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# The Everyday Occupation of Families With Children With Autism

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The purpose of this qualitative research study was to understand a family's experiences negotiating family daily life and the meanings they ascribed to these experiences when they had a child with severe autism. In-depth, semistructured interviews were conducted with five family units. The interviews explored the meaning of the family's participation in daily life activities. The transcribed interviews were analyzed with a phenomenological method. The results emerging from this study indicate that families with children with severe autism may experience difficulty engaging in daily activities that hold positive meaning and rely on stringent patterns of routines that revolve around the child with autism to meet the demands of daily life.

Werner DeGrace, B. (2004). The everyday occupation of families with children with autism. *American Journal of Occupational Therapy, 58*, 543–550.

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As a supervisor of occupational therapy I worked at a combined preschool and elementary school for approximately 230 children receiving special education services under the disability category of Autism in accordance with the Individuals With Disabilities Education Act of 1997. As I struggled with how to tap into the occupational needs of the children, I encountered a situation that has shaped how I view appropriate services and supports for children with developmental disabilities, particularly autism, and their families.

One morning as I was walking out of the school I saw a group of four mothers and one young child engaged in a conversation. I overheard the mothers talking about the intensity of the services their children with autism needed and how much money their families had to pay in order to get these services. Then one mother spoke, just as I was passing. She said her family was “on hold” because of the significant needs of their child with autism. She went on to say that their younger child without autism needed to understand that he will never be a priority in the family. I was immediately filled with sadness, as I wondered whether or not I contributed to their family occupations being on hold.

When I examined the literature on occupational therapy for children with autism I noticed that it focuses predominately on how the child processes sensory information (Case-Smith & Miller, 1999; Cook, 1990; King, 1992; McClure & Holtz-Yotz, 1991; Ray, King, & Grandin, 1988; Sanders, 1993; Zissermann, 1992) and how this affects functional skill performance (Stancliff, 1996). These studies focus on services provided to the child with autism.

A lack of research exists examining services aimed at supporting the occupation of families of children with autism. This is important, for literature suggests that family life provides rich sources for child learning and development (Dunst, Trivette, Humphries, Raab, & Roper, 2001; Gallimore, Weisner, Kaufman, & Bernheimer, 1989; Imber-Black & Roberts, 1998). Dunst et al. (2001) suggest the role of the provider is helping the family expand and enhance these opportunities for their children. Thus, if our interventions do not help the family engage in what

they want and need to do together as a family we may be creating interventions that actually interfere with the family's ability to participate in their occupations and this in turn may hinder child development. Therefore, understanding how families with children with autism experience everyday life may provide valuable information on how occupational therapy practitioners can support a family to engage in their occupations.

## Method

For the above reasons, I chose to study the following research questions: "How does a family with a child with autism negotiate the occupations of being a family?" and "What are the meanings they ascribe to these experiences?" With support from the literature, the occupations of a family were defined as a family's ability to create and engage in daily routines and meaningful rituals (Dunst, Hamby, Trivette, Raab, & Bruder, 2000; Kellegrew, 2000). A phenomenological method was used to explicate the structure and the meaning of families' lived experiences of daily occupation.

### *Participants*

The participant, for the purposes of this study, was considered the collective family unit, and a sample of convenience was used. I attempted to recruit eight families, with whom I had worked over the past 4 years. By drawing the sample from families of children on my caseload, I was able to include families who likely had similar experiences with occupational therapy. Five families gave their consent to be a part of the study. To be included in the study, each family unit had to be a family who currently lived with a child with autism and thus, experienced the phenomenon being studied. Furthermore, there had to be at least two family members who lived with the child with autism. The institutional review board approved the study and participants gave informed consent on the day of the interview.

The Jones family included a 9-year-old son George, who had autism, and a daughter, 12 years of age. The Browns had a 10-year-old son Chip, who had autism, and an 18-month-old daughter. The Smith family consisted of a son 17 years of age and Louise, a 10-year-old girl who had autism. The Park family included an 11-year-old boy and Amy, a 10-year-old girl with autism. The Green family consisted of Derek, a 10-year-old boy with autism and his 11-year-old sister. All siblings and the parents, except for the daughter in the Brown family, participated in the interviews. Each family had a mother and a father. The family members provided a collective narrative about their experiences of negotiating daily routines and rituals. All names have been changed to protect the family's identities.

