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# Including the Family Perspective in Sensory Integration Outcomes Research

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*Occupational therapy, along with other health and rehabilitation professions, is experiencing an increased emphasis on measurement of intervention outcomes. The results of outcomes research are being used to develop practice guidelines, set standards for reimbursement, and justify health care policy. The outcome assessments used by therapists reflect our belief systems and the assumptions about behaviors we expect to influence. Using a sensory integration perspective to illustrate key points, we present a conceptual framework that is based on the disablement framework and Coster's occupational functioning for children model. We highlight the need to examine each of the multiple levels at which intervention may influence child and family function and the links among levels. Sensory integration theory and efficacy studies are reviewed to identify assumptions relative to how sensory integration affects the everyday occupations of children in the context of their families. Potential research methods and assessments are suggested to include the family perspective in outcome studies.*

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The occupational therapy profession—and health care in general—has experienced a dramatic change in the conceptual understanding of measuring meaningful outcomes. There has been a shift from a deficit perspective to a functional perspective and a shift from the measurement of clinical behaviors of the individual to the measurement of role behaviors in the context of family-centered functional activities (Haley, 1994; Trombly, 1993). Focus on outcomes has been driven by a health care environment concerned with establishing a balance between cost and the quality and effectiveness of intervention. Outcomes research is at the forefront of this change in health care: Outcome studies are being used to justify policy, develop practice guidelines, set standards for third-party reimbursement, and determine who should provide the service (Jette, 1995). Ultimately, outcomes research focuses on what occupational therapy actually achieves for the consumers of its services and how these achievements can be identified (Fuhrer, 1987).

The outcome assessments we choose implicitly display our belief systems and the underlying assumptions regarding the behaviors we hope to change. In practice, the assessment tools and the variables measured often become the operational definition for the changes we are attempting to measure (Haley, 1994). In a review of sensory integration efficacy research, Miller and Kinnealey (1993) highlighted the need to clarify the choice of outcome measures and relate that choice back to the assumptions underlying sensory integration theory. They argued that changes in test scores are meaningful only if “documentation can be supplied that the test scores are indicative of changes in performance in daily life” (p. 5). For example, in sensory integration intervention studies, occupational therapists have used standardized assessments of academic, perceptual, motor, and cognitive functioning (Daems, 1994; Humphries, Wright, Snider, & McDougall, 1992; Schaffer, Law, Polatajko, & Miller, 1989). Although these studies imply that competence in academic, perceptual, motor, or cognitive abilities relates to performing tasks, activities, and roles of daily living for children, the relationships between and among the various components of development have been studied only minimally. Reliance on academic, perceptual, motor, and cognitive assessments provides a limited focus for determining what sensory integration actually achieves for our consumers: the children and their families. By focusing primarily on the underlying components of performance of children, occupational therapists have neglected to explore how sensory integration affects the everyday occupation of children in the context of their families.

Numerous occupational therapy authors have highlighted the need to examine the outcome of sensory integration therapy from the child and family perspective. In

Roley and Wilbarger's (1994) interview with Dunn on the evolution of sensory integration theory, Dunn reminded us that therapeutic outcomes need to be relevant to the needs and desires of clients and their families. Parham and Mailoux (1996) echoed this observation by suggesting the need for sensory integration studies to "explore which intervention outcomes are most meaningful to the families and children with sensory integrative dysfunction to ensure that intervention programs are responsive to the needs of the people served" (p. 349). Although family-centered outcomes have been espoused in the sensory integration literature (Bundy, 1991), and many parents have provided testimonials that sensory integration therapy has improved the quality of their family life (Anderson & Emmons, 1995; Occupational Therapy Associates, 1995), the impact of sensory integration interventions on parents of children with sensory integrative dysfunction has not been empirically investigated.

Accordingly, the main purpose of this article is to describe potential measures to examine assumptions related to how sensory integration therapy affects children and their families. The disablement framework and the model recently proposed by Coster (1998) are used to examine the multiple levels at which sensory integration therapy may affect change and to discuss the importance of looking at each of the functional levels and the relationship among them. Sensory integration theory and efficacy studies are reviewed to identify variables for further outcomes research.

### Conceptual Framework for Outcomes Research

Numerous conceptual models and classification systems of disablement have been proposed to guide thinking relative to assessing and interpreting outcomes (Coster & Haley, 1992; Nagi, 1991; National Center for Medical Rehabilitation Research, 1993; Wood, 1980). Disablement has been portrayed as a multilevel process (including impairment, functional limitations, disability, and social role and societal limitations) that describes the spectrum and specifies the complexity of limitations in function that persons may experience as a result of a particular disease or illness. Butler (1995) argued that although each disablement model defines levels of the disabling process somewhat differently, evaluation of the effects of the outcomes of interventions at multiple levels is necessary to fully understand which variables contribute to the integration of persons with disabilities into valued social contexts.

