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Rehabilitation Medicine:
Serving People With Disabilities



Sargent Rehabilitation Center
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Leadership in Publication

Marilyn F. Serra, MS/MEd, CCC-SLP, President/CEO of Sargent Rehabilitation Center, was invited to be a contributing writer for an issue of *Medicine Health Rhode Island*, a publication of the Rhode Island Medical Society. Guest editor for the publication, Jon Mukand, MD, PhD, Physiatriest from Southern New England Rehabilitation Center, invited Marilyn to participate as featured writer for the April 2010 issue on rehabilitation medicine.

The article submitted is entitled, '*Pediatric Rehabilitation: Day Treatment for Children with Brain Injury and Neurodevelopmental Disorders*' and it highlights Sargent Center's unique delivery model, philosophy and outcomes of day treatment programming for children and adolescents.

Pediatric Rehabilitation Day Treatment For Children With Brain Injury and Neurodevelopmental Disorders

Marilyn F. Serra, MS/MEd, CCC/SLP, and Colleen McCarthy, BASW

The pediatric rehabilitation literature offers many studies on models of care for autistic children with medical, behavioral and psychiatric co-morbidities as well as adolescent brain injury victims with cognitive and physical impairments.^{1,2} This article describes a day treatment program at a comprehensive outpatient medical rehabilitation center specializing in neurological disorders. Sargent Rehabilitation Center has an adolescent traumatic brain injury (TBI) unit and a private day school for children with special needs who are diagnosed primarily with autism spectrum disorder (ASD).

Legislative federal and state initiatives in maternal health, child care, and education have defined the need to develop community systems and delivery service

models for children with special needs, which includes TBI and ASD.^{3,4,5,6,7} Developing a continuum of care to address the severe problems of these children has challenged medical, psychosocial, rehabilitation, and education professionals. Likewise, selecting appropriate programs of service has challenged families, physicians, public/private referrers, and purchasers of service.

More than one million children in the US suffer closed head injuries annually, with acute and persistent impairments.⁸ With an incidence of ASD of 1 per 150 births, the prevalence of childhood autism in the US could reach 4 million in the next decade.⁹ Although school systems have traditionally not focused on rehabilitation, the continuum

of public and private programs should provide levels of care based on the severity of the condition.

PHILOSOPHY, FEATURES, AND THE PYRAMID OF TRANSITIONAL CARE

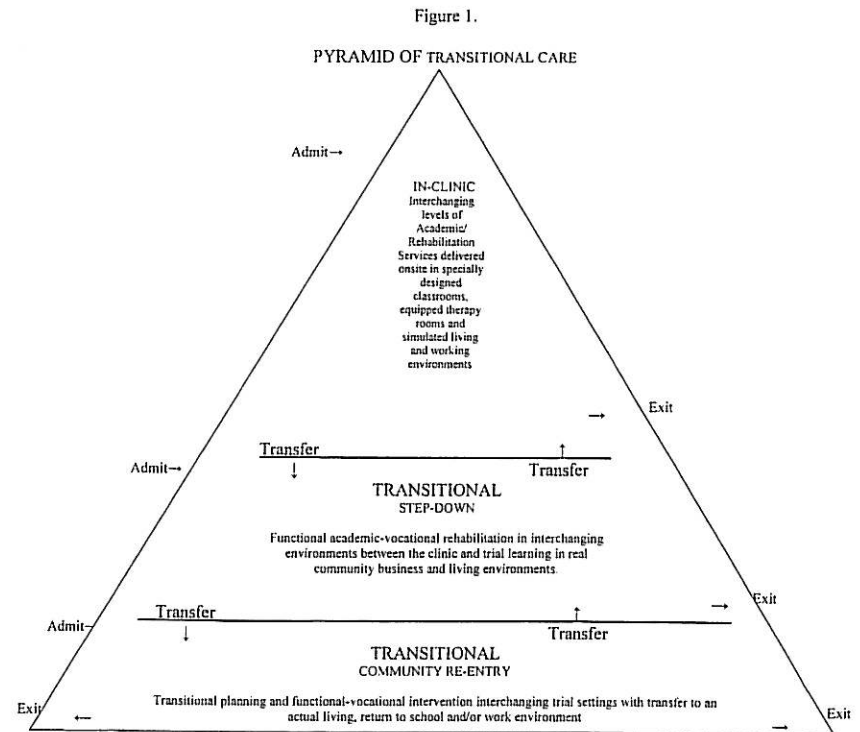
Sargent Rehabilitation Center's programs for children and young adults are offered six hours daily, 230 days a year. Both the TBI and ASD programs are located in specially equipped rehabilitation settings, with vocational training areas. Clients are treated as "whole persons" who live with their families in the community. The impact of a clinical problem will often arise or change with developmental stages. Care needs to be readily accessible, coordinated, and continuously provided by an experienced interdisciplinary team.