### *Data Collection*

For many types of qualitative studies, including phenomenological studies, the process of collecting information involves in-depth interviews (Creswell, 1998; Dukes, 1984). The purpose of in-depth interviewing in this phenomenological study was to understand the experience of the participants and the meaning given that experience (Seidman, 1991). The family interviews were conducted with all family members who were verbally able to share their experiences.

Prior to conducting the interviews, I sat and wrote my thoughts about: (a) being a family, (b) what it might be like to have a child with autism in my family unit, and (c) my personal experiences and views about being a family, doing things as a family, and sharing family experiences. This process, recommended by Moustakas (1994), made conscious the perceptions I had regarding the experiences being researched. My beliefs about parenting a child with severe autism and who had multiple behavioral challenges was that being able to engage in everyday meaningful occupations would be very difficult. I perceived family life for these families to be filled with the need to control the behavior of the child with autism, so moments for relaxation within the family unit would be minimal. I also believed that having a child with autism would mean pursuing and attempting a wide variety of treatment options, which could be a source of discord within the family unit.

The in-depth, semistructured interviews with each of the five families explored the meaning of the family's participation in daily routines and rituals. The focus of the questions was on how the family structured daily living activities, the significance of the family's daily activities, the meaning associated with the enactment of these activities, and describing moments when they felt like a family (see Appendix A for the questions). The questions were provided to the family ahead of time in a letter. In the letter, the families were also asked to bring items to the interview that might further my understanding of their family and their lived experiences. The families were invited to share letters, photographs, artifacts, or videotapes with me. I explained that these items would help me to better understand their family and how they engaged in their daily experiences. During the interview, I reminded the families of my interest in seeing anything they felt would help me to understand their family life.

Each family was interviewed once, for an average of 2 hours. The family was able to designate where they wanted to be interviewed. Four of the families chose to be interviewed in their home. One family, the Browns, chose to be interviewed at a restaurant. The interviews were

tape-recorded and then transcribed. I maintained a journal throughout the study to record self-reflections about the interview process. The information kept in the journal included site observations, personal impressions, and experiences. The self-reflection was a preparatory step to interviewing (Polkinghorne, 1988) and an initial step in data analysis (Moustakas, 1994).

### *Analysis*

I followed the methodology for phenomenological analysis suggested by Moustakas (1994). The first step included the identification of the researcher perspective, which I accomplished through the journaling previously described. Next began the process of reducing the narratives. I read the narratives repeatedly and reflected upon the meaning of the families' statements in their original context. Significant statements made by the families were highlighted on the original transcripts by using a word processing program. These significant statements were first identified by emotional content, for this gave insight into the meaning of their lived experiences. For example, if the family made reference to being angry, sad, or frustrated then these statements were highlighted and extracted from the narrative. Many of the families' statements were void of specific words depicting emotions. Therefore, during repetitive reading, the definition of significant statements was expanded to include those that *implied* emotional content. For example, statements such as "it is just not sensible," "kind of a mood killer," and "it robs you" were included because I perceived an emotional tone in these narrative accounts and I believed they were relevant to the experience being researched.

The significant statements were read through again and clustered according to thematic labels. I analyzed and interpreted the meanings hidden in the various contexts of the phenomenon as present in the original descriptions. This process resulted in creation of the final core themes of the family's experience. I referred the clusters of themes back to the original descriptions for validation, to ensure the significance of the statements was captured.

From the integration of these data, an exhaustive description of the phenomenon resulted and provided an essential structure of the phenomenon as experienced by these families. From the significant statements and themes, an Individual Textural Description of each family's experiences was created. These textural descriptions were excerpted from the verbatim transcriptions. The textural descriptions provided an account of the underlying dynamics of each family's experience. Feelings, thoughts, and qualities associated with being a family with a child with autism were captured and emphasized for each family in the textural description. I focused on the quality of the experience and

the meaning of the experiences for each family. This led to an overall description of the meaning and the essence of the experience and a composite description of the phenomenon was written. Thematic labels were given to the core themes of the experience. Four outside readers with varying backgrounds and life experiences read and reviewed the descriptions and labels. If these readers found information not explicitly expressed by the participants or the themes were not compatible to the descriptions, this information was deleted.