On the basis of Rogoff's (1990) work, Coster and Haley (1992) raised developmental and contextual concerns to consider specifically the manifestation of disablement in relation to children. They defined limitations in social role performance as the most global level of their disablement framework. This level is characterized by the person's limitations in performing social, family, and personal roles. For children, the successful management of functional tasks and participation in society depends on adults

and children working together to structure the environment (Rogoff, 1990). Coster and Haley emphasized the need to consider the transactions between children and their families or caregivers and to design interventions and outcome studies to address the needs of children within the broader context of family, home, school, and other environments in which children participate.

Drawing on the disablement models and Trombly's (1993) model of occupational functioning, Coster (1998) more recently proposed an alternative approach to defining the most global level of functioning for children. In her model, the most global level focuses on

the extent to which a child is able to orchestrate engagement or participation in occupations in a given context that is positive (which, for a developing child, would often include growth enhancing), personally satisfying, and acceptable to the adults in society who are responsible for children (e.g., parents, teachers). (p. 340)

Coster termed this level *social participation*, defined as "active engagement in the typical activities available to and expected of peers in the same context" (p. 341). This model of occupational functioning for children provides clinicians and researchers with a broad, functionally relevant perspective to conceptualize outcome measures.

Building on the need to focus on multiple levels of the disablement process, Jette (1995) further argued for research designs and outcome assessments that address the hypothesized relationship between and among the different levels in the disablement model. For example, when applied to sensory integration theory, direct evidence would need to be established relative to the degree to which improvements in modulating sensory stimuli (impairment level) result in improvement in peer interaction and family adjustment (social participation level).

### Sensory Integration Efficacy Studies: Neglected Outcomes

Occupational therapy using sensory integration procedures is both the most widely researched and the most controversial intervention within occupational therapy (Miller & Kinnealey, 1993). Since Ayres' (1972a) seminal paper reporting that sensory integration, when coupled with special education, is a promising method for improving academic scores of children with learning disabilities, various authors have attempted to validate these findings. Ottenbacher's (1982) meta-analysis of eight studies concluded that empirical support exists for sensory integration therapy, whereas subsequent reviewers have claimed that the evidence in support of sensory integration therapy was inconclusive (Arendt, Mac Lean, & Baumeister, 1988; Polatajko, Kaplan, & Wilson, 1992; Schaffer, 1984).

Although previous studies have addressed the impairment, functional limitation, and disability levels, outcomes at the social participation level have not been documented. At the impairment level, researchers of sensory integration have measured underlying processing such as dichotic lis-

tening (Ayres, 1978), responsiveness to sensory input (Ayres, 1972a, 1978; Ayres & Tickle, 1980; Carte, Morrison, Sublett, Uemura, & Setrakian, 1984), and duration of postrotary nystagmus (Carte et al., 1984; Humphries et al., 1992; Humphries, Wright, McDougall, & Vertes, 1990). Researchers have used motor, cognitive, academic, reading, and language scales to measure changes in children's performance (Densem, Nuthall, Bushnell, & Horn, 1989; Humphries et al., 1990; Humphries et al., 1992; Polatajko, Law, Miller, Schaffer, & Macnab, 1991; White, 1979; Wilson & Kaplan, 1994) because they believed that improvements in basic underlying functional processes provided the foundation to enable changes in higher level skills. However, neither social participation nor the link among impairments, disability, and social participation has been empirically examined in sensory integration efficacy studies.

Parham and Mailloux (1996) recently presented a comprehensive review of expected outcomes of occupational therapy using sensory integrative treatment principles. Outcomes were conceptualized into six general categories: (a) increase in the frequency or duration of adaptive responses; (b) development of increasingly more complex adaptive responses; (c) increase in self-confidence and self-esteem; (d) improvement in gross and fine motor skills; (e) improvement in daily living and personal-social skills; and (f) improvement in cognitive, language, and academic performance. Parham and Mailloux suggested that achievement of a simple adaptive response (such as staying with an activity for more than a few seconds) may eventually lead to a change at the social role level (e.g., participating in the reading circle in school for the required amount of time, staying at the table during a family meal). To validate the hypothesized links between the various levels of the disablement model relative to sensory integration outcomes, research needs to be conducted at each level, and the relationship between levels needs to be articulated.

