worried about “my baby Caitlin.”

Now the big questions are starting to emerge: How do you take care of a premature baby? What should you do to help a baby who is blind learn what other children learn? When will you know about the cerebral palsy? Will Jayne, John, and Ben together be able to handle the apnea monitor and the oxygen system? What training can you get for all the skills you don’t have? Whom can you call on for help? Jayne, you can’t even think about going back to school in 3 weeks, after all you’ve been through—but that’s another issue.

A Family Service Coordinator from Early Intervention will come to visit you. She will tell you about Early Intervention services and share information about resources available in the community to help support Caitlin’s development. She may even know about some special activities to help Rachel make sense of Caitlin’s challenges. Ask the Family Service Coordinator lots of questions.

Before or after you meet with the Family Service Coordinator, the three adults in your family might talk and decide what issues are most important for your family and what resources you want to call on first. You may want to make calls right away, or you may wish to just stay at home together and get to know each other better first. Think about what additional questions you might have as you get into this totally new experience. Other resources might include:

- The parent organization, where you can meet other parents who have had a premature baby or who have a child who is blind.
- The health department or the special education office, which may be able to help you gain more information about visual impairment, including some national 800 numbers to call or websites to check out.

After you have made sense of some of the information, and only then, read the “support” cards inside the envelope.

Talk with some others and decide: What is most important for your family right now in helping Caitlin and the other children? What resources do you want to locate?
Washington Family Experience: The Financial Dilemma

John, you just can’t imagine how your family is ever going to get on top of this financial challenge, and you worry about it day and night. You wonder whether you should take on a part-time second job. You don’t see how Jayne can go back to work, with a preterm baby who needs an apnea monitor and oxygen tanks. Jayne is exhausted, and Caitlin isn’t even home yet. Rachel needs Jayne, too.

You want to develop a plan to pay bills. You realize that you can pay them all by yourself and want to know what outside resources might be available. The social worker at the hospital suggested you check out these possibilities (not necessarily in this order):

- Public assistance to learn about SSI and other public support
- The state’s health insurance for children with low income
- Consumer Credit Counseling
- Your insurance agent
- Early Head Start, if your community has one
- Services for Children with Special Health Care Needs
- Maternal and child health programs at the health department

After you have made sense of some of the information, and only then, read the “support” cards inside the envelope. During your family discussion time, decide how to approach your financial situation, what resources you will use, and what additional questions you have.

As you can see, many people and agencies are available to help you with the dilemmas you face. Plan your activities and work with agency personnel and informal community contacts to help your family cope with its challenges. Note what you have learned that might make a difference for your family.
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Washington Family Support Cards – Caitlin Dilemma

Jayne, you have a close relationship with your sister, who lives in the same neighborhood, has always been there when you need her, and usually has great advice. What difference will this make in your planning and actions?

The state’s family training and information center is sponsoring a half-day session on helping siblings cope with the demands of an infant with a disability. What difference might this make in your planning and actions?

Your parents live in town, love your children, and are available to take them on outings. What difference will this make in your planning and actions?

Both your birth families are large, emotionally close, and willing to help each other. What difference will this make in your planning and actions?

Jayne, your best friend from high school just moved in down the block. She also has three children. The oldest one was born preterm. Your friend is also a teacher. What difference will this make in your planning and actions?

A family nearby has a 16-year-old daughter who is willing to babysit.

The Young Couples’ Club at your house of worship has been providing child care and meals while you have been at the NICU. They have offered to keep helping you as long as you need it, but you feel uncomfortable using them as much as you have been. What difference will this make in your planning and actions?

La Leche League is a group of young mothers interested in breastfeeding. They have offered to help you get used to Caitlin. What difference will this make in your planning and actions?
Washington Family Support Cards – Financial Dilemma

John’s mother lives in town and helps her son’s family in many ways, including with finances as needed. What difference will this make in your planning and actions?

A co-worker suggested that you refinance your house. Homes in your neighborhood have appreciated in value about $20,000 since you purchased. What difference will this idea make in your planning and actions?

John’s godfather, who has always been a mentor for him, is an accountant. What difference will this make in your planning and actions?

