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# Using Participant Observation to Study the Meaning of Occupations of Young Children With Autism and Other Developmental Disabilities

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## KEY WORDS

- occupational science
- qualitative method

Understanding the individual meaning of daily activities for children with developmental disabilities such as autism is both important and challenging for researchers and practitioners. Rigorous participant observation offers a method for developing this knowledge base by including the child's perspective. Through literature and examples from an ethnography of young children with autism, this article illustrates the application of participant observation to children with developmental disabilities. Specific strategies can promote valid interpretations despite developmental, linguistic, and perceptual differences between adult researchers and child participants.

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Playing with dolls, fabrics, and dirt and water are not likely to be the typical images one has of researchers collecting data. However unconventional such behavior may seem, it may be quite ordinary in the work of a researcher using a participant-observation approach to study the occupations of young children with developmental disabilities. As an active participant, the researcher can explore the meaning of occupations from the child's perspective. It is the individual's subjective experience that is believed to be critical in understanding occupations and coming to know that person as an occupational being (e.g., Clark & Larson, 1993; Curtin, 2001; Fidler & Velde, 1999; Yerxa, 1998). Without the child's own perspective, individual meaning can be lost. Participant observation offers a sound method for incorporating the child's perspective and enhancing our understanding of occupations.

Drawing from diverse literature and examples from my own research, this article offers strategies for conducting rigorous participant-observation research with children with developmental disabilities. Suggestions are offered for interpreting occupational meaning that bridge the developmental, linguistic, and perceptual gaps between adult researchers and child participants. I argue that analyzing the meaning of occupations of children with autism and other developmental disabilities is not necessarily more difficult than are all attempts to interpret the subjective meaning of occupations for individuals. Its form is merely different as it is based in an analysis of action rather than words. It is occupation-mediated rather than linguistically mediated.

## The Importance and Challenge of Understanding Individual Meaning in Daily Occupations

Central to an understanding of people as occupational beings is the meaning of occupations (Clark & Carlson, 2000; Clark et al., 1991; Johnson, 1996; Peloquin,

1997; Yerxa et al., 1990). Humans make and express meaning through occupations (Crabtree, 1998; Mattingly & Fleming, 1994). That is, occupations hold significance for an individual beyond the actual movement patterns themselves (Fidler & Velde, 1999; Gray, 1997). It is the subjective experience of an occupation that distinguishes it from an “activity,” a general idea or category about doing (Pierce, 2001).

An understanding of the human as an occupational being necessarily involves an interpretation of the meaning of occupations. To measure and quantify the occurrence of occupations may provide valuable descriptive information, but it does not contribute to an understanding of personal meaning. After all, personal meanings exist only as “subjective, first-person phenomena” (Searle, 1992, p. 70). Consequently, the meaning of engagement in an occupation needs to be interpreted rather than simply observed or measured, “for there are no causes to be grasped with certainty where the act of creating meaning is concerned, only acts, expressions, and contexts to be interpreted” (Bruner, 1990, p. 118). The need for interpretation is why qualitative methods have been recommended for studying the individual meaning and complexity of occupation (Yerxa, 1991).

## Participant Observation: A Qualitative Method

For young children with autism and other developmental disabilities who do not consistently use language, participant observation may be the primary method available to understand the meaning of their occupations from their own perspectives. The children cannot be interviewed as they can in other studies. The parents can be interviewed to provide secondhand interpretations of their children’s activities. Quantitative methods of measuring and counting the number and type of activities in which the child participates can provide valuable descriptive data, but cannot provide interpretations about individual meaning of occupations. Although a range of alternative techniques have been suggested for qualitative research with children, most of these still rely on a shared linguistic and perceptual knowledge between child and adult such as drawing pictures, interviewing through the use of object props, interviewing in groups, or playing word guessing games (Curtin, 2001; Graue & Walsh, 1995). These strategies may not be adequate for young children and those with developmental disabilities such as autism. Participant observation provides a nonlinguistic alternative to studying young children as occupational beings.