Other outcomes that have not been adequately addressed in research include the effects of occupational therapy using sensory integration procedures on children's attention and organization, the importance of consumers' knowledge of sensory integration, and the effect of disorders of sensory integration on the family system. In 1972, Ayres proposed that the goal of sensory integration therapy was to help children "direct themselves meaningfully" (Ayres, 1972b, p. 257). Concerns with children's ability to organize themselves are frequently reported by parents. Anecdotal comments such as, "My child is more organized; he can get himself dressed in time for school now" (Occupational Therapy Associates, 1994, p. 2), are used to market sensory integration approaches to the public. Comments such as these imply that there may be changes in attentional and organizational behavior, yet these anecdotal responses have yet to be examined systematically. Cermak and Henderson (1989, 1990) noted in their review of sen-

sory integration outcomes studies that only 5% focused on behavioral outcomes. These authors recommended that future studies investigate immediate changes in behavior (e.g., attention, organization).

One of the major assumptions of sensory integration intervention is that by helping parents understand the nature of their child's sensory integration problems, parents will better understand their child's behaviors (Koomar & Bundy, 1991). This understanding in turn helps parents respond to their child and structure their child's environment to facilitate more adaptive responses. This assumption recognizes the family-centered perspective that children's development is intimately related to transactions between children and their caregivers (Humphrey & Case-Smith, 1996).

Koomar and Bundy (1991) highlighted the valuable role occupational therapists can play when educating others about sensory integration dysfunction. They advocate "enabling our clients to understand the impact of their sensory integrative dysfunction and the purpose of their intervention, and that we help them to develop strategies to adapt to, and compensate for these dysfunctions" (p. 263). Parham and Mailloux (1996) posited that providing information to those who are in ongoing contact with the child can indirectly have a positive impact on the child's life.

A quote from a parent of a child who is receiving sensory integration therapy illustrates that parents value having a better understanding of their child's sensory integrative functioning because the knowledge of sensory integration has helped them to understand, respond to, and live with the associated problems in their child:

It was explained to me that his body was not organizing all of the stimulation that was coming into him because of his senses. And for him it was overwhelming, and he couldn't sort it. They explained everything about the nervous system, the arousals, and this had never been explained to me before. It was so helpful to understand my child's behavior in this new way. (Cohn, 1996)

The effects of educating parents to increase their knowledge of sensory integration provide yet another example of potential outcomes to explore in relation to sensory integration therapy. Children with attention deficit hyperactivity disorder (ADHD) often exhibit sensory integration dysfunction (Cermak, 1988), and some of the outcomes relevant to the study of sensory integration literature have been examined in the ADHD population. Anastopoulos, Shelton, DuPaul, and Guevremont (1993) examined changes in parent functioning resulting from parental participation in a behavioral parent-training program specifically designed for parents of children with ADHD. Significant posttreatment gains were noted in both parent and child functioning. Parents reported reductions in parenting stress and increases in parenting self-esteem as well as reductions in the overall severity of their child's ADHD symptoms. This study raises many important considerations for sensory integration intervention and efficacy studies. The

effect of educating parents about how sensory integration dysfunction affects children's behavior has not been systematically studied as an outcome of sensory integration.

The construct of parenting stress, well documented among families of children with ADHD, provides us with one example of how a broader social role perspective may relate to families with children who have sensory integration dysfunction. Clinicians providing services to children with sensory integration dysfunction frequently hear the children's parents describe challenges to the parenting role. A mother of a child with tactile defensiveness and gravitational insecurity described the struggle to wash her son's hair:

He didn't like to have his hair washed. My husband would have to come into the bathroom to help. My son would scream and yell. He didn't want to put his head back. He would scream "NO" and refuse to wash his hair. I'd have to wait until my husband came home to wash his hair. Everything had to be scheduled just so. It was so stressful. (Cohn, 1996)

As this parent reflected on the daily family routines, she indicated that the characteristics associated with sensory integrative dysfunction in her child were a source of parenting stress.

There has been limited attention to documenting parenting stress in the parent-child interaction in children with sensory integration dysfunction, but there has been considerable attention to parental stress as it relates to ADHD. Although a directional, causal connection between the functioning of a child with ADHD and parent functioning has yet to be firmly established, there is correlational evidence that parents of children with ADHD experience stress in the parental role (Anastopoulos, Guevremont, Shelton, & DuPaul, 1992; Baker & McCal, 1995; Baldwin, Brown, & Milan, 1995; Fischer, 1990; Mash & Johnston, 1983, 1990). Thus, one of the possible outcomes of sensory integration intervention is decreased stress in the parent-child interaction because we expect that a change in parents' understanding of their children will relate to coping with and minimizing parental stress.