A sorority in town has offered to do a fundraiser for Caitlin’s medical expenses. What difference will this make in your planning and actions?

The people Jayne works with have offered to have a shower for Caitlin. How could this be helpful?

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Washington Family Follow-up Questions to Discuss

After completing work on both experiences—the Caitlin Dilemma and the Financial Dilemma—review your experiences and note what you learned. Questions to answer:

How did the addition of informal supports (family, neighbors, community groups) on the “support” cards help you find solutions to your dilemmas?

What formal services did you choose to use? Why? Why did you avoid others?

How did the presence or absence of a Family Service Coordinator affect your decision making?

What additional questions do you have about these issues?

What have you learned that might make a difference for your family in the future?

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Materials for Wilson Family Packets

**In This Sleeve**

**Family Name**
Make one copy for each Wilson family packet, to serve as the “front page” for their packet.

**Family Profile**
Make three copies for each Wilson family packet.

**Sample Introduction and Schedule of the Simulation**
Customize this information for your community and make one copy for each Wilson family packet.

**Name Tags**
Make three tags—one each for Jayne, John, and Ben—for each Wilson family packet.

**Experiences 1 and 2: the Caitlin Dilemma and the Financial Dilemma**
Make one copy of each Experience for each Wilson family packet.

On half the copies of the Caitlin Dilemma, write “Do this first”; on the other half, write “Do this second.”

**“Support” Cards**
For each Wilson family packet, randomly choose two “support” cards for the Caitlin Dilemma and two “support” cards for the Financial Dilemma from among those on the masters. Put each pair of cards in a separate, small envelope and seal it. To each envelope, clip the appropriate

**Color Code:**
dark yellow (goldenrod)

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“Experience” sheet (above) and include in the family’s packet.

Follow-up Questions about the Experiences
Make one copy for each Wilson family packet.

In Addition
Each Wilson family packet also should contain two doll cutouts. The master for the doll cutout is in Sleeve 1, “Materials for Facilitators.”

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Wilson Family Profile
• Mother, Jayne, 31, is employed as a receptionist at a small business 30 miles from home. She is now on maternity leave but has only 3 weeks remaining.
• Father, John, 45, is employed by a grocery store 20 miles from home.
• Baby, Caitlin, was born 3 months premature at 26 weeks gestational age. She had low birth weight (1,365 grams or approximately 3 pounds) and high level bilirubin (jaundice). She is being followed for possible cerebral palsy, which is likely, but diagnosis is uncertain at this time. Due to retinopathy of prematurity, Caitlin is blind. The baby will be released from the hospital next week at 1 week corrected age. Caitlin will be on an apnea monitor and an oxygen system when she comes home.
• Rachel is 5 and in kindergarten; she loves school.
• Ben, a son from John’s first marriage, is 19. He attends the community college near where his dad works. He lives at home but is gone a great deal.

Assets and income
• The family lives together in a small three-bedroom home that they rent.
• John’s income is $15,000 a year. Jayne’s income is $13,520 a year. Together, they bring home about $2,027 a month.
• The family has two old cars.

Monthly expenses
• Rent: $350.
• Car payments: $250.
• Food: $400–$500.
• Health insurance: John has health insurance provided by his employer, but Jayne and the children are not covered.
• Other insurance: $100.
• Utilities: $300 both winter and summer.
• Medical: The family is still untangling costs of the NICU and physicians for Caitlin’s care, but these are expected to be very high. They have no health insurance for Caitlin or Jayne. They also borrowed money ($1,700) to pay for transportation, food, and lodging during the baby’s hospitalization.
Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Families of young children with special needs face many challenges. One of the most persistent is finding and coordinating resources available to support the family and their child with special needs.

The goal of this event is to help participants better understand families' experiences in finding resources for their young child with special needs. We also will learn a great deal more about the services that are available to support families in various circumstances. The objectives for today’s session are printed on your lavender information sheet.

We hope you will enter into this activity seriously and participate actively in your family’s dilemmas. Many people from area agencies are here to serve us, and we appreciate their time.

