Triage of the Autistic Spectrum Child Utilizing the Congruence of Case Management Concepts and Orem’s Nursing Theories

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The purpose of this project was to design and implement a case management framework for the benefit of children diagnosed with an autistic spectrum disorder (ASD). The process consisted of selecting two children exhibiting symptoms of an ASD and managing them across a continuum of care. Methodological structure was derived from case management standards of practice and Orem’s Nursing Theories. Although some objectives sustained a slight delay because of variances, findings revealed successful outcomes based on progression toward measurable case management goals. The children were directed to appropriate school placements and habilitative therapies in an efficient manner. Their parents received support and education related to special needs children. The process yielded assurance that Orem’s Nursing Theories and case management concepts articulate seamlessly within nursing care boundaries.

For families facing the diagnosis of a neurobehavioral disorder, recommended treatments can be an overwhelming prospect. Remediation usually involves care from multiple providers who originate from varying disciplines. Because services are usually multifaceted, families are often perplexed by the necessary plan of care. Lost in a sea of foreign diagnoses, medical terminology, referrals, and spiraling costs, clients may end up recoiling from one or more treatment options or committing to services that are nonproductive. Due to complex needs, this can be especially true for families challenged with the care of an autistic child characterized by convoluted neurobehavioral issues and diverse interventions.

Impaired children are usually unable to participate fully in their own self-care development, and parents who care for their disabled children are often overwhelmed. For these reasons, autistic children and their families are perfect candidates for case management and the application of Orem’s Theory of Self-Care Deficit.

Case management seeks to streamline complex care by guiding clients through episodes of illness while facilitating appropriate treatment at the right time and in the right place. Orem’s Theories help the nurse case manager navigate clients through “health deviant” experiences in an organized fashion designed to restore independent “functioning and development” (Orem, 2001, pp. 43, 47-48).

PROJECT OBJECTIVES AND THEIR SIGNIFICANCE TO AUTISM, CASE MANAGEMENT, AND NURSING

The goal of this project was to apply case management concepts in tandem with Orem’s nursing model to demonstrate a usable link between the two constructs for the provision of seamless, theory-driven care.
care. Children with autism will gain from the comprehensive nature of the assessment, triage, and implementation of best-practice care. Parents will benefit from the clarity of guidance resulting from the process. Case managers will acquire new insights related to theory-based client management. Providers will benefit from organized, seamless care for their patients. Payers will profit from careful use of resources.

**LITERATURE REVIEW**

**Introduction**

The literature is rich in detailed information espousing autism, case management, and Orem’s nursing theories; however, there is minimal reference to the interrelation of all three. Thus, the literature review documents ideas and sources of topics mentioned in this paper; later, the writer makes some assumptions about their linkage.

**AUTISM**

Autism can first be noticed in infancy as evidenced by developmental delays, or between the ages of 12 to 36 months presenting with “regression and loss of previously acquired skills” (American Academy of Pediatrics (AAP), 2001; Minshew, 1997, p. 818). Autism, often referred to as autistic spectrum disorder (ASD), is considered a “neurodevelopmental” condition characterized by social skills deficits, play impairments, language delays, stereotypical behavior, motor abnormalities, and a narrow range of interests (AAP, 2001; Folstein, 1999; Gillberg & Coleman, 2000; Minshew, 1997; Nass & Ross, 1998). Comorbid symptoms also can include hyperactivity, aggression, delayed motor development, apraxia, altered pain sensation, sensory integration difficulties, vision and hearing deficiencies, inattention, psychoses, obsessive-compulsive tendencies, mood and anxiety disorders, sleep disturbances, tics, and seizures (Folstein, 1999; Gillberg & Coleman, 2000; Minshew, 1997, p. 821; National Institute of Mental Health, 2000). Cognitive abilities in the ASD child can range from mentally retarded to gifted, with the prognosis favoring those with higher aptitudes (Brasic, 2001; Nass & Ross, 1998). Autistic spectrum disorder syndromes include autism, atypical autism, pervasive developmental disorder (PDD), childhood disintegrative disorder, Rett syndrome, and Asperger’s syndrome (Brasic, 2001; Gillberg & Coleman, 2000; Minshew, 1997).

**ETIOLOGY**

The origins of ASD continue to be a mystery. Theorists believe causes may be due to genetic makeup, brain lesions, brain abnormalities, altered internal chemistry, viruses, or toxic chemicals (AAP, 2001; Carlson, 1998; Cowley, 2000; Gillberg & Coleman, 2000). Whatever the reason, autism afflicts males more than females across all social classes. Approximately 10 years ago, the incidence of autism was 1 child in 10,000. That ratio is now 1 in 500 (LaFee, 2002). Gillberg and Coleman (2000) report a “yearly increase—highly statistically significant of almost 4 per cent from 1966 through 1997” (p. 89). The increase in ASD may be due in part to improved screening and diagnosis; however, scientists believe the unknown rise in cases is reaching epidemic proportions (LaFee, 2002).