A customized plan of care should address immediate and emerging clinical needs as well as the transition to the community. Finally, the model should be dynamic.

Young adults (13 to 21 years) with TBI are referred from acute care hospitals or rehabilitation units. Private insurance coverage is later transferred to school systems. Eligibility criteria include function at or above Level VI in the Rancho Los Amigos scale (confused, but generally appropriate) and care managed by a physician. There should be no severe unstable depression, psychosis or substance abuse. The activities of daily living such as eating and toileting should be dependent to minimal assist. The client should be capable of developing skills for functional communication and have a participating family member.

Children (3 to 21 years) with ASD often have co-morbidities, including dysphagia, sleep disorders, acquired brain disorders, and psychiatric conditions such as obsessive-compulsive disorder, depression, and anxiety. Local education agencies (school districts) are usually both referrers and purchasers. Referrals are also made by the family physician, specialty physician, and hospital-based or community centers. A physician must be in charge of the child's care and the child must have an IQ of two standard deviations or more below the mean. The child should be capable of developing skills for communication, self-care, mobility, and social functions. In addition, the child should be appropriate for an instructional environment of multi-disciplinary strategies and have a family member who actively participates in the rehabilitation program.

The core interdisciplinary teams for both the brain injury unit and day school include a pediatrician who is a bridge between the family and/or specialty care physicians and the interdisciplinary team. A nurse monitors ongoing medical conditions. Other team members include a physical therapist, occupational therapist, speech/language pathologist, social worker, behavior analyst, and special educator for daily, coordinated therapies. When students are age 14, transitional and vocational specialists join the team. Neuropsychology and audiology are available to assess impairments and guide treatments. Service teams for these complex clients should have clinical experience and expertise¹⁰ with an analytic



diagnostic-remedial process, individualized treatment, evidence-based interventions, and counseling.

Unique features of the treatment model are the transfer of care services between clinical and functional levels. Program evaluation measures the effectiveness of the frequency, duration and intensity of services. Evaluating planned versus actual outcomes measures the efficiency and appropriateness of the care model.

The Pyramid of Transitional Care is the philosophical model for the provision of clinical intervention and functional training. Stability of function is achieved by regularly adjusting the type and intensity of interventions. The Pyramid is dynamic, allowing for age, clinical severity, co-morbidities and families. It is designed for use as a continuity of care system, but each level of care can also be an admission or exit point. The levels of care are: In-Clinic, Transitional Step-Down, and Transitional Community Re-Entry. (Figure 1).

Exit decisions are based on criteria for continued care and the expectation of functional gains; they are subject to external economic and family constraints. Transfer decisions are based on achievement measured against predicted performance, through a process that includes families, referrers, and reimbursers of services.

The family, attending physicians, referring source, and reimbursement agency

are critical to the provision of each level of care. Furthermore, community mental health agencies and businesses are important at the Step Down and Re-Entry levels to ensure continuity of functioning.