In participant observation research, it is the doing of occupations that is observed and analyzed. Typically

research about children that uses participant observation occurs in the natural settings in which the children engage in their realm of daily activities (Silverman, 1993) such as home, school, therapy sessions, fast-food restaurants, stores, and parks. The researcher observes the child’s daily activities, accompanying him or her, and, at times, engaging in these activities as another participant (Ely, Anzul, Friedman, Garner, & McCormack Steinmetz, 1991; Krefling, 1991; Lofland & Lofland, 1995; Silverman, 1993; Strauss & Corbin, 1990).

Although the continuum of participant observation ranges from full participation to quiet observing, active participation may be necessary to explore the subjective meaning of children’s occupations. Sometimes active participation with children is limited by what is appropriate to the field. For example, the policies and procedures of school settings may prescribe strict adult roles of watching or instructing, rather than playing, with children. When possible, active participation with children enables the development of a relationship and rapport for the children to trust and be open and unguarded with adults (Lawlor & Mattingly, 2001). It provides a sort of dialogue of action in which the children are their own informants on what is important to them and why. The children are active participants in the research project by indicating their interests in particular aspects of the occupation, by responding to the researcher’s interaction, and by having a response to their initiations with the researcher. Through active participation, the researcher’s own body becomes a means of collecting data on the felt experience of an occupation. Active participation provides another mode of gaining information about the process of occupational engagement that may be difficult for informants to describe in words.

Typically when the researcher takes on an active participant role, the researcher shares some of his or her analysis with the participants and invites them to comment on, correct or refine these interpretations (Ely et al., 1991; Krefling, 1991). A participant-observation approach with a child who has a developmental disability and who does not consistently use language may involve similar practices but in a different form. The researcher monitors the child’s responses as signs of the child’s interests and motivation (Spitzer & Smith Roley, 2001). The researcher can use his or her interpretations of the child’s occupations to guide interactions with the child in activities, such as offering a toy or suggesting a change within the occupation. In these “natural experiments” (Goode, 1980), the child’s responses to the researcher’s interactional attempts serve to clarify the researcher’s evolving interpretations. A child’s acceptance and incorporation of a researcher’s initiations into his or her activity may serve to affirm the credibility of the researcher’s

interpretations. Likewise, a child's decline, resistance, or refrain might be understood as a disagreement with the researcher's interpretation of what is meaningful to the child in the given context.

Furthermore, when a child attempts to engage the researcher, the researcher reciprocates and responds to the child (Lawlor & Mattingly, 2001). For example, I repeatedly tried to bang dolls quickly but gently against the floor with Britany (a pseudonym) but she kept taking them away from me. I tried different dolls in different ways, but she continued to resist. After months of attempts and practice, I was able to flip my wrists in the same way as Britany did when banging her dolls to create the same motion and sound. Once I mastered this, Britany handed me her dolls to bang with her indicating that the way the dolls were banged was, for her, an important aspect of banging them. In this way, the researcher and the child negotiate meaning through the activity just as another participant and researcher may negotiate meaning through words in an interview to create a single "communal horizon of understanding" (Clark, Ennevor, & Richardson, 1996).

Active participant observers have to be mindful of maintaining ongoing, rigorous data analysis of the child's occupations while simultaneously being immersed in those activities. With active participation, researchers are cautious in making conclusions about frequency and duration of specific occupations and processes and cautious in applying the findings with the children in one study to the larger population of children with developmental disabilities. As is true of all research, the researcher's presence, whether active or unobtrusive, influences the "natural" activities of individuals (Ely et al., 1991) and is the researcher's responsibility to attend to, minimize, and report his or her impact on the everyday occupations he or she is studying. Furthermore, it is acknowledged that the research about a child's occupation is a *representation* of that occupation, "always the result of a complicated interaction between. . . [a researcher] at work and children at play" (Schwartzman, 1995, p. 253).

## A Research Project With Young Children With Autism

The use of participant observation as a method to understand the occupations of children with developmental disabilities will be illustrated through examples from my own research with five 3- and 4-year-old children diagnosed with autism. Two children participated in a short-term pilot study and three in the longer-term main study. The children were from middle- to upper-middle class, two-parent households in the western United States. Although they had

various speech abilities, the children did not consistently use any form of language to communicate spontaneously. The primary source of data was participant observation at home, fast-food restaurants, and other natural settings. During the pilot study, I visited each child 4–6 times, with each visit lasting 1–2 hours, over the course of 3 months. During the main study, I visited each child on 14–15 different days, with each visit lasting 1–4 hours, over the course of 6 months. As appropriate to the setting and with the child's assent, I interacted with each child in his or her daily activities. Interviews with adults in each child's daily life provided another source of data for triangulation, thereby enhancing reliability. After each session and interview, field notes were written and interviews transcribed as soon as possible, generating over 800 single-spaced typed pages of data.