Accordingly, how children and their families understand the problems associated with sensory integration dysfunction may affect their daily life and their performance of occupational roles of childhood (i.e., player, family member, student, friend). Although clinicians educate consumers about how sensory integration affects performance, outcome studies to establish links among parents' understanding, children's behavior, family functioning, and social roles have overlooked these potentially powerful relationships.

### Research Methodology To Examine Outcomes

To fully understand the effects of sensory integration therapy, outcomes must be investigated at multiple levels of the disablement process and must be related to family perspectives. To investigate the family point of view, the essence

and meaning that sensory integration therapy has for children and their families must be understood. One effective way to understand meanings of actions from the actor's point of view is through qualitative or interpretive methodologies. Qualitative studies, which are concerned with how participants make sense of their reality and how their understanding of their reality influences their behavior, are well suited to explore the consumer perspective (Charmaz, 1990; Maxwell, 1996; Strauss & Corbin, 1990) and can tell us about the meaning of problems associated with sensory integration dysfunction for families. By understanding what outcomes consumers value, we can then identify measurement tools to operationalize these important variables and design studies to investigate the nature of the hypothesized relationship among outcomes of the various disablement levels.

### Potential Assessment Tools

#### *Measurements of Attention and Organization in Children*

Although qualitative measures will help researchers understand the consumers' point of view of therapy, existing quantitative measures may help analyze some of the relevant constructs, such as children's attention and organization. Assessments such as the Child Behavior Checklist (CBC) (Achenbach & Edelbrock, 1991), the Conners Rating Scales-Revised (Conners, 1997), and the Home Situations Questionnaire-Revised (HSQ-R) (DuPaul & Barkley, 1992), scales used to assess child characteristics and discussed in the ADHD literature, may be useful in assessing the impact of sensory integration therapy on specific child behaviors.

The CBC, used extensively in the child psychopathology literature, is a 118-item checklist composed of the most common behavioral and emotional problems of children referred to mental health centers. The checklist addresses a broad range of internalizing and externalizing psychological symptoms for children and adolescents, which are rated by parents or parent-surrogates. This instrument is well standardized and has strong reliability. The inter-interviewer and test-retest reliabilities are above .90 (Achenbach & Edelbrock, 1991).

The Conners Rating Scales-Revised is a widely used four-point parent rating scale that can help identify behavioral problems in children 3 years to 17 years of age. The 80-item version yields seven factors: Oppositional, Cognitive Problems, Hyperactivity, Anxious-Shy, Perfectionism, Social Problems, and Psychosomatic. Studies indicate that this scale has adequate reliability (coefficients for internal consistency ranged from .73 to .94, and coefficients for test-retest reliability ranged from .70 to .77 for total scores). Factorial validity studies support the use of the different subscales. Validity studies on earlier versions also indicate sensitivity to treatment effects for ADHD (Anastopoulos et al., 1992; Mash & Johnston, 1983). The

Conners Rating Scales-Revised shows a strong correlation with the CBC (.82) (Conners, 1997).

The 14-item HSQ-R assesses the degree to which a child's inattention interferes with commonly encountered home situations (e.g., getting dressed, mealtimes, homework). Parents are asked to indicate whether problem behaviors occur in these situations and, if so, to rate the severity on a nine-point scale. The HSQ-R assesses the child's behavior in relation to the task demands and is the only measure that includes the context in the appraisal of the child's behavior. The HSQ-R has high internal consistency (.93) and test-retest reliability (.91). Parent ratings on the HSQ-R were significantly correlated (.69) with parent ratings on the ADHD rating scale (DuPaul, 1991) and have been found to be sensitive to the effects of medication and behavioral interventions on children (DuPaul & Barkley, 1992).

### *Measurements of the Family System*

Another level of assessment is the family system. This level of assessment was often the criterion measure or outcome measure for studies exploring the effects of therapy in families with children with ADHD. The most commonly used tool in research exploring the multiple levels of family functioning is the Parenting Stress Index (PSI) (Abidin, 1990). Parenting stress has been conceptualized as a complex transactional process influenced by extrafamilial or environmental, interpersonal, and child characteristics that are moderated through components of parents' personality and parental cognitions (Abidin, 1992). The PSI, designed to measure different domains of stressors in the parent-child relationship, is a 101-item self-report questionnaire for use with parents of children up to 13 years of age. The test is composed of a Parent domain and a Child domain. Each domain has subscales that provide a breakdown of intensity of stress in each area. The subscales in the Child domain include the child's adaptability to the environment, the acceptability of the child to the parent, the child's mood, the distractibility and hyperactivity of the child, and the child's reinforcing qualities. High scores indicate that the child may be showing behaviors or have certain qualities with which parents have difficulty coping. The subscales in the Parent domain include parent depression, unhappiness, and guilt; parent attachment to child; restrictions imposed by parental role; parent's sense of competence; social isolation; relationship with spouse; and parental health. High scores on the Parent domain indicate that the stress in the parent-child system may be related to aspects of the parent's functioning in his or her role as a parent. Total scores cover both domains and indicate the overall stress in the parent-child relationship. Reliability coefficients (internal consistency) are .89 for the Child domain, .93 for the Parent domain, and .95 for the total score (Abidin, 1990).