**INTERVENTION**

Early sustained intervention “has been shown to be associated with improved long-term outcomes” (AAP, 2001). Recommended treatment can include structured programs such as the Applied Behavioral Analysis (ABA) or Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH); Floor Time; Picture Exchange Communication System (PECS); behavior management; pharmacological intervention; occupational therapy; physical therapy; social skills training; speech therapy; parent education; and sometimes alternative therapies (AAP, 2001; Levy & Hyman, 2002). Older children and adolescents require structured programs at school with generous amounts of support services such as those mentioned previously (American Academy of Child and Adolescent Psychiatry, 1999).

Successful intervention programs for ASD children share some common threads: a curriculum aimed at teaching communication, social, and play skills; a 1:1 instructional environment where individual needs can be met; a structured setting; “a functional approach to problem behaviors”; transition goals; and “family involvement” (AAP, 2001, p. 8). Overall, instructional strategies should include speech therapy, communication devices, occupational therapy, social skills remediation, and parent support (AAP, 2001). Dawson (1997) as cited by the Autism Society of British Columbia (2001), believes exceptional early intervention programs should be “highly structured, predictable and routine” with a “1:1 or 1:2” ratio between student and teacher (p. 4). Other components prescribed by Dawson (1997) include “minimal distractions ... repetition ... interesting materials ... modeling ... physical prompts,” and social skills intervention (p. 4). KidSource (2000) notes effective early intervention programs to include frequent monitoring of “child and family behavior...
objectives,” identification of “teacher behaviors and activities that are to be used in each lesson,” use of “task analysis procedures,” regular evaluation of progress on goals, and modification of instruction on a consistent basis (p. 4).

**Case Management Concepts**

Given the rapid and monumental changes in healthcare over the years, case management has taken on an important role in healthcare delivery settings. Cesta, Tahan, and Fink (1998) believe the old carte blanche fee-for-service reimbursement system, unable to handle spiraling costs, forced new methods of disease management. In the 1980s, diagnosis-related groups (DRGs) and managed care emerged as answers to cost containment (Cesta et al., 1998). Quality of care took a back seat to financial considerations. According to More and Mandell (1997), “pluralism,” “multicentricism,” and “fragmentation” heightened the crisis yielding a “lack of unity in decision making and ... duplication of some services and large gaps in others” (p. 2). In order to reincarnate top-notch care, continuous quality improvement and case management evolved to meet the need (Cesta et al., 1998). Horst, Werner, and Werner (2000), referencing an ANA task force, define case management as “a mechanism to optimize the patient’s self-care abilities and to effectively use resources” (p. 5).

Case management seeks to streamline complex care and can best be defined as a team approach for implementing seamless, cost-efficient care whereby, under the leadership of a case manager, collaborative information is used to assess, plan, implement, coordinate, monitor, and evaluate “an individual’s health needs” (Ling, 1999, p. 2). The delivery of case management can take place internally (through institutions such as hospitals, physician offices, managed care organizations, and long-term facilities) or externally (through insurance companies, community agencies, government agencies, and independent case managers) (Ling, 1999). Case management can be delivered through on-site methods or by telephonic means, and is applicable to wellness services, ambulatory care services, long-term care, acute care, and chronic disease management (Ling, 1999). “The duration of case management can range from a few days to several years” (Ling, 1999, p. 31).

Basic case management components include case screening and selection; assessment of the chosen client; problem identification and planning critical pathways; preparing a care plan (keeping in mind the physician treatment plan, existing objectives of providers, and available resources); implementing goals and objectives; coordination of services and health team members; monitoring care and progression of goals; evaluating effectiveness of the goals; and termination (Case Management Society of America, 1995). Summers (2001) labels the case management process as the development of an individualized plan.

**Case Management of the Special Needs Child**

As stated previously, treatment for children with ASD generally requires multiple providers. This is due to complex symptomology and, often, comorbid conditions. It is not unusual to see ASD children with co-existing deficits such as learning disabilities, attentional disorders, executive function deficits, behavioral problems, visual-motor-perceptual differences, processing issues, and sensory integration difficulties. Thus, neurologic care, behavior therapy, psychotherapy, occupational therapy, speech therapy, physical therapy, remediation, school interface, medication management, and parent/child education may be needed simultaneously for the patient to realize a significant degree of success. Costs and time commitments for such interventions are daunting. For some, even early intervention may not produce significant change. For these ASD children and their parents, case management will be of benefit. Involving parents in “planning and decision-making” facilitates empowerment and prepares the family for self-advocacy (Horst et al., 2000, p. 5).