The aim of the research was to understand how the children create and convey meaning through their daily activities. Specific research questions included:

1. What occupations are participated in by individual young children with autism, who do not use words consistently to communicate?
2. How do the children engage in these occupations?
3. What does this suggest about who they are as occupational beings? (What is important to them in creating meaning and how can this be understood?)

Analysis occurred concurrently with data gathering, helping to further focus the data gathering process, a typical practice in conducting qualitative research (Charmaz, 1983; Ely et al., 1991; Lofland & Lofland, 1995; Strauss & Corbin, 1990). The first preliminary coding occurred as the field notes were being written and completed, with most subsequent analysis clarifying and expanding on this initial coding. Limited recoding occurred periodically during fieldwork. After all the fieldwork was completed, the field notes were completely and thoroughly recoded.

The field notes were coded by occupations. An occupation was defined as a "set of directed actions connected by physical movements, materials, space, or purpose within a time period, in a way that is meaningful to the individual executing them" (Spitzer, in press). For each child, all the occurrences of an occupation were grouped together and compared with each other to identify and examine similarities, differences, and themes within and between occupations. The field notes and transcripts were further examined and categorized for general concepts related to the research questions such as themes of meaning and preferences, interactive activities, and others' opinions and understandings of the child's actions.

Interpretations about meaning were made using a similar approach as that developed by Fidler and Velde (1999).

They state that occupational meaning can be identified by, first, “developing a sophisticated understanding of the unique qualities of the activities” (p. 2) and the biopsychosocial characteristics of the person. I first considered the sensory experience of what the child was doing, its physical characteristics, the child’s skill, and the child’s general characteristics. Next, Fidler and Velde recommend making uncensored associations, speculations, and suppositions about the action’s possible meaning and purpose. They suggest that researchers ask such questions of themselves as “What comes to mind?” and “What might this mean?” I asked these questions, considering the possible function of the activity for the child and potential symbolic or representational meanings. Reading and listening to the recollections of adults with developmental disabilities about their childhood activities and behavior generated additional questions and considerations. After creating a number of suppositions, I evaluated each and selected the interpretation that was logically most probable “in the light of what we know, rather than claiming that it is true” (Mook, 1994, p. 49). To promote consistency and authenticity, I reviewed the data and analysis with an interdisciplinary academic committee, other doctoral students, and a teacher of an autism class at an elementary school. A detailed account of the study is available in Spitzer (2001).

## Leveling Power Differences in the Research Relationship

An issue in conducting qualitative research is the differential of authority and power that exists between the researcher and participant, a differential that can be especially strong in conducting research with children (Curtin, 2001; Eder & Corsaro, 1999; Fine & Glassner, 1979; Fine & Sandstrom, 1988; Graue & Walsh, 1995). Given that in our society adults have authority, power, and responsibility over children, it is difficult for researchers to set up a relationship of equality with their participants.

Fine and colleagues (Fine & Glassner, 1979; Fine & Sandstrom, 1988) recommend that researchers adopt a “friend role” to the greatest extent possible by avoiding an authority role and having positive contact with the child. The researcher would not stop or direct a child’s behavior except when concerned for the child’s safety or the safety of another. The researcher conveys that, although an adult in age, size, and privileges, the researcher is there to be a participant rather than an authority figure. For example, in my research, when a child made a mess with toys, I ignored my impulse to direct the child to clean up and followed the child to the next activity, leaving the teacher or parent to

call the child to clean up. If a child did something they were not supposed to do, such as throw dirt or climb on top of a table or stereo speakers, I did not stop or chastise the child. When a child objected to my behavior or resisted my attempts to interact, I immediately stopped. Although I tried to interact with the children, my interactions were not directed toward skill development or meeting other therapeutic or developmental goals. This approach seemed to allow me to observe the children as they engaged unguardedly in individual occupations.