Polkinghorne (1989) suggested that additional material in varying sources be obtained to further validate the phenomenon under investigation. I sought data from previously developed descriptions of the phenomenon "being a family" that included poems, books, and photographs. For example, I read the books *Family: A Celebration* (Campbell, 1995) and *The Family of Man* (1955). The books contained stories, photographs, and poetry that provided a culturally rich view of "being a family." As I researched the meaning of the phenomenon in varying resources, the information gathered contributed to the authenticity of the data analysis. This was done before, during and after data analysis.

### *Findings*

As significant statements were extracted from the original transcriptions, the categories of routine, ritual, influence of autism, and being a family emerged. The data analysis process continued with clustering and thematizing the data, and tying together a general description of the experience in accordance with each theme. This resulted in the following themes: (a) whole family life revolves around autism, (b) robbed as a family, (c) occupy and pacify, and (d) fleeting moments of feeling like a family. Each theme will be described and select significant family statements will be included to support the theme.

#### *Whole Family Life Revolves Around Autism*

To families, autism means more than an impairment of the child. For the families, autism is an entity of its own. It, "autism," controls their daily lives. A significant part of the family's day revolves around the needs of the child with autism. The families describe their days as "insane" and "hectic" where "every second counts." From the time the children rise until the time they go to sleep, they require the attention of a family member. For example, the children require prompting and assistance to get dressed, to get a bath, and to brush their teeth. This was best captured by the Greens, who referred to having a child with autism as being "like having an infant."

Since the children with autism in this study were each

about 10 years old, these families have been experiencing demands related to autism for at least the past 7 years. The accrued stress these families experience can be appreciated. As the families described, these experiences were overwhelming and stressful. As described by the Jones's:

It's on a daily basis, it's difficult and tiring and stressful and what we might be able to take, what we might be able handle better in short doses, when it's there day after day after day . . . it just constantly builds up and snowballs up . . . many things are difficult . . . it becomes incredible. . . . It's frustrating, and complicates your whole life. Your whole family's life is always revolving around this situation, making compromises, because of doing extra work . . . he makes all the basic things a lot more harder, whether you're having a meal, whether you're taking care of your everyday activities, it's a lot of work . . .

The other families also expressed the feeling that the demands of autism are nonstop, where they expend so much energy and time dealing with the child with autism.

The anticipation of challenging encounters affected these families' daily experiences. As the Browns said, "There's this underlying, always this underlying current of 'it's' about to happen, he's going to start spitting, something is going to happen." The Parks shared, "We, I'm very stressed out. I get anxiety. I freak out, I get frustrated, because she can't say what's wrong." This unknowing and the inability to plan indicates further that family life revolved around the needs of the child with autism.

The families alluded to how powerless they felt in relation to autism. "He has the run of the house," was a common sentiment expressed in the families' disclosure about their lives. The Greens stated:

He controls where he wants to go to a certain extent, because if he doesn't want to get out of the car, no one can make him get out of the car. So if we go to church . . . and he doesn't want to get out of the car, then you have to drive back home. If [my daughter] says the mall, and then [Derek] wants to go home, he just drops on the floor. He tries to control everything.

With laughter, the mother added:

There was one time last spring . . . he went to [a local supermarket], and it was great, he didn't grab anything; he was having the greatest time. He pushed the cart. We were at the check-out counter and while waiting for the grocery to be bagged . . . and he got on the floor. The manager and assistant manager had to come and pick him up.

Family holidays, vacations, and celebrations tended to also revolve around the child with autism. The families were unable to take vacations for longer than a few days, or they had "narrow options," limited to what the child could tolerate. As the Jones's talked about their vacations:

From experience it is totally impractical and not enjoyable . . . because he is out of his routine, you don't have all of

your stuff . . . even though it sounds fun when you think about doing it . . . you know, we didn't see half of what we wanted to see, so was it really worth spending all of this money, is it really worth getting everybody out of whack?

Thus, autism seemed to limit the options of the families in this study. Even on supposedly joyful (e.g., birthdays) or peaceful (e.g., vacations) times, their family's life appeared to revolve around autism. The families appeared to be frequently living moment to moment, while attempting to meet the demands of autism.

### *Feeling Robbed*

As family life has developed around the needs of the child with autism, these five families each expressed feelings of being "robbed." Autism appears to have robbed the families of naturally experiencing satisfaction and happiness, making it hard to enjoy the day as a family. As shared by the Jones's:

Because you know, even if you won the lottery that day, it would always be tempered by, yeah, but you know we got this . . . it kinda robs you of, any chance of having, you know, a real personal level of content inner satisfaction. It's kinda like a burden that's always, always hanging over you.