**Orem’s Theories**

Orem’s original Theory of Self-Care was first devised to benefit nursing curricula (Meleis, 1997). It was designed to determine the “boundaries of nursing as a field of practice and a field of knowledge” (Orem & Taylor, 1986, p. 39, as cited in Hartweg, 1991, p. 3). Self-care asserts an individual’s ability to “regulate his own functioning and development” (Orem, 2001, p. 43). Orem’s Self-Care Theory is categorized as a grand theory. However, out of this theory emerged her Theory of Self-Care Deficit, which is considered a mid-range theory and more applicable to nursing practice (McKenna, 1997). It represents a person’s need for care based on deviations from a state of wellness. A third component to Orem’s theories is called Nursing Systems. Nursing Systems Theory describes the relationship between the patient, nurse, and type of care delivered (Orem, 2001). The overarching nursing goal within this theory is to “overcome or prevent the development of self-care limitations or provide therapeutic self-care for a person who is unable to do so” (Leddy & Pepper, 1998, p. 181).
Although best suited for adults and hospital care, application of Orem’s theories can be useful with the pediatric population and for community health (Meleis, 1997). To fully understand Orem’s ideas, it is important to have knowledge of her three interrelated theories as introduced above: Self-Care, Self-Care Deficit, and Nursing Systems.

**Theory of Self-Care**

Orem’s Theory of Self-Care presumes that “individually initiate and perform [activities] on their own behalf in maintaining life, health, and well-being” (Orem, 1991, p. 117, as cited in Hartweg, 1991, p. 14). Orem labels an independent-care individual as “Self-Care Agent” and their activities as “Self-Care Agency” (Hartweg, 1991, p. 16). Self-care assumptions are true except for children, some elderly, and compromised adults (Hartweg, 1991). The designation for those providing assistive care is “Dependent-Care Agent” and their activities are considered “Dependent-Care Agency” (Hartweg, 1991, p. 17). Elements affecting the Self-Care or Dependent-Care Agency are labeled by Orem as “basic conditioning factors” (Orem, 2001, p. 167). These factors include age, gender, developmental state, health state, environment, family system, sociocultural underpinnings, and support systems (Orem, 2001).

Orem believes that every person has “Self-Care Requisites” that require action. These requisites are “universal” (air, water, food, elimination, activity, rest, quiet, socialization, and avoidance of hazards), “developmental” (fetal growth, birth, neonatal, infancy, childhood, and adulthood), and “health deviant” (pathologically provoked needs) (Orem, 2001, pp. 47-48). Closely aligned with the topic of Self-Care Requisites is the concept of “Therapeutic Self-Care Demand” also known as “courses of action or care measures” required to guide self-care (Orem, 2001, p. 52). Therapeutic Self-Care Demand includes “all the self-care actions that should be performed by the individual over time to maintain life, health, and well-being” (Hartweg, 1991, p. 20).

**Self-Care Deficit Theory**

Orem’s Theory of Self-Care Deficit emerges from a base of holism where the patient is cared for from a viewpoint of body, mind, and social/emotional well being (Leddy & Pepper, 1998). It represents “what nursing is and what nursing should be ... in concrete nursing practice situations” (Orem, 2001, p. 136). When the patient deviates from a position of health or is unable to sustain self-care, a Self-Care Deficit presents itself and health deviant or Developmental Self-Care Requisites are generally present. In turn, these requisites stimulate “Dependent-Care Demands” (Leddy & Pepper, 1998, p. 181; Orem, 2001, p. 140). Self-Care Deficits can be “partial” (some ability to meet “the Therapeutic Self-Care Demands”) or “complete” (no ability to meet “the Therapeutic Self-Care Demands”) (Hartweg, 1991, p. 24). The nurse, family members, and other providers all work together as Dependent-Care Agents to provide Dependent-Care Agencies (activities designed to remediate Dependent-Care Demands).

**Nursing Systems Theory**

This theory helps to explain Orem’s “general theory of nursing” (Hartweg, 1991) and is closely aligned with her Self-Care, Self-Care Deficit, and Dependent-Care Theories. Simply put, the Nursing Systems Theory is a structure to define nursing actions and interactions related to patient care. Orem labels nursing care as “Nursing Agency”—a term that embodies a nurse’s education, training, knowledge, and abilities used to assist others in meeting their Therapeutic Self-Care Demands and Self-Care/Dependent-Care Agencies (Hartweg, 1991, p. 24). Meleis (1997), referencing Orem (1991), suggests that nursing activities are “‘compound actions’ meaning that actions need to be coordinated, performed simultaneously, or related” (p. 394).

According to Orem (2001), functions of the Nursing-Care Agent can be broadly categorized as “wholly compensatory,” “partly compensatory,” or “supportive-educative systems” (p. 350). Wholly compensatory suggests a patient requires total care (such as in quadriplegia or coma). Partly compensatory represents a complementary relationship where both the patient and nurse “share the responsibility of care (the nurse monitors the patient’s IV and the patient feeds himself). In the supportive-educative role, the nurse acts as a resource for the patient (the breast-feeding mother who needs instruction on appropriate techniques) (Hartweg, 1991).