A threat to neutrality in this as well as many other qualitative studies is related to the social and acculturated nature of human beings, specifically the researcher. Due to physical, developmental, and social differences, an adult can never become a total participant (Fine & Glassner, 1979; Graue & Walsh, 1995). Despite attempts to avoid adult roles and be a participant-observer, sometimes a researcher slips back into ingrained social roles and adult-child expectations and interferes with the child’s action. Sometimes, for the sake of safety, the situation morally may require the researcher to step back into the adult role to stop or redirect a child’s behavior as the following excerpt from my field notes illustrates:

*Mike walked over to where a wooden structure was leaning against a tree. It resembled a ladder, except the distance was twice as great between “rungs” and the “rungs” were only about a 1/2-inch wide. It looked just strong enough to support Mike’s weight. Mike started to climb it like a ladder. “Mikey. Careful. Yea. I don’t know how strong it is. Careful,” I urged. As he climbed, I stood right behind him with my arms ready to catch him if I needed to. He reached for the top rung that was about a foot above my head. I did not think I could protect him if he went onto the next rung and slipped. I directed him, “Not that high, Mikey. Mikey. Come down. No. Not that high. Not that high. Stay. Thank you. Thank you. Thank you.”*

As Fine and Glassner (1979) note, not altering behavior is an ideal to aim for, but not always possible to achieve.

## Children’s Assent and Understanding of the Research

Giving child research participants the opportunity to understand a research proposal and the option to refuse to participate is difficult but essential for ethical research. Although a parent or legal guardian is the one responsible for giving initial legal consent, it is still important to convey the nature of the study and their rights to children and allow them to refuse to participate. It can be difficult to fully explain the research to children so that they can understand the project and the potential ramifications of being a participant.

As the research progresses over time, children may develop their own experiential sense and understanding of the research through the researcher's actions (Fine & Glassner, 1979; Fine & Sandstrom, 1988) and assent or refuse to participate in the research. In my own research, I simply informed children that I was going to watch them play and play with them. The children appeared to be comfortable with my presence. On occasion, they would hold out a hand to me as we walked. At times, when I was observing more than participating, a child would look around for me, apparently to see if I was still there watching or following them, establish momentary eye contact with me, and then return to what they were doing. The children seemed to have a sense that I had a different role than the other adults in their lives, one of following, watching, and being with them. I evaluated child assent by monitoring the children for signs of their willingness to participate. I tried to move slowly and not force interaction on the child. I was prepared to discontinue the research with a child if the child consistently showed signs of not wanting to participate (such as resisting, whining, or avoiding me), but this did not happen.

## Recognizing and Managing Limitations

Although participant observation is well suited as a method for understanding occupational meaning, there are two significant limitations with which to contend. First, the method cannot capture the full detailed richness of lived experience. During my own research, I found it difficult to record the details of my observations, a threat to the credibility and dependability of the data (Krefting, 1991; Silverman, 1993). To describe in words the movements and glances that might occur in a few minutes often took 1–2 hours and pages of notes. I may not even have seen, heard, or felt all the details to record them. As it was, my field notes were very detailed, as the collection of small details, “the specifics of everyday life” (Eder & Corsaro, 1999, p. 523), was necessary for my analysis. For example, in my first few months of visiting with Emma, her only interaction with the family's cat was to slightly move her bare leg against the cat's fur as it brushed up against her or pet the cat slightly after I did. I dutifully recorded the fleeting details of her interactions with the cat. Later, Emma began to include the cat extensively in her play—first by holding and carrying the cat, then in giving the cat a “drink” with a cup and putting it to bed, and then imitating her cat. Had I not been attending to Emma's initial apparently unimportant interactions with the cat, I might not have recognized how these occupations emerged and developed or how she

was experimenting with a living creature and action in her play.

Given the importance of microscopic analysis, especially of details that initially seemed insignificant, it is likely that some important details may be left out unintentionally. Even if the researcher uses a video camera or audiotape (which is not logistically possible in all natural settings), some details still would be missed as not everything can be captured in a video screen or picked up by audiotape. To minimize the impact of inevitably missing details, the researcher needs to attend to and record as many details as possible and compare the details of multiple observations to present interpretations in a comprehensive and responsible manner. To assist readers in interpreting findings, the researcher may clarify whether the interpretation is based on a low frequency of occurrences or multiple and consistent occurrences.