Today you will be role-playing the experiences of a family with a young child who has a disability or serious illness. Please use your imagination and creativity and really get into this. If your family is a whiz and solves everything immediately, please put more human dynamics into the discussion. It will be more meaningful and more fulfilling if you can do that. We hope that today’s activities will be worthwhile while you are doing them and will help you to improve your practice after you leave.

In the first 15 minutes, please become familiar with your family and your environment.

1. Read your family’s description.
2. Within your family grouping, choose among described roles. Children under age 15 are represented by doll cutouts.
3. Put on your name tag, and try consistently to be that person for the next 2 hours.
4. Notice the variety of resources around the room to assist you in solving your family’s most pressing issues. Pamphlets are available from each agency for each participant during or at the end of the session. Feel free to consult an agency that you don’t know about. The people who work there will help you figure out what is best for your children and family.

After that 15-minute orientation period, you will have two 30-minute periods (or 25 or 35 minutes, depending on the schedule) during which you and your family members work together with service providers to meet your ongoing family needs as well as locate assistance for your child. You will be given two dilemmas—one is about Caitlin and the other is Financial—to stimulate your need to explore resources. These dilemmas are in envelopes in your packet.

A signal will sound each time your family should regroup for discussion. After each experience, your family will have time to touch bases with one another and discuss your next steps. Then we will have small- and large-group reflection times to learn from the experiences of other families. We plan to conclude at or before noon (or, the hour you have set). If you have questions, please ask the facilitators who are moving among the families.

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<table>
<thead>
<tr>
<th>Time</th>
<th>Event Details</th>
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<tbody>
<tr>
<td>8:45</td>
<td>Registration and seating</td>
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<tr>
<td>9:00</td>
<td>Introduction</td>
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<tr>
<td>9:15</td>
<td>Family study and planning in individual family groups</td>
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<tr>
<td>9:25</td>
<td>Experience #1</td>
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<tr>
<td>10:00</td>
<td>Family discussion and planning</td>
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<tr>
<td>10:10</td>
<td>Experience #2</td>
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<td>10:40</td>
<td>Family discussion and planning</td>
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<td>10:55</td>
<td>Small-group discussion</td>
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<tr>
<td>11:25</td>
<td>Whole-group processing</td>
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<tr>
<td>11:55</td>
<td>Evaluation and closing</td>
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Navigating the Resource Maze: A Simulation of Resource Finding for Families of Young Children with Special Needs

Name Tags — Wilson Family

Jayne Wilson (mother)

John Wilson (father)

Ben Wilson (teenage son)

Jayne Wilson (mother)

John Wilson (father)

Ben Wilson (teenage son)

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Wilson Family Experience: The Caitlin Dilemma

Your dear little baby, Caitlin, is finally coming home from the hospital. She has had a tough start in life, and it appears there will be many more hurdles to jump for her and for the rest of the family. You want to do the very best you can to help her learn and grow.

The time since Caitlin's birth has been difficult for the whole family. Jayne has tried to be at the hospital as much as possible, even sleeping there many nights. John has always worked long hours, and he needs the extra pay to support all the expenses. He showed up at the hospital at very unexpected times, whenever he could snatch a few moments away from work and sleep. Ben helped out a lot, especially in caring for Rachel. He even cut back his courses at college so that he could assist at home. Ben is already really fond of Caitlin. Jayne and John feel guilty about the way they have slighted Rachel during this time, but she seems pretty resilient. She is very worried about “my baby Caitlin.”

Now the big questions are starting to emerge: How do you take care of a premature baby? What should you do to help a baby who is blind learn what other children learn? When will you know about the cerebral palsy? Will Jayne, John, and Ben together be able to handle the apnea monitor and the oxygen system? What training can you get for all the skills you don’t have? Whom can you call on for help? Jayne, your boss wants you back at work, but you can’t even think about going back right now after all you’ve been through—but that’s another issue.

A Family Service coordinator from Early Intervention will come to visit you. She will tell you about Early Intervention services and about community resources available to help support Caitlin’s development. She may suggest ways to help your family cope with all its challenges. She may even know about some special activities to help Rachel make sense of Caitlin’s challenges. Ask the Family Service Coordinator lots of questions.