The Nursing System encompasses three interrelated “subsystems” (Orem, 2001, p. 346): “social, interpersonal, and technological” (Hartweg, 1991). These three subsystems are interwoven with Nursing Agency (Orem, 2001). The goal of nursing agency is to “meet patients’ Therapeutic Self-Care Demands and to protect and to regulate the exercise or development of patients’ Self-Care Agency” (Orem, 2001). The social system is required for defining the “role of the person as patient and the role of the nurse as the provider of care” (Hartweg, 1991, p. 26). Within the social system, the patient and nurse form a “contractual relationship” outlining the “boundaries of nursing care” (Hartweg, 1991, p.
26). Through interpersonal interactions, the nurse and patient work together (including family when appropriate) to promote Self-Care Agency (unless, of course, the patient is totally disabled) (Orem, 2001). The technologic system embodies operative terms such as nursing diagnoses, prescription, regulation, and control (case management according to Orem) “for meeting the Therapeutic Self-Care Demands of individuals” (Orem, 2001, p. 309).

Diagnostic operations “incorporate investigative operations to accumulate data that is relevant to the problems for which people seek care from specific health services” (Orem, 2001, p. 310). Prescriptive operations designate plans of care based on diagnostic findings (Orem, 2001). Regulatory operations execute nursing care or treatment (Orem, 2001). Control operations are considered by Orem (2001) to be case management functions such as observing, monitoring, and evaluating care.

Nursing Agency with a child is more complex than with adults. Special considerations must include knowledge of developmental age versus chronological age, cognitive ability, adaptive ability, motoric/sensory integration abilities, emotional status, gender, genetic background, temperament, environment, sociocultural orientation, family support, family systems, and healthcare needs (Gaffney & Moore, 1996; Orem, 2001). Meeting parental as well as pediatric patient needs must be taken into consideration. Biehler (1992) emphasizes that the ill child’s “emerging Self-Care Agency is enhanced through collaboration between Dependent Care Agents” and Nursing Agents (p. 32).

**The Congruence of Case Management and Orem’s Theories**

After an exhaustive search, the writer found no citations linking case management and Orem’s Theories. Therefore, several assumptions and propositions are presented to support the congruency of both constructs.

Although the concept of case management has long existed in the healthcare arena, it is a new specialty for the advanced practice nurse (APN). The APN case management role has grown as a result of rising healthcare costs, managed care domination, and the need for quality care. Studies have shown a correlation between nursing case management and improved outcomes (Hamric, Spross, & Hanson, 2000). Rieve (2001) reports case manager involvement positively impacting cost containment and case success. Alvarez (2000) sees case manager roles as highly effective in coordinating complex patient care leading to efficient, empowering provision of services, resulting in satisfied clients and appreciative third party payers.

To maintain an identity in the case management world, nurses must cling to nursing theory. “Theory is a tool that renders practice ... more effective” and “... essential to all professional undertakings” (Meleis, 1997, pp. 8, 20). With increased numbers of nurses entering the field of case management, it is essential they adopt a theoretical base from which their practice will evolve. Theories help define nursing as a discipline and their use encourages knowledge development. Knowledge development “advances the discipline of nursing” and “facilitates better care for clients” (Meleis, 1997, p. 8). Orem’s theories of Self-Care Deficit and Nursing Systems easily articulate with nursing practices embedded in case management structures (see Figure 1).

Using the ASD child as an example, Orem’s theories can be applied to case management progressions. The ASD child would be identified as a Self-Care Agent with a Self-Care Deficit requiring the assistance of a Dependent-Care Agent and Nursing-Care Agent. The case management process of assessment would utilize Basic Conditioning Factors, Self-Care Requisites, Self-Care Deficits, Therapeutic Self-Care Demands, and Dependent-Care Demands in identifying problems. Problem formation would evolve into nursing diagnoses and critical pathway development. The nurse would then design a case management care plan (Prescriptive Operation) incorporating Therapeutic Self-care Demands and Dependent-Care Demands. Implementation would be considered a Regulatory Operation whereby the case manager would coordinate, observe, monitor, and evaluate patient progress (Control Operations).

**Summary**

Children with neurobehavioral disorders usually require assistance from adults for fulfillment of self-care. Autistic spectrum disordered children present with complex symptomology and comorbid conditions. Given the need for multiple providers and interventions, medical care for ASD children is best facilitated using a case management approach. Utilizing nurses as case managers for supervision of complicated medical conditions is growing in popularity. With more nurses entering the field of case management, adoption of nursing theory to support their practice increases the potential for positive patient outcomes.

**Methodology**

**Introduction**

To test case management procedures in concurrence with Orem’s theories, the case manager must have a population from which to choose. Selecting ASD
children within an age range helped to narrow the focus of this writer's study. Managing children under the age of 6 was preferable, given the evidence that early intervention can be key to positive, sustained outcomes (AAP, 2001).

The structure of this project is in accordance with the Case Management Society of America's Standards of Practice (1995) and Orem's Nursing Theories. Evaluation and review of data were realized using concepts specific to qualitative analysis. Because the scope of this endeavor included only two families faced with ASD, it is important to keep in mind the limited generalizability of reported outcomes.

**Selection of Participants**

At the beginning of this project (spring 2002), two families with pre-schoolers were available and willing to participate. Recruitment of these developmentally delayed children took place through a pediatric neurobehavioral center near Chicago, Illinois, and through a colleague providing social/emotional psychotherapeutic support to children. Both children had recently been diagnosed with pervasive developmental disorder (PDD) and both exhibited autistic tendencies.