Second, the validity or credibility of such research is limited by the nature of its topic. The research is, in large part, an attempt to put words to a nonverbal experience, one that lies within and between individuals. The children's thoughts and feelings cannot be completely accessed. Only signs of the experience can be observed and these signs are highly individualized (Goode, 1994), subtle (Spitzer & Smith Roley, 2001), and initially “may be inconsistent or difficult to read” (Holloway, 1997, p. 176). In the process of translating interpretations of the participants' experientially based subjectivity into words, undoubtedly some meaning is lost or distorted. “Words, of course, are not the same as meanings” (Fine & Sandstrom, 1988, p. 71). The researcher needs to be consciously aware of this limitation and make every effort to minimize its potential impact on the study. Researchers live with the frustration that words cannot fully describe the richness of the observed and experienced events encountered in the research process (Goode, 1994; Kelly-Byrne, 1989; Spitzer, 2001). Inevitably, the researcher's descriptions of the experience of a child are not complete or definitive. However, spending extensive time, conducting multiple observations, and developing an intimate relationship with each child will improve the quality of the data, maximize the potential for an accurate reading of the child's cues, and promote valid interpretations (Eder & Corsaro, 1999; Goode, 1994; Graue & Walsh, 1995; Krefting, 1991; Lawlor & Mattingly, 2001; Llewellyn, 1995; Silverman, 1993). Detailed comparisons of differences, similarities, and changes in daily activities also enable the researcher to feel confident that his or her interpretations are valid. Furthermore, participation with the child, rather than relying exclusively on noninteractive observations, can also be helpful to test and refine interpretations (Goode, 1980).

## Considerations and Strategies for Interpreting Children’s Occupations in Participant-Observation Research

Interpretation is a complex and challenging endeavor especially with children who have developmental disabilities such as autism. Some may question whether it is possible to make valid interpretations about the meanings of such children’s occupations from their own perspective. It is very difficult to determine the child’s perspective when the researcher physically, emotionally, and cognitively experiences the activity differently due to differences in embodiment. The two inhabit significantly different physical bodies distinguished by (1) developmental differences between adults and children; (2) different forms of communication; and (3) brain processing differences between those with and without autism and other developmental disabilities. These differences of embodiment (Frank, 1986) can be bridged to promote interpretive analysis of occupational meaning for children with developmental disabilities (see Table 1).

### The Adult–Child Gap

Most adults see children regularly and have their own ideas about children and what it is to be a child. The challenge as a researcher is to avoid what Goode (1994) has labeled “adultcentric” interpretations of children and their actions. Researchers (e.g., Fine & Glassner, 1979; Fine & Sandstrom, 1988; Goode, 1994; Graue & Walsh, 1995) have argued that adults tend to interpret children and their actions in relation to adult standards and social meanings. Adults may experience the same event differently from a child (Kaplan, 1997). Children’s meanings are situated in their own worlds, which are both a part of and different from an adult’s. Children organize their “kid society” around their own needs and wants (Glassner, 1976) through what Corsaro and Eder (1990) term interpretive reproduction, the taking of information from the adult world and adjusting it to produce a unique “peer culture.” The younger the child is, the more difficult it may be for the researcher to understand the child’s view (Fine & Sandstrom, 1988).

#### *Bridging the Adult–Child Gap*

It is problematic for adults to make interpretations of children’s experiences based exclusively on their own as this fails to take into account what the child might be experiencing. This is a form of bias (Waksler, 1986). Fine and Sandstrom (1988) assert that we can begin to tackle this methodological problem by recognizing it as a problem. Only by “bracket[ing] our commonsense understandings and thereby mak-

**Table 1. Differences Between Adult Researchers and Children With Developmental Disabilities, and Related Research Strategies to Facilitate Interpretation of the Child’s Occupations**