Parenting self-esteem, a construct that encompasses both perceived self-efficacy as a parent and satisfaction derived from parenting, is a component of parental cognition that is measured by the Parenting Sense of Competence (PSOC) (Gibaud-Wallston & Wandersman, 1978). Each of the 17 items on the PSOC is answered on a six-point Likert scale. The factor structure of the PSOC revealed two dimensions of parenting self-esteem: (a) satisfaction, the degree to which the parent feels frustrated, anxious, and poorly motivated in the parenting role, and (b) efficacy, the degree to which the parent feels competent, capable of problem solving, and familiar with parenting. The PSOC has been shown to possess satisfactory internal consistency (.79), although reliability over time varies from .46 to .82. This test correlates moderately with the CBC (Johnston & Mash, 1989).

The Questionnaire on Resources and Stress-Short Form Adapted (QRS-SFA) (Salisbury, 1986) addresses the types of stress experienced and the coping resources available to caregivers. The QRS-SFA is a 48-item true-false inventory that provides information about seven factors of stress: life-span care, cognitive impairment, child characteristics, family disharmony, pessimism, physical limitations, and financial stress. Further, the measure provides an overall summary stress index by collapsing each of the factors. The reliability coefficients (internal consistency) for the measure range from .65 to .84.

The Family Environment Scale (FES) (Moos & Moos, 1981) assesses multiple dimensions of family climate and is a widely used measure of family characteristics. The FES consists of 90 true-false items about the family's social environment within three broad domains composed of 10 component subscales. The Relationship domain reflects the type of and emphasis on interpersonal relationships within the family; the Personal Growth domain represents types of family interests, goals, and activities; and the System Maintenance domain reflects the extent and role of structure, organization, and rules in planning and running family life. Reliability (internal consistency) coefficients range from .61 to .78. Numerous studies have supported the utility of the FES as a tool for identifying characteristics of family adaptation to its members (Kronenberger & Thompson, 1990).

These four assessments are examples of the types of instruments that could be used to assess changes in family functioning over the course of sensory integration therapy. Including the family in evaluating the effectiveness of sensory integration reflects the belief that children's functioning must be assessed within the broader social context.

### **Summary**

There has been a shift in conceptualization of outcomes research. This shift has focused attention on the need to incorporate family perspectives and to include outcome measures that address function and context. We must an-

swer the fundamental question: What does occupational therapy using sensory integration procedures actually achieve for consumers? Knowledge of the consumer's perspective can be understood through qualitative approaches that help us understand what matters to our consumers, what they value, and what their perceptions of therapy outcomes are.

The assumptions embedded in our practice are based on ideas proposed by Ayres (1972b) when she identified the ultimate goal of therapy as facilitating "a being which wants to, can, and will direct himself meaningfully and with satisfaction in response to the environmental demands" (p. 257). Thus, the overarching goal of occupational therapy using sensory integration procedures is to improve children's ability to organize their behaviors in order to meet demands from the environment. Because most children live in environments that are structured by adults, we must consider the entire caregiver unit when designing and evaluating interventions. Consequently, therapy should include educating caregivers and parents about sensory integration to help them create nurturing environments for their children. We assume that providing direct therapy to children to facilitate organized behavior responses coupled with educating caregivers will have a positive effect on children and the entire family system. For example, challenges to the parenting role, such as parental stress, may be decreased. Further, we assume that increased organized behavioral responses will enable children to better perform the social roles of player, friend, student, or family member. These assumptions must be validated as part of our research efforts.

Inclusion of measures that assess outcomes at the family level and evaluate children's behavior in context will enable us to complete the multilevel analysis advocated by proponents of the disablement model. Thus, we will have a more knowledgeable understanding of whether occupational therapy using sensory integration procedures improves functioning and quality of life for children and their families. The addition of the types of outcome variables discussed in this article will also allow us to begin to evaluate interactions among the various levels in the framework of occupational functioning for children in order to better understand the effects of occupational therapy interventions. ▲

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