**Consent and Confidentiality**

Parental consent was obtained on behalf of the project participants. After providing a description of case management procedures, a consent form usable for case management purposes was given to parents, keeping in mind their “capacity to make clear, competent decisions,” their ability to comprehend the process of case management, and their willingness to participate in the study (Summers, 2001, p. 10).

Efforts were made to maintain patient and family privacy. This included keeping records in a locked room and maintaining confidentiality.
ETHICAL CONSIDERATIONS
The writer’s ethical principles parallel the philosophies of the American Nurses Association (ANA) Code of Ethics (2001), the Commission for Case Manager Certification (CCMC) Code of Professional Conduct for Case Managers (1997), and the Case Management Society of America (CMSA) Standards of Practice for Case Management (1995). Salient points related to this study are patient rights; respect for clients and colleagues; commitment to the patient; collaboration with patients, families, colleagues, and others; maintaining privacy and confidentiality; patient protection; acting within the scope of practice; continuing professional competence; promotion of healthy environments; and maintenance of objectivity and integrity.

PROCEDURES
Assessment and Problem Identification
Assessment occurred through review of medical, developmental, neurobehavioral, and academic records (including the child’s Individual Educational Plan [IEP]), plus an interview session with the parents. To date, neither child has had a neuropsychological work-up. To gain greater understanding of the subjects to be managed, the writer observed each child in the classroom for 1 hour. History and performance levels were logged on a case management assessment form (see Figures 2 and 3). Each child’s profile and needs were recorded on a case management summary sheet (see Figure 4).

Critical Pathway and Care Plan Development
Upon completion of the assessment and subsequent summary, critical pathway development (see Figure 5) took place in cooperation with the parents and existing treatment plans from private and public school providers. Including parents and all team members in the planning maintained collaborative efforts and provided broad intervention programs for the children. Subsequently, the writer compiled a case management care plan prioritizing patient needs. Measurable goals were prioritized and entered on the care plan form, which included expected outcomes and expected dates of completion (see Figures 6 and 7).

IMPLEMENTATION, MONITORING, AND COORDINATING CARE
To facilitate adherence to the treatment program as established through the care plan, parents were encouraged to contact referral sources (such as occupational, speech, and social skills therapists) to initiate interventions designated in the critical pathway. After obtaining release forms, the writer collaborated with providers and kept in consistent contact with parents. The writer maintained frequent updates with providers when applicable.

EVALUATION AND DATA ANALYSIS
Evaluation of this project was based on the continuity and comprehensiveness of care as projected by measurable goals and objectives shown on the individualized case management care plans (see Figures 6 and 7). Also considered was the relationship of case management concepts and Orem’s Nursing Theories in conjunction with the triage of ASD.

FINDINGS
Assessment
The following represents summaries from parent interviews, school observations, and a review of school, medical, psychiatric, audiologic, occupational therapy, and speech therapy assessments. Both Boy Y and Girl X carry recent diagnoses of pervasive developmental disorder (PDD) with autistic traits. Both also exhibit symptoms of language deficits, socialization impairments, sensory-motor difficulties, altered sleep patterns, hyperactivity, and inattentiveness. However, each has a unique presentation. (See Table 1 for a participant comparison.)

Boy Y
Boy Y was 4.1 years old at the assessment initiation. He lives with his mother in the city of Chicago and attends an early childhood program in one of the Chicago public schools. Boy Y has no siblings. Initial concerns centered on the absence of expressive language, deficits in social interaction, limited play activity, insufficient eye contact, incomplete toilet training, and sleep disturbances.

Boy Y was the product of a normal pregnancy and an uncomplicated induced delivery. He weighed 7 pounds, 5 ounces at birth. His Apgar scores were unavailable. Infant health status is reported to be without incident. Mother describes Boy Y as an easy baby who had no sleep difficulties, was happy, episodically responded to cuddling, and preferred longer feedings during the night. Until the age of 2 years, medical history was unremarkable except for recurrent ear infections. Boy Y has had no hospitalizations, no injuries, no serious illnesses, and takes no medication. An electroencephalogram (EEG) obtained in 2001 was normal, and an audiogram from 2000 was deemed normal.
Developmental milestones were within normal limits, with the exception of stunted language development and atypical social skills. Mother reports some babbling at 6 to 8 months and early utterances of “mama,” “baba,” and “lala,” which soon disappeared. Currently, Boy Y uses minimal expressive language, but understands much of what is said to him. When Boy Y wants something, he takes an adult to the

object or activity of interest. Boy Y occasionally uses basic sign language to express his wants. He knows the signs for “please,” “more,” and “thank you.”