Differences in	Strategies
Adult–Child Development	<ul style="list-style-type: none"> <li>• Suspend adult assumptions</li> <li>• Scrutinize data and interpretations for effect of adult presence</li> </ul>
Use of Language	<ul style="list-style-type: none"> <li>• Assume all actions are potentially communicative</li> <li>• Attend to communication through occupational engagement, especially shared occupations</li> <li>• Look for individualized communication strategies around shared routines, physical environment, likes and dislikes, and bodily expressions</li> <li>• Develop a shared history with the child</li> <li>• Interview adults knowledgeable about the child</li> </ul>
Perception	<ul style="list-style-type: none"> <li>• “Passive obedience” (Goode, 1980)</li> <li>• Physically simulate child’s sensory experience of the occupation</li> <li>• Sharpen conscious awareness of various sensations</li> </ul>

ing these neighbors into strangers (and, in turn, making these strangers into peers by taking their roles) can we begin to get a sense of what it means to be a child” (p. 35). Researchers need to try to suspend assumptions of adult superiority, be willing to respect and acknowledge children as experts about their own lives, and be open to learning from children (Curtin, 2001; Waksler).

To insure valid interpretations, the researcher scrutinizes the data and interpretations for possible effects of an adult presence (Fine & Sandstrom, 1988; Graue & Walsh, 1995). Interpretations are scrutinized as to whether they are adult interpretations or whether they represent a child’s perspective. In my research, it was not uncommon for me to have difficulties reconciling apparent inconsistencies in the data, only later to recognize that the inconsistency resulted from the fact that I was using an adult interpretation of the activity. For example, I initially defined “group activities” as one category of occupations for Emma but was puzzled by her inconsistency in initiating and engaging actively in these activities. In my attempts to understand these differences from Emma’s perspective, it seemed likely that Emma’s internal definition of these activities was different from my adult interpretation. That is, Emma participated in group activities of body movement songs but she did not actively participate in group activities where she had to wait her turn. It seemed that Emma distinguished among these “group activities” and that these distinctions were meaningfully different from her perspective even if they could be masked by an adult-oriented categorization.

### The Language Gap

Interpretative analysis with people who seldom use language may be especially difficult because of cultural bias and

limited methodologies. Our culture values the verbal because power in Western countries is framed in and by discourse (Foucault as cited in Rabinow, 1984). Academic culture especially values linguistic and intellectual skills (Taylor, 1996). Most of the methodologies developed for collecting information about personal meaning are linguistically based, such as interviews and text (Silverman, 1993). Yet young children often use less language, use language differently from adults, and rely more on nonverbal communication (Curtin, 2001; Graue & Walsh, 1995). Understanding the personal meaning of occupations in children who seldom use language presents a challenge for researchers to respect differences and diversity in humans, to shift from a predominately linguistic perspective, and to develop and expand research methods.

### *Bridging the Language Gap*

In order to interpret the subjective meaning of activities for children who use limited language, researchers need to bridge the language gap. Adults need to assume children's competence and adjust their methods to collect and analyze occupation-based communication.

Researchers need to suspend judgment and operate under assumptions that recognize all of a child's actions as being potentially communicative. Durig (1996), whose research focused on meaning in daily life for individuals with autism, has recommended an "asset approach" to studying how "meaningful perception, emotions, and logic are interrelated on a nonverbal level" (p. 19). Most basically, the researcher operates under the assumption that all humans have dignity and worth. Secondly, it is assumed that "[E]ach of us does everything we do for the most meaningful reason possible" (p. 22). Only if we first assume each child's actions are as meaningful as are those of other people, can we begin to understand meaning for individuals with autism and other developmental disabilities. In this way, actions can be seen as "natural responses of a given mind state to social circumstances. Thus, all perception and behavior is seen as a meaningful strategy for coping with the social environment" (p. 11).

Adult researchers of children have to be alert and attend to personal meaning as communicated through the doing of occupations. Temple Grandin (Grandin & Scariano, 1986) and Donna Williams (1992), adults with autism, noted that successful communication often occurred through interactions around tangible objects such as toys or buttons. They both recalled as children having interacted with others by playing with toys and objects and, as adults, used this strategy successfully to interact with children who have autism. Donna Williams described her communica-

tion as symbolic and indirect, which was frequently misunderstood as indifference or insanity. Her feelings could not be verbalized in the usual way. She describes a type of communication that seems to rest on occupational engagement, especially in shared occupations, as it is *felt*:

*While people around me judged me by their eyes and ears, I was screaming out from beneath the empty facade of my shell to get them to feel who I was; to close their eyes and their ears, and to try to sense me. (p. 164)*