Many families described autism as a "nightmare." For example, the Browns describe their latest vacation attempt as:

It was such a nightmare, because [Chip] did not want to go in the ocean, he didn't want to go onto the dunes. . . . We had to go to the community, find a community pool that was a camp . . . it was miserable . . . it was a nightmare . . . we came home early because he was freaking out, screaming, writhing . . . we left . . . it was a nightmare, it was really a nightmare. It could've been the most fabulous, and I visualize sitting on the beach, two beach chairs, Chip playing in the sand, you know what I mean, a typical day, like families, I know families that go to the beach and they spend the day at the beach from early in the morning until late at night and they eat meals on the beach.

The families also felt robbed of dreaming of the future. The families hesitated to think about what the future might bring. As the Jones's stated, "The future is actually the only thing that's more depressing than the present" and the Browns response to a recent ceremony at school, "I was crying for their future, because everybody was clapping for them now and what was running through my brain was 'I'm glad somebody's clapping for them now, because this is probably it.'" The Parks shared:

There never seems to be an end to it. You never see an end to it because with children that are as severe as Louise, the chances of them being independent are really not that great. . . . You look into the future and go, this is never going to be over and that's difficult.

The families felt robbed because they had difficulty doing things families often do together. For instance, the

inability to incorporate both children on a vacation, going to the mall or out to dinner created a feeling of “family” loss. As the Browns shared, “We’d rather do a lot more and I’d rather do a lot more but . . . to tell you the truth. . . the most I will do, I get him in the car and . . . just drive. Derek loves it and my daughter, for a little while she’ll like it, and then she gets bored . . . so it’s stressful.” They felt robbed when watching other families engaging in typical family activities, such as going to the beach or out to eat. Each family expressed a sense of “doing it on their own” and the families felt that they “deserve some time to relax,” to have time away from autism. However, it is hard for them to find a babysitter who is able to deal with a child with autism. Even asking extended family, who know the child with autism, robbed the family emotionally. They often “feel a bit guilty” about asking for their support, and often need to “ration” their requests.

The families felt robbed because there were no easy answers for negotiating the day with a child with autism. The negotiation of their daily experiences was never leisurely. Each family member endured personal sacrifices, at the cost of their own health and well-being. The sense of being trapped, unable to attain a moment to regroup was felt. The Parks shared, “I feel like we deserve some time to relax and to have some time . . . we need time . . . we don’t have time to ourselves . . . in order for us to be able to deal with Amy, we need time too.” Common feelings of anger and frustration were expressed, at their inability to achieve peace. The Browns expressed:

We went [nearby] to a bed and breakfast, which was wonderful . . . a craving for solitude. I can’t describe it to you, like we have this swing, it was beautiful, the bed and breakfast was nice, but the door looks onto the bay, and they have this Jacuzzi and they have a swing. I couldn’t decide, but it wasn’t Jacuzzi weather . . . we sat on this swing hanging from the tree. . . I just sat there and sat there and sat there and I wanted to cry because we had to leave, all I want to have was just solitude and it was peaceful. I was angry that we only had one day. . . I have never enjoyed peace so much in my entire life . . . it’s just not adequate, I felt robbed. And then when I got home, he was sick. I felt robbed, and I was angry that how come other people can do it and we can’t?

### *Occupy and Pacify*

The families frequently used means of occupying and pacifying the child with autism, to keep him or her away from a behavioral crisis and in a “manageable” state. Videos were frequently used to entertain the child. The families used baths as another means to pacify the child since it appeared “to relax” the child. By occupying the child with autism, the families could attempt to manage portions of their day

without challenging episodes. The use of home behavioral therapy appeared to be a means of keeping the child occupied and pacified since the therapists would come into the house, and keep the child involved for hours. The Greens said that “it would be ideal to have someone every night to come in to interact with her, to keep her busy and not just watch tapes.” When the child is “working” with the behaviorist, the family does not have to take the responsibility of keeping the child occupied, nor do they have to expend as much of their emotional and physical energy.