Given his young age, Boy Y has minimal pre-academic history. Boy Y’s teachers describe him as having difficulty following directions, limited peer interaction, minimal class participation, stiff and rigid body movements, decreased attention, organizational
deficits, fine motor difficulties, no expressive language, restlessness, impulsivity, poor task completion, absent pre-academic skills (numbers and letters), and a positive affect. Again, language is impaired, which impedes much of Boy Y’s learning. Teachers have tried to employ the Picture Exchange Communication System (PECS) with Boy Y, as well as a communication board, but he shows little interest in using them.

As reported previously, Boy Y lacks appropriate social interaction abilities. Although showing social interest, he does not speak or demonstrate reciprocity with his peers. Boy Y prefers puzzles and fasteners to typical interactive, imaginative play.
Boy Y displays a happy affect most of the time, evidenced by a continual smile. Occasionally he shows discontent by whining or yelling when he is unhappy or with limit setting. Boy Y is compliant when given structure and repetitive directives.

In the sensory-motor domain, Boy Y demonstrates weaknesses in motor planning, coordination, oral-motor function, and fine motor skills. Sensory integration weaknesses may also be present, as shown by sensitivities to loud noises. Progress has been noted in functional skills such as zippering, buttoning, and using utensils.

Boy Y has difficulty with regulation, as evidenced in his inattentiveness, reported impulsivity, incomplete
toilet training, limited eye contact, and dysregulated sleep patterns. Executive functioning may also be impaired, as shown by motor planning issues and, perhaps, by a lack of organizational ability.

Current interventions are delivered by his public school system's early childhood program with adjuvant speech therapy on a weekly basis. Boy Y receives outside support from private speech and occupational therapists.

Boy Y's strengths lie in his pleasant disposition, his curiosity in learning how objects work, his patience, and his love of music. Other assets are most likely yet to be revealed, because Boy Y's language is significantly compromised at this time.
<table>
<thead>
<tr>
<th>Problem/Goal</th>
<th>Expected Outcome</th>
<th>Evaluation</th>
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<tbody>
<tr>
<td>1. School placement inadequate to remEDIATE deficits</td>
<td>Boy Y will be enrolled in the appropriate classroom by 8/30/2002</td>
<td>-Parent and CM talking with Chicago Public School Dept. of Autism -Chicago Public School re-eval -Agreement for placement in autism ECC class -Visit to new school to view classroom and speak with teacher</td>
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<tr>
<td>2. Moderate to severe language delays have not been remediated</td>
<td>Boy Y will be using communication assists by 8/30/2002 and be receiving continued speech therapy</td>
<td>-Boy Y not interested in PECS and ASL -Ongoing -ST 2x/week privately &amp; 1x/week at school</td>
</tr>
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<td>3. Sensory-motor deficits are not stabilized</td>
<td>Boy Y will be receiving continued occupational therapy as evidenced by twice weekly sessions privately and once weekly in school</td>
<td>-OT 2x/week -Ongoing -OT 2x/week privately &amp; 1x/week at school</td>
</tr>
<tr>
<td>4. Social skills are delayed</td>
<td>Boy Y will be engaged in Floor Time therapy by 7/2002</td>
<td>-Two visits to Floor Time therapist -Parent not comfortable with therapists -discontinued therapy -Social skills at school 9/2002</td>
</tr>
<tr>
<td>5. Private and public school providers have not collaborated</td>
<td>Boy Y's team of providers will have collaborated and developed common goals by 8/2002</td>
<td>-Refer to 9/2002 when all staff is available -School meeting will be held in 9/2002</td>
</tr>
<tr>
<td>6. Regulatory deficits impede learning</td>
<td>Boy Y will be receiving teacher strategies and using compensatory mechanisms to structure regulation by 10/2002</td>
<td>-Refer to 9/2002 when all staff is available -School meeting will be held in 9/2002</td>
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<tr>
<td>7. Parent is new to special education</td>
<td>Boy Y's academic program and IEP will be comprehensive and parent will have understanding of special education processes by 8/2002</td>
<td>-Handouts to parent -Discussions on working with the school to secure services -Discussions about school re-evaluation -Visit to school in 8/2002 to discuss curriculum and support services</td>
</tr>
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</table>

FIGURE 6
Case management care plan for Boy Y.
Important to this assessment are familial and environmental circumstances. Boy Y’s mother is a single parent with limited resources. Most of the private evaluations to date have been covered by public insurance. Portions of the assessments were obtained through the public school system. Boy Y’s father is not actively engaged in his child’s activities; thus, his mother is solely responsible for providing care. On the positive side, his mother is intelligent, willing to learn about her son’s neurobehavioral challenges, and interested in providing learning opportunities and support at home.
Girl X

Girl X was 4.9 years of age at this project’s initiation. She lives with her mother, father, and younger sibling in a rural suburb northwest of Chicago, and attends an early childhood program in a local public school. Initial concerns included sensory-motor problems, weak muscle tone, attentional issues, poor sleep patterns, selective eating habits, socialization deficits, and language delays.