Since its inception, 90 young adults and 1,040 children have completed the pyramid system. Each client is assessed with the Sargent Rehabilitation Center Functional Evaluation Scale, with data collection at admission, during the program, at discharge, and at six months and one year after discharge. The evaluation scale is similar to the FIM (Functional Independence Measure) and FAM (Functional Assessment Measure) for self-care, mobility, communication, cognition, behavior, health and safety, transportation, vocational potential, and leisure. Outcome information on functional measures is analyzed from grids that have baseline, predicted, and actual outcomes from admission through discharge.

The first test of functional achievement is at the In-Clinic level. A controlled environment with optimal intensity of services is intended to achieve and maintain maximum independence in the learning or re-learning of cognitive, communication, self-care, mobility, and socialization skills. The Step-Down level assesses the stability of functional achievement in environments that simulate the real world as well as trials in the actual

community. Training can be returned to In-Clinic services to improve stability with ADLs and education. The Community Entry level moves functional achievement from simulated and actual trials to performance in the actual community with decreasing interventions and assistance. Final measures establish the application of maximum levels of independence achieved to returning to district schools, living at home and preparing for employment. The following case demonstrates some of these principles.

Susan was a 17-year-old high school student who had wanted to be a teacher when she was an unrestrained passenger in a rollover vehicle accident. She was unresponsive, required intubation, and had a Glasgow Coma scale of 4. Radiologic studies revealed diffuse axonal injury and a subarachnoid hemorrhage. Her complicated month-long hospital stay included G-tube placement.

She received intensive rehabilitation for 4 weeks and was referred to the Sargent Rehabilitation Center Adolescent Brain Injury Unit. Susan was admitted to the Program for 5 days/week. At admission she presented with moderate-severe deficits with memory, cognitive processing speed, complex attention and executive function.

She also had moderate left neglect, impaired left upper extremity function, and decreased range of motion and strength in left lower extremity. Her speech/cognitive therapy, occupational therapy, physical therapy and psychological counseling were conducted in individual and group sessions with a focus on cognitive and executive function. After one month, Susan demonstrated carryover of some memory strategies and her self-monitoring and self-cueing skills (i.e. double-checking her work) had improved. As a result, educational services were initiated, including 4th-5th grade math, reading, science and social studies. Through the interdisciplinary and collaborative model of education and rehabilitation, at the end of 5 months, Susan's academic testing indicated she had gained 2 ½ years. Susan continued to make progress. Ten months into the program she read at the 8th grade level. She continued to require therapy for memory and executive function in order to stabilize these areas. When Susan was 18 years old, she was transferred to the transitional step down level of care,

with vocational services. Given her goal to be a teacher, she worked with her teachers and therapists on activities as such a basic lesson plan and resume writing. The vocational specialist worked on interviewing skills while the speech therapist worked on pragmatics. Ultimately Susan used her lesson plan to read to a Sargent Center day school pre-school child and then to the entire classroom. After this success, her program was transitioned to community re-entry.

At this level of care, Susan went to a community day care to work with young children.

This included helping them with clothing, snacks, lunch, and reading to them. Back in the clinic, 1 day/week she continued to work on activities such as job applications. Less than two years after the accident, Susan was hired as a teacher's aide in a local school department and has not missed a day of work.

In conclusion, the pyramid of transitional care provides a rehabilitation model for neuro-developmental disorders and traumatic brain injury. Clients are transferred through a pyramid of care levels from intensive clinical services to functional ADL training in order to return to community living. A key element to this model is establishing stability of function by regularly adjusting the type and intensity of interventions. Level of care decisions are based on achievement measured against predicted performance. Each client is evaluated on a scale of functional achievement that can ultimately be applied to productive living in the community. The model itself continues to be a work in progress.

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Disclosure of Financial Interests

The authors and spouses and significant others have no financial interests to disclose.

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