### *Fleeting Moments*

The majority of the families found it difficult to identify a specific time when the essence of being a family was felt. The most frequent example stated was driving in a car, when the child with autism was held “captive” and appeared to be enjoying the experience. Many of the families had a desire to engage in positive life activities, but recognized that plans were often altered or attempts were fruitless. Some of the families had decided that the effort was not worth the hassle. Many of the families expressed a lack of inner satisfaction. When satisfaction was felt, it was generally in response to the child not displaying autistic behaviors (e.g., sleeping, riding in a car) so that a sense of being a family was felt momentarily. The example provided by the Jones’s captures this phenomenon:

Wow, everything’s going good, George is not doing anything . . . I mean, last weekend, we were out eating at a [local restaurant] and, we were all sitting there as a family, and he’s dipping his French fries into the ketchup, and he’s not making noises or anything and you know, we feel like a family.

There was also a sense of sadness about autism and the family unit. Many of the families appeared to mourn for a “family” life that they did not experience or feel that they could create. Statements made by the families such as “We would rather do a lot more [together]” and “We try to do what we can do, and it’s not been easy,” conveys the message that negotiating the day with a child with autism was difficult. Throughout my interviews, I was struck by the lack of family photographs in the house. When family photographs were present, the photos were at least 6 years old. None of the pictures was recent, or taken when the child with autism was older than 3 years old. These families were also asked to bring items to the interview that may further the researcher’s understanding of their family. Such items could have included letters, photographs, artifacts, or videotapes. None of the families provided these items; this lack of response also suggests that limited moments existed when these families experienced the phenomenon of feeling like a family.

## Discussion

These themes suggest a pervasiveness of autism in family experiences. From these data, it appears that families frequently experience difficulty establishing positive ways of occupying their time and their lives frequently revolve around the needs and desires of the child with autism. The families in this study often lived moment to moment, as they attempted to meet the demands of autism. Additionally, the families felt robbed due to the dependency of the child with autism and inability to engage in positive social and emotional family experiences. Furthermore, the family spent a majority of the day occupying and pacifying the child with autism. This focused the energies of the family on only one aspect of family life—the child with autism. Finally, the families in this study had difficulty articulating experiences where they have felt the essence of being a family. Altogether, these themes signify how autism affects the creation of and engagement in family occupations by the participants in this study.

As the families in this study structured the negotiation of their daily experiences within the family system and within larger social systems, the identity of their family had become “autism.” This conclusion is supported by the literature on family identity. A family’s identity forms as the unit negotiates tasks of daily living and develops routinized ways of living (Patterson & Garwick, 1998). The daily routines, adhered to by the family unit, provide the structural integrity for family life (Boyce, Jensen, James, & Peacock, 1983). As suggested by previous research and supported by this study, families with a child with autism have difficulty negotiating their daily routines and family life frequently revolves around the circumstances related to the child with autism (Cohen, 1998; Cook, 1996). The data that emerged from this phenomenological research supports previously described literature about families with children with autism where autism affects the identity and growth of the family unit (Agnetti, 1997; Cattell-Gordan & Cattell-Gordan, 1998; Cohen, 1998; Dillon, 1995).

These findings are of concern to occupational therapy practitioners because family routines have been suggested to be: (a) a stabilizing force in the family, (b) a means for family identity development, (c) a protecting force that promotes the health of family members, and (d) a measure for ensuring the well-being of family members during stressful times (Boss, 1988; Newby, 1996; Schuck & Bucy, 1997; Wolin & Bennett, 1984). These families created rigid and routinized family days that tended to revolve around the needs of the child with autism. This contributed to the identity of the family unit as “autism.” Thus, the patterns of routine created by the families have not afforded them a

health-promoting way to engage in meaningful shared life occupations.

The families in this research frequently engaged in family activities to keep the child with autism “occupied and pacified,” yet they did not experience a sense of satisfaction with how they engaged in their daily lives. The families described doing their occupations as “day after day after day,” and the experiences were “overwhelming” and “stressful.” The findings of this research suggest that the families have filled their days with “doing” occupations to keep the child with autism away from behavioral outbursts. This “controlling” of occupations may have left little time for the family to create time for enjoyable and health promoting family occupations. Family time has been exhausted and depleted through the constant doing and controlling of occupations.

The results of this research suggest that families with children with severe autism have difficulty creating and experiencing positive family occupations. It has been difficult for these families to make times for occupations that foster a sense of belonging as a family. Although these families continually worked to manage the demands of the child with autism, opportunities to be together and share time together as a family have been lost. It seemed that the families have learned over the years that occupations that bring the family together (e.g., family celebrations, birthday parties, and holidays) were not worth the “hassle.” The time spent by these families has been focused on doing things to control the behaviors of the child with autism.