Girl X was adopted at 12 months, and no birth history or early infancy information is available. At the time of her adoption, she was not crawling or able to sit on her own. Parents report her to have sleep delays, difficulty staying asleep, irritability, and poor eating habits. Girl X has allergies to beef and environmental substances. Since her adoption, Girl X has had no hospitalizations, no injuries, no serious illnesses, and takes no medication. A recent EEG revealed frequent posterior sharp waves and spikes. Audiologic and central auditory processing exams were normal.

Girl X crawled at 15 months, stood at 16 months, walked independently at 20 months, was toilet trained at 41 months, spoke her first word at 15 months, spoke in complete sentences at 24 months, and could name colors at 36 months. Girl X can lace her own shoes and use the bathroom independently. Although linguistically adept, Girl X has moderate expressive and mild receptive language issues. Although showing slight cognitive delays in the past, Girl X can form sentences of 4 to 5 words, tell a story, use past tense, carry out multi-step directions, point and name primary colors, identify simple shapes, understand who and why questions, create rhyming words, match pictures to objects, count to 30, recite her street and town, and has a substantial vocabulary. Basically, Girl X is kindergarten-ready.

Social interaction with peers appears to be Girl X’s greatest weakness. Impairments in pragmatic skills, reciprocal interactions, eye contact, and proxemic awareness interfere with developing friendships. Girl X shows no interest in her peers, yet does engage with adults. Play is typically solitary.

### TABLE 1

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<thead>
<tr>
<th></th>
<th>Boy Y</th>
<th>Girl X</th>
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<tr>
<td>Age at time of assessment</td>
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<td>4.9</td>
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<td>PDD</td>
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<td>Yes</td>
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<tr>
<td>Autistic Traits</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Expressive Language Deficits</td>
<td>Severe</td>
<td>Moderate</td>
</tr>
<tr>
<td>Receptive Language Deficits</td>
<td>Moderate</td>
<td>Mild</td>
</tr>
<tr>
<td>Cognitive Delays</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Responds to Directives</td>
<td>With Support</td>
<td>With Support</td>
</tr>
<tr>
<td>Inattention</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Impulsivity</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Task Completion</td>
<td>No</td>
<td>Yes (Slow)</td>
</tr>
<tr>
<td>Muscle Weakness</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Sensory-Motor Deficits</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Social Interest</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Interaction with Peers</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Play</td>
<td>Solitary</td>
<td>Solitary</td>
</tr>
<tr>
<td>Imaginary Play</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Eye Contact</td>
<td>Limited</td>
<td>Limited</td>
</tr>
<tr>
<td>Toilet Trained</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td>Self-Help Skills</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Sleep Disturbances</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Hearing</td>
<td>Normal</td>
<td>Normal</td>
</tr>
<tr>
<td>EEG</td>
<td>Normal</td>
<td>Abnormal</td>
</tr>
</tbody>
</table>

PPD = pervasive developmental disorder, EEG = electron cephalogram.
Girl X has undergone several occupational therapy evaluations. Results revealed hypotonicity, weakened postural stability, diminished strength, and fine and gross motor difficulties. Sensory integration dysfunction was observed in her sensitivities to taste, sound, and texture.

Poor regulatory abilities are evidenced by inattention, obsessions with objects, poor sleep habits, difficulties with transitions, and hyperactivity when overstimulated. Girl X was able to complete work, but the tasks took longer than for her peers. Parents also report a low frustration tolerance.

Current interventions are provided through Girl X’s public school system’s early childhood program, with adjuvant speech and occupational therapy. Private treatment is delivered by an occupational therapist.

Girl X’s strengths include an interest in music and the computer. She also demonstrates clear cognitive abilities. Significant to Girl X’s assessment are her family’s support and willingness to provide whatever she needs for improvement. Both parents are intimately involved in her care.

It is important to note the parents of both children were unclear about their child’s diagnoses and were uncertain as to their legal rights related to school services. They also were not totally informed about intervention or treatment options.

Worthy of mention is the school environment for each of these children; neither school placement was appropriate. Boy Y actually required a low-census, early childhood classroom setting with curriculum specific to meeting ASD needs, as well as supportive therapies. Girl X’s cognitive strengths, coupled with her regulatory and socialization deficits, called for a small, structured mainstream kindergarten classroom with the support of a one-to-one aide and habilitative therapies.

**Critical Pathway**

Critical pathway directions were similar for both children, with some distinct differences. Because of language deficits, Boy Y and Girl X both were candidates for continued speech and occupational therapies. Because neither child was receiving appropriate academic support, both would benefit from a curriculum change, structured environments, Floor Time therapy, and Social Story intervention. Once the Floor Time therapy has brought these children to a more advanced level of relating to others, then the addition of social skills work would assist in peer interactions. As the children turn 5 years of age, a thorough neuropsychological exam, including attentional and social cognition batteries, would create a more comprehensive picture of weaknesses and strengths. The more inclusive testing would yield a larger baseline from which specific goals and objectives could be launched. Based on reported sleep difficulties, sleep studies on both children might be indicated. Girl X also requires diagnostic follow-up with a neurologist based on her abnormal EEG.