Before or after you meet with the Family Service Coordinator, the three adults in your family might talk and decide what issues are most important for your family and what resources you want to call on first. You may want to make calls right away, or you may wish to just stay at home together and get to know each other better first. Other resources might include:

- The parent organization, where you can meet other parents who have had a premature baby or who have a child who is blind
- The health department or the special education office may be able to help you gain more information about visual impairment, including some national 800 numbers to call or Web sites to check out

After you have made sense of some of the information, and only then, read the “support” cards inside the envelope.

Talk with some others and then decide: What is most important for your family right now in helping Caitlin and the other children? What resources do you want to locate?
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Wilson Family Experience: The Financial Dilemma

John, you just can't imagine how your family is ever going to get on top of this financial challenge, and you worry about it day and night. You wonder whether you should take on a part-time second job. You don't see how Jayne can go back to work, with a preterm baby who needs an apnea monitor and oxygen tanks. Jayne is exhausted, and Caitlin isn't even home yet. Rachel needs Jayne, too.

You want to develop a plan to pay bills. You realize that you can't pay them all by yourself and want to know what outside resources might be available. The social worker at the hospital suggested you check out these possibilities (not necessarily in this order):

• Public assistance to learn about SSI and other public support
• The state's health insurance for children with low income
• Consumer Credit Counseling
• Your insurance agent
• Early Head Start, if your community has one
• Services for Children with Special Health Care Needs
• Maternal and child health programs at the health department

After you have made sense of some of the information, and only then, read the “support” cards inside the envelope. During your family discussion time, decide how to approach your financial situation, what resources you will use, and what additional questions you have.

As you can see, many people and agencies are available to help you with the dilemmas you face. Plan your activities and work with agency personnel and informal community contacts to help your family cope with its challenges. Note what you have learned that might make a difference for your family.
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Wilson Family Support Cards — Caitlin Dilemma

Jayne, you have a close relationship with your sister, who lives in the same neighborhood, has always been there when you need her, and usually has great advice. What difference will this make in your planning and actions?

The state's family training and information center is sponsoring a half-day session on helping siblings cope with the demands of an infant with a disability. What difference might this make in your planning and actions?

Your parents live in town, love your children, and are available to take them on outings. What difference will this make in your planning and actions?

Both your birth families are large, emotionally close, and willing to help each other. What difference will this make in your planning and actions?

Jayne, your best friend from high school just moved in down the block. She also has three children. The oldest one was born preterm. Your friend is also a teacher. What difference will this make in your planning and actions?

A family nearby has a 16-year-old daughter who is willing to babysit.

The Young Couples' Club at your house of worship has been providing child care and meals while you have been at the NICU. They have offered to keep helping you as long as you need it, but you feel uncomfortable using them as much as you have been. What difference will this make in your planning and actions?

La Leche League is a group of young mothers interested in breastfeeding. They have offered to help you get used to Caitlin. What difference will this make in your planning and actions?
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Wilson Family Support Cards – Financial Dilemma

Jayne’s parents have offered to help financially, but John is reluctant to accept their assistance. What difference will this make in your planning and actions?

John’s mother lives in town and helps her son’s family in many ways, including with finances as needed. What difference will this make in your planning and actions?

John’s godfather, who has always been a mentor for him, is an accountant. What difference will this make in your planning and actions?

A sorority in town has offered to do a fundraiser for Caitlin’s medical expenses. What difference will this make in your planning and actions?

The people Jayne works with have offered to have a shower for Caitlin. How could this be helpful?

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Wilson Family Follow-up Questions to Discuss

After completing work on both experiences—the Caitlin Dilemma and the Financial Dilemma—review your experiences and note what you learned. Questions to answer:

How did the addition of informal supports (family, neighbors, community groups) on the “support” cards help you find solutions to your dilemmas?

What formal services did you choose to use? Why? Why did you avoid others?

How did the presence or absence of a Family Service Coordinator affect your decision making?

What additional questions do you have about these issues?

What have you learned that might make a difference for your family in the future?

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