Highly individualized, communication systems can be built on the shared experience of participating in daily activities. Based on his ethnographic research with children with multiple developmental disabilities including profound mental retardation, deafness, blindness, and without language, Goode (1994) concluded "a well-articulated non-symbolic communication system could exist with an alingual child" (p. 82). The communication difficulties arise because children who do not talk lack an intact model for understanding the cultural ways of doing. This is not to imply that such children are acultural, only that many actions and skills of "normal" cultural members are not evident because of the absence of language. What Goode (1994) discovered is that it is still possible to communicate because there are nonlanguage, felt understandings of the human world that we all share. In his study, he found that the "adults and children both lived and experienced in direct and indirect ways an intersubjective world of daily life, the interpretation of which rested upon previous shared experience" (p. 110). These highly individualized shared communication strategies involved shared routines (temporal ordering), organization of the physical environment, likes and dislikes, and bodily expressions.

To understand this occupation-based communication, researchers need to develop a shared history with each child (Goode, 1980, 1994). Many objects, sounds, locations, and body movements have particular meanings or purposes based on their association with past activities. For example, after developing a shared understanding with my research participants, I could anticipate that when Mike was reaching for dirt, it was to drop it; when Emma got out a small bowl, it was for ice cream; and when Britany pulled on the closet door, it was to get the treadmill. Through a shared history of repeated participant-observation, I came to share a child's understanding of an object or behavior's purpose. Emma used toy figures for decorating, not for action; Britany used them for banging; Mike for exploring physical traits of objects; Justin for holding them and comforting himself; and Alex for creating suspense. This shared history even allowed for greater ease in understanding interaction styles. For example, I would do what Mike seemed to be directing me to do but then that never seemed quite what

he wanted. Eventually, I found that Mike was often directing me in the first step of what he wanted me to do. He would pull me down when he wanted to go up as I first had to bend down to pick him up. Once I realized that he was often getting my body in a position to do something else, I could look for possible second steps instead of becoming fixated on the initial small action. Without this shared occupational history as a context, many behaviors otherwise seem confusing.

Interviewing parents, teachers, and others who know the child may also provide helpful information about the child and his or her social context. However, if the objective is to understand a child's experience, then the voices of these other people cannot substitute for the child's perspective (Taylor, 1996). The children's "voices" are heard through reading their highly individualized cues in the context of their occupations.

## The Perceptual Gap

People with autism and other developmental disabilities process information such as sights, sounds, touch, and body sensations differently from other people (Grandin, 1996; Ornitz, 1974; Rapin, 1991). These differences are best viewed as a continuum of traits and experiences shared by those with and without developmental disabilities rather than dichotomous us/them categories (e.g., Grandin, 1995). The greatest challenge is to understand the perspectives of individuals who may be at an extreme end of the continuum, with significant differences from ourselves. Physically, a child with autism who has a different sensory processing system may "feel" the world in a different way (Durig, 1996; Grandin, 1995). Goode (1980) described the children with congenital deafness and blindness in his study as "living and acting in a different perceptual place than I" (p. 187).

Because of differences in sensory perceptions, opportunities may be lost for understanding the meaning of individual occupations to a child with autism or sharing in social occupations with that child. Even shared activities can be physically experienced in different ways. For example, I am fairly sensitive to sounds and visual stimuli and often hear sounds and notice visual patterns that other people do not. However, initially during my research, I did not always "hear" everything there was to hear, at least not in the moment in which it was occurring. I would hear it later when listening to the audiotapes. The tape recorder did not filter out the auditory stimuli that I did. Especially when I first started my research, I was often surprised by all the other noises I could hear when replaying the tapes. Sometimes, I would have to play and replay a segment as I

tried to figure out what a particular noise was because it did not "fit" into my scheme of the ongoing activity. These were "background" noises such as the sounds of birds chirping, a neighbor's lawnmower down the street, footsteps, the clothes washer and dryer, a clock striking the hour, and a car driving by outside. They sounded loud on the tape and yet I had no awareness of them having occurred. An example from my field notes, from the first time I used an audiotape, demonstrates this point:

*We were outside. Alex was staring off as I was talking with his mother. His mother said to him, "oh, you're listening to the birds." I looked around and was surprised to see the electric lines covered with small birds chirping. (Upon listening to the tape, I could clearly hear the birds for several minutes before his mother commented on them. But I had not "heard" them, been aware of them, at that time.)*

A variety of sensory stimuli is always present but different people do not attend to all of it in the same way. Neurologically, we attend to the "relevant" stimuli and filter out other competing stimuli (Dunn, 1997; Ornitz, 1974). What stimuli are "relevant" may be partly determined through physical processes, but may also be a social-cultural, learned behavior or based on individual preferences (Hall, 1982). Certainly, if two people are attending to different sensory aspects of the environment, they will have difficulty understanding each other's perspective of an activity.

### *Bridging the Perceptual Gap*

Several strategies can be helpful to try to understand the children's activities from their perspectives, to establish intersubjectivity on the child's own terms. The first is what Goode (1980) has labeled "passive obedience." To the extent possible, the researcher follows each child's directions about what and how to do something. For example, in my research, I picked up objects and opened doors the children guided my hand to; I followed as they pulled my hand. I even followed along with socially unsanctioned tasks and despite physical discomfort. During one of my early visits with Britany, she insisted I scoop up and pour water for an hour nonstop, which I continued despite my cold, wrinkled, fatigued hands. Following a child's direction does not always yield immediately new insight; but to do so offers the possibility of understanding what features of the activity are most salient for the child and thus why the activity is of interest and importance to the child.

A second strategy is to imitate the child's actions to physically "feel" the activity from their perspective. Goode (1980) did this in his research with congenitally deaf-blind children by using gauze over his eyes and earplugs to simulate the children's different sensory experiences and then imitated their body movements in activities to gain the chil-



dren's perspective. Although such differences cannot be fully simulated, Goode used these strategies to give him more insight into the children's experiences and the functions of their behaviors. In my research with children with autism, it was more difficult to simulate the children's perceptual world; however, I also attempted to place my body in the same plane and imitate the child's actions to understand the child's experience of the activity. For example, when near a child, I usually knelt to be able to see the world from the same orientation. By kneeling near Mike and aligning my vision in the same orientation as his while he dropped hands full of dirt, I was able to see the beauty of the falling dust particles when the sunlight hit them at a particular angle.

A third strategy is for the researcher to attune his or her senses. I learned to sharpen my conscious awareness of sounds and sights through heightened attention and repeatedly listening to my audiotapes to "hear" what had happened even though I had been there. Over time, this process caused me to sharpen my conscious awareness of my senses. I became more aware of sounds being made in the moment. I was no longer surprised by a sound on the tape. In fact, I became more sensitive to subtle sounds on the audiotapes, which signaled physical movement from inside to outside, room to room, and one area of a room or the yard to another. By the end of my research, I was aware of how many sounds the audiotape had missed that I had heard. My conscious awareness of my sense of hearing had become more sensitive. This increased sensitivity enhanced my ability to recognize what a child might be attending to. I later found that other adults used this same strategy, as one mother explained about her daughter:

*She stopped in her tracks and she was like wouldn't walk with me back to the car. And I'm like "OK, what's going on, you don't want to leave the school?" And I'm like oh yeah, focus in on what her, what would be bothering her, possibly a sound. OK, then I focus on my own sound. I'm hearing that annoying noise. That's bugging me. Of course it's bugging her. It's bugging her like this much [holds hands out wide] if it's bugging me this much [brings hands close together]. You know? And it's just, it's taking the time to go OK, stop what I'm doing, put myself in her shoes.*

## Conclusion

To understand the subjective meaning of occupation is a complex and challenging endeavor, especially when developmental, linguistic, and perceptual differences exist between researchers and participants. Rigorous participant observation is a method well suited to handle the contextualized complexities of this quest. Through active participa-

tion of the researcher, power differences can be minimized; the child's "voice" can be heard in a dialogue of action with the researcher; and the child may acquire his or her own felt sense of the research process. Through interpretive analysis, researchers can incorporate the child's own perspective on the meaning of their occupations. The developmental, linguistic, and perceptual gaps between child participants with developmental disabilities and adult researchers can be narrowed to promote valid interpretations. In this way, we can have a greater understanding of children with developmental disabilities as occupational beings. ▲

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