**Case Management Plan**

Care plan development took place after patient assessment and problem formulation. Identified problems included inadequate school placements, speech/language delays, sensory/motor deficits, social skills impairments, regulation disorders, fragmented care, and uninformed parents. In the examples of Boy Y and Girl X, case management goals were remarkably similar (see Figures 6 and 7).

**Implementation, Monitoring, and Coordination**

Care plan implementation and oversight took similar paths for both families, but each child had unique needs. Coordination between parents and schools was probably the most delicate operation of all the case management proceedings. Until new school placements were obtained, patience, diplomacy, and clear communication were always at the forefront. Suitable school placements were a priority for both children. Each needed a structured, individualized curriculum. Boy Y required a program that could offer basic pre-academic instruction, assistance with socialization, adjuvant therapies, and intense language development. Girl X needed a cognitively challenging classroom without excess stimulation, as well as social skills intervention and habilitative therapies. Both children have language delays that necessitated diverse interventions: Boy Y has minimal ability to communicate, while Girl X has strong vocabulary skills with diminished reciprocity. Although receiving adequate amounts of private occupational and speech therapy, school habilitative therapy time will need enlarging. Neither child had regulatory problems addressed on their 2001/2002 Individual Education Plans (IEP); thus, these issues will need to be dealt with through the new school placements. Key to the success of this case management project was (and will continue to be) collaboration of all providers to the point of working as a team. Given the limited knowledge all the parents had regarding special needs, parent education related to diagnosis, treatment, and legal rights was a constant quest throughout the case management process. Through various perspectives, federal, state, and local mandates were explained by the writer and team members.
Outcomes

It is possible to classify outcomes in five main categories: clinical (associated with “level of care, diagnosis, length of treatment,” and so on), functional (related to a person’s lifestyle, self-care, ability to work), financial (costs of care and/or savings), process (useful for looking at clinical efficiency), and perceptual (measuring customer beliefs and judgments about care) (Noble & Klein, 2000, p. 200; Powell & Ignatavicious, 2001; O’Connor, Trinh, & Shewchuk, 2000). For the purposes of this paper, process outcomes will be evaluated.

The most difficult goal to achieve during this project was securing appropriate school placements for both subjects. Between summer personnel and bureaucratic red tape, it was difficult to pin down meetings and present a case. However, with many telephone calls from parents and myself, school meetings were arranged and placements were successfully finalized at the end of August 2002. Boy Y received placement in a low-census, one-teacher, two-assistants classroom designed to meet the needs of ASD children. The curriculum is an eclectic mix of structured strategies along with the delivery of the Picture Exchange Communication System (PECS), Social Stories, theraplay, speech therapy, occupational therapy, pre-academics, behavior management, gym, library, art, music, and ample amounts of home/school communication. Girl X was granted placement in a mainstream intermediate morning kindergarten program with a one-to-one aide, and a smaller special education kindergarten in the afternoon with supportive services such as speech therapy, occupational therapy, physical therapy, and social skills intervention.

Both sets of parents plan to continue with private speech and occupational therapy. Girl X’s parents will maintain private Floor Time work.

Parents’ knowledge base related to special education has increased substantially. All have a general understanding of their legal rights, how the special education system works, how to maximize and evaluate the special education their children receive, how to look at their child’s strengths and weaknesses, and how to best utilize case management support.

Most therapies and recommendations were realized within the timeframe predicted. Variances typically came from meeting delays. For instance, it was hoped to have school placements settled during the summer so that transition activities and IEP development could be planned in advance to facilitate a more organized transfer to the new settings. As it stands now, IEP changes and provider collaboration are in progress. It also seemed important for Boy Y to continue on with Floor Time therapy, but the parent decided to discontinue the intervention.

Looking back at the case management plans, they seem comprehensive and reflective of the best practices supported by the AAP. The writer believes this case management approach was effective in the triage of the young ASD child.

Impact on Nursing

Although various professionals (nurses, social workers, physicians, occupational therapists, and speech therapists) are qualified to assume the role of case manager, this project’s framework is most applicable to nursing. Particularly salient to nursing case management is the use of Orem’s theories to guide care.

Given that 1 child in 500 is diagnosed with ASD, parents’ initial concerns most likely will be communicated during routine visits to pediatric practices. Follow-through will most likely fall to nurses for completion. Having a framework such as the one established through this project will guide nurses and their colleague pediatricians in developing a comprehensive, best-practice, workable plan.

Summary

As written earlier, case management seeks to streamline complex care and can best be defined as a team approach. Autistic spectrum disordered children realize improved outcomes from early intervention and fare better with a multidisciplinary/interdisciplinary plan of care. Orem’s Nursing Theories navigate a course similar to case management concepts. For the nurse who relies on theory to enhance her professionalism, Orem’s constructs are congruent with case management and are workable for that purpose.

References


Catherine J. Oliver, MSN, RN, C, is an independent case manager in the Chicago area. Her clinical expertise is in pediatric neurobehavioral medicine. She is also a co-investigator in a research study comparing early intervention programs for children with autism. This article was written during graduate studies.