

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

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Abstract

One of the most persistent challenges for families with young children with special needs is finding and coordinating the resources available to support them and their children. These challenges are simulated in an interactive workshop designed for 25 to 75 participants to sensitize them to the day-to-day realities faced by a family with an infant, toddler, or young child with disabilities. The simulation has been used successfully with community service providers from multiple agencies and disciplines. It has applicability to all practitioners who work with children and their families.

Rationale

One of the most persistent challenges for families with young children with disabilities is finding and coordinating resources needed for child and family support. Parents may have other children to nurture along with work and community responsibilities. In addition, they are coping with the emotional stress of the unexpected diagnosis of disability.

This simulation fosters the understanding of family dynamics and helps practitioners or students plan to meet families' needs. It is particularly appropriate for human service practitioners, child care providers, teachers, counselors, paraprofessionals, undergraduate and graduate students, family advocates, and policy makers.

Navigating the Resource Maze provides an opportunity to increase knowledge of services available for children with special needs and find ways for families to access those services. Participants explore the many demands of disabilities, developmental delays, or serious health issues on families. The purpose of the three-hour simulation is to sensitize participants to the day-to-day realities of life faced by a family with a young child with special needs. The

situations represented include a premature infant who is blind, a toddler with Down syndrome and diabetes, and a young child with emotional and behavioral disturbance. As in real life, multiple challenges occur during the simulation, and conditions change over time.

Program

Educational simulations have been used in family education to illustrate divorced and remarried families (Crosble-Burnett and Elsen 1992) as well as interactions between partners (Osmond 1979). The ROWEL welfare simulation [\[1\]](#) has been used by many Extension Service staff to model the realities of families struggling to make ends meet. The interactive nature of a role-play simulation promotes engagement and is more likely to challenge misconceptions than traditional teaching methods (McClintock 2000; Shor 1992).

Navigating the Resource Maze is an interactive educational experience in which participants take on the roles of family members or agency representatives. It is designed for 25 to 75 people to enact the lives of family members according to scenarios presented to them. Each attendee joins a family for two 30-minute "weeks."

The family members locate information about their child's condition, talk with formal and informal support networks, and solve problems in order to meet their needs. Families participate in home visits, and they visit agencies represented in the simulation. Sometimes they have to wait in lines or persevere when an agency representative is out of the office. Each family faces two dilemmas during the simulation. Informal supports are represented by offers of help that each family receives during the session, offers that they can select or reject. In addition, new challenges occur as families work through their dilemmas.

There are three different family configurations, and each configuration has both a limited-income and a middle-income profile. Participants don't know this as the simulation begins, but during the group debriefing after the simulation, it becomes clear that people in different income levels have access to different services.

The roles of agency representatives are assumed by the actual staff of community agencies. Families consult these representatives as they attempt to navigate the resource maze. The representatives are very important to the success of the simulation because they characterize the possibilities and challenges in the resource maze. The simulation conveys some of the typical issues that families encounter when seeking services; for example, agencies have constraints of time, money, and personnel.

Agencies include public assistance (administers TANF and Food Stamps), child care resource and referral, Early Intervention, the special education cooperative, Early Head Start/Head Start,

health department, services for children with special health care needs, State Children's Health Insurance Program (SCHIP), and Consumer Credit Counseling. Other recommended organizations include a physician or nurse practitioner, parent education center, community developmental disabilities organization, parent support group for disabilities, and a faith-based counselor. Using volunteers to play some of the agency representatives is an option that can work, especially if these individuals have relevant experience.

Several agency representatives are essential resources for families with limited incomes, some for families with middle incomes, and some for all families. Some agencies are so important that more than one representative is necessary in a simulation with 30 or more participants. Particular resources are located within different agencies in various states and communities. For example, a child care resource and referral agency may operate within a health department, a community college, a University Extension Service, or be a stand-alone agency. Simulation planners need to involve the organizations that perform the functions required by the simulation.

Agency representatives appreciate the opportunity to participate because *Navigating the Resource Maze* gives them the opportunity to share information about their agencies' services, increase their own awareness of local services, and develop greater sensitivity to family resources, priorities, and concerns. During debriefings, agency representatives begin by talking in a small group. They report that this discussion is helpful in improving services to families.

Pilot evaluation

This simulation was developed and piloted at the Associated Colleges of Central Kansas in collaboration with the Kansas Coordinating Council for Early Childhood Developmental Services. It was conducted on two occasions for 139 participants. Individuals attending the workshops reported:

- "This was the best workshop I've been to in years!" (a preschool teacher)
- "This reminded me what challenges families face on a daily basis in trying to navigate our systems" (an elected official)
- "I enjoyed this very creative simulation. It explained available resources so that the topic wasn't overwhelming" (a therapist in private practice)

In Oregon, this simulation has been conducted at three conferences for early childhood professionals (N = 83). The simulation was also presented at the International Conference of the Division for Early Childhood, Council for Exceptional Children, and the National Early Childhood Conference of the Office of Special Education Programs, U.S. Department of

Education (N = 49). Here are some typical responses to open-ended evaluation questions from the Oregon simulations.

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

- "I enjoyed being a part of a family and seeing the 'system' through their eyes and being able to feel their frustration and know their experience."

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

- "Gaining empathy through the family perspective."
- "It will help me to know how important it is to give clear information to families -- have good contacts at other agencies and know what kinds of materials they will need when they go there."

Participants often comment on potential uses for the simulation:

- "This would be great to do for not only educators but all service providers who work with children."
- "Do this training with students/new people in agencies before they start working with families. It's excellent."

At the conclusion of the family dilemmas, participants engage in a debriefing, where common insights are shared. Depending on the number of participants in the simulation, workshop leaders may begin with small group debriefings (similar family profiles debrief together and agency representatives debrief together). The whole group then reflects on the experience.

Each simulation is a unique experience, depending on the participants, but certain common themes have emerged during the debriefings. Typically, participants express frustration and discuss strategies to marshal more resources for families. They comment on the fragmentation of services, the confusion among different standards of eligibility for services, and the lack of awareness even among agency staff about the services available from other local agencies. Participants discover new community resources and reflect on various service approaches to families. They talk about their own interactions with client families. Family members regularly report that the experience is "overwhelming," and they don't know where to go first for help. Some are "worn out" going from one service to another. Some families report the need for "hand holding," underscoring the importance of family service coordinators.

Implications for Extension and early childhood professionals

This simulation of the experiences of families with young children with special needs is appropriate for Extension professionals who deliver parent education or child care training. It is useful for practitioners who deal with families with young children, such as Head Start, Early Intervention, or child care resource and referral agencies. *Navigating the Resource Maze* is a great experiential tool for the classroom, for example, training preservice or inservice teachers and counselors. For an Extension professional new to a community, pulling this workshop together can be the start of networking to assist practitioners working with families with children.

The simulation is available in a notebook with masters for \$40.00, including shipping and handling.

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Notes

[1] The ROWEL welfare simulation may be difficult to obtain because ROWEL closed its offices in 2002; however, they are still listed as a nonprofit organization in Missouri. [[Return to text.](#)]

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Cite this article:

Bowman, Sally, and Sharon Rosenkoetter. 2003. Navigating the Resource Maze: A simulation of resource finding for families of young children with special needs. *The Forum for Family and Consumer Issues* 8(1).