These families have illustrated that the challenging behaviors associated with autism have had a very broad impact on family occupations. The children in this study demonstrated behaviors challenging the ability of their families to share occupations as a whole family. Other researchers investigating the effects of problem behavior on family life have found similar outcomes, where the daily routines of the family are disrupted and community life is almost nonexistent (Fox, Vaughn, Dunlap, & Bucy, 1997; Fox, Vaughn, Wyatt, & Dunlap, 2002; Turnbull & Ruef, 1996). Collectively these findings suggest children with severe autism and their challenging behaviors can pervasively affect how families engage in occupation and the meanings they ascribe to their occupations. This finding suggests the need for comprehensive family interventions and supports for families who have children with severe autism that deemphasize controlling behavior and emphasize supporting the meaningful, shared occupations of the family.

## Limitations

My prolonged engagement and previous relationships with the families in this study influenced my interpretation of

the data and the information the families shared with me. Although I made conscious efforts to recognize and suspend my beliefs about what life was like for these families while I constructed the analysis, my perspectives influenced how I interpreted the essence of family occupations for these families with a child with severe autism. During the interview process, I began experiencing a sense of shame for not taking the time previously to understand the challenges these families faced at creating, engaging in, and sharing meaning in their families' occupations. During the analysis, I was drawn to those family statements that supported my growing belief that commonly used interventions for children with severe autism are more focused on having family members do things to the child, which I came to believe encouraged families to spend more time controlling behavior versus creating opportunities for shared family occupations.

The families likely shared information with me as a therapist rather than as a researcher. Their stories may have focused on barriers and challenges of living, which they perceived an occupational therapist would want to hear. This may have limited their description and my interpretation of family occupation.

## Future Directions

If we recognize that as with individuals there is a link between family occupations and the health of the family, researchers and therapists will want to further understand how families spend their time in ways that give them a sense of belonging and shared meaning. I encourage occupational therapy practitioners to take a step back, and gather information that will contribute to the growing knowledge base on family occupations. Practitioners working with families may want to explore what contributes to a family's shared sense of being fulfilled in their occupations and identify the processes that encourage the feelings of being a family. As occupational therapy practitioners elicit this information from families we may identify ways to help families construct ways of engaging in occupations that are satisfying, enduring, and fulfilling to the family.

Again, although I worked with these families for 4 years, it was not until I conducted this research that I heard their voices as "a family." I was caught up in doing things to the child to help the child process sensory information so he or she could do things children typically do and also to ease the burden of caregiving. I wish I had asked the questions that would have provided insight into what would have helped the family unit participate and share meaning in their occupations. So I encourage practitioners to use these questions as a way to assess intervention and supports promoting family occupations. Are we creating supports to

help the family participate together in positive health promoting daily life activities or are the interventions we provide interfering with shared family occupations? Are we reflecting upon the impact of our interventions on the family's ability to be together and engage in shared occupations? Are we building, expanding upon, and creating opportunities for positive and meaningful family occupations? Asking these questions may help us identify and address the shared occupations of the family. Eventually, we may learn better ways to identify if and how occupation affects the health and well-being of those (individuals and families) we support in practice.▲

## Acknowledgments

This research was conducted in partial fulfillment for a doctoral degree in occupational therapy from Nova Southeastern University. I thank my dissertation committee members Rosalie Miller, PhD, OTR, FAOTA; Georgiana Herzberg, PhD, OTR, FMOTA; and Carol Niman Reed, EdD, OTR, FAOTA, for their valuable input and assistance. I am grateful to the families who participated in this study by sharing their stories. Portions of this article were presented at 81st Annual Conference of the American Occupational Therapy Association, April 2001, in Philadelphia and the Canadian Occupational Therapy Association Annual Conference, May 2002, in Saint John, New Brunswick.

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## Appendix A List of Family Questions

1. Describe a typical weekday (probes: work, school, mealtimes, hello and good-bye, bedtime).
2. Describe a typical weekend day (probes: schedule, leisure, church, mealtimes, bedtime).
3. Describe how you feel about these daily routines (probes: pleasure, stress, joy, anger).
4. Describe the special times your family has shared together (probes: birthdays, anniversaries, vacations, weddings, reunions, seasonal celebrations, picnics).
5. Describe how your family participates in traditions and celebrations (probes: symbols, music, protecting time and space, recipes, flowers, dress).
6. Describe those moments when you feel like a family.