

# Greater than the Sum of its Parts: An Integrated, Patient and Family-Centered Approach for Adolescents with Med/Psych Presentations

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## INTRODUCTION

The importance of comprehensive, inter-professional care for adults, adolescents and children has been widely recognized as the ideal way to deliver care. Integrating medical and behavioral health practices leads to lower health care costs, decreased readmission rates and improved outcomes including greater functioning and quality of life. Data support the concept that mental and physical health disorders are risk factors for each other; the presence of one can complicate the treatment and outcomes of the other.<sup>1</sup> This connection is supported by emerging data that identifies shared physiologic pathways connecting mind and body.<sup>2</sup>

In addition, there is strong evidence to support the efficacy of family-based treatments for youth with chronic medical illness.<sup>3</sup> At the foundation of patient and family-centered care is a partnership amongst patient, family and providers across levels of care.<sup>4,5</sup> The family and patient are considered the experts regarding their experiences; decisions are made from a perspective that the existing family relationships combined with the family's understanding of the illness constitute powerful forces in treatment.

When caring for adolescents, prioritizing family in this partnership may seem counterintuitive given the developmental focus on emerging autonomy. However, a variety of studies have identified the importance of maintaining an intensive level of collaborative family involvement around refractory illness presentations across adolescence and young adulthood. These studies suggest that parents remain important mediators of illness experience and level of impairment, and their involvement fosters self-efficacy and better psychological health.<sup>6,7,8</sup>

For patients with disabling illness and functional impairment refractory to more standard interventions, bringing together these two important approaches into an integrated, patient and family-centered model is an important step aimed at maximizing treatment success. Despite clear advantages of this truly integrated paradigm, challenges exist in translating these concepts within the confines of current

practice as it can be difficult to bring together the resources, expertise and perspectives needed for effective implementation. The Hasbro Children's Partial Hospital Program (HCPHP) and the Hasbro Inpatient Medical-Psychiatric Unit are two unique, nationally recognized programs that have operationalized this integrated, patient and family-centered intervention, that transcending traditional practice models. In addition, the model of integrated care extends to several outpatient areas including specialty clinics, primary care, and home-based services.

These hospital-based programs provide an inter-professional, patient and family-centered, collaborative approach to pediatric and adolescent care in two levels of treatment. HCPHP opened in 1998 as a 5-day/week program serving up to 24 patients, ages 6–18 years old, with an average length of stay of 4 weeks. The Hasbro Inpatient Med-Psych Unit opened in 2012 to accommodate patients requiring a higher level of care due to medical and psychiatric safety concerns. The inpatient unit is a secure, locked unit with a length of stay that ranges from days to weeks. This treatment continuum remains the only combined pediatric medical and psychiatric treatment in the region and beyond for patients with a wide range of illness presentations.

Patients enter either setting with a broad range of presentations including gastrointestinal illness, eating disorders, diabetes, asthma, seizures, and chronic pain syndromes. Patients are referred from inpatient or outpatient treatment when they require more intensive support due to impaired functioning with limited improvement after traditional outpatient interventions. Many patients and families utilize both levels of care throughout their course of treatment. Both programs provide inter-professional, developmentally appropriate treatment in a safe, nurturing environment with the expectation that patients and their families actively engage in treatment. Inter-professional care includes nurses, milieu therapy, pediatricians, psychiatrists, psychologists, social work, nutrition, PT/OT, speech, educators, subspecialty consultation and comprehensive diagnostic testing when needed.

Across levels of care, a strong partnership is established with patients, families and identified outpatient treatment providers. Individualized treatment plans incorporate a balance of medical and psychological support with the goal of a successful transition to optimal functioning at home and school. From the onset of treatment, there is a strong focus

on joining with families around their experiences, with a primary goal of “meeting them where they are” which fosters trust in the partnership. As the trust builds, the team often experiences a shift in how the family understands the illness presentation.

Family involvement can include participation in nursing and nutrition education sessions, inter-professional team meetings, family therapy and multi-family groups. Effective treatment prioritizes the identification of the family members’ individual and collective need for support including medical and psychiatric treatment. Throughout, the relationships that patients and families have with their outpatient providers are valued and utilized. Collaboration with these providers is essential, not only to maximize treatment efficacy but also for discharge planning and continuity of care.

This combined paradigm allows for a comprehensive understanding of illness presentation and leads to utilization of appropriate treatments targeted at medical, psychological and psychosocial factors contributing to illness. For example, the influence that a family’s belief of illness origin - primarily medical, psychological or a combination - is an important consideration when interpreting a child’s symptoms, illness and response to treatment.<sup>1</sup> Within this expanded model, the integrated team, including the patient and family, is then able to consider beliefs about the origin of illness and emotional responses to the illness in conjunction with the reported symptoms and objective signs. Moreover, this evidence-based practice supports improved outcomes for patients in the areas of quality, safety and patient/family satisfaction.<sup>9</sup>

At discharge, patients often step-down to outpatient family therapy embedded into their medical home or to home-based treatment with a specialized med-psych team trained in integrated, patient and family-centered care. For patients unable to access outpatient care in one of these settings, discharge planning includes identifying services that best approximate these tenets. Throughout the course of treatment, effective, cohesive partnerships amongst the health care team and families remain the foundation for ongoing therapeutic change.

A case example highlighting the flow of treatment across different levels of care follows:

*JC is a 13-year-old boy, diagnosed with Crohn’s Disease (CD) at age seven, with two recent medical admissions for “flares” of his pain attributed to his CD. He presented to his gastroenterologist with suicidal ideation including a plan to overdose on his medications in the context of ongoing pain complaints, sleep difficulties and poor functioning. Of note, past treatment course included multiple medication trials including steroids contributing to a 50-lb. weight gain over the previous 6 months. JC was angry about the treatment’s side effects, fearful about bowel “accidents” at school, and exhibited explosive behavior at home. JC’s mother described him as oppositional and “probably depressed” and wondered whether*

*he was taking his medications as prescribed. When JC was four years old, his father died from complications of surgery for his own Crohn’s disease. JC’s father had also been diagnosed in childhood and he had experienced significant disability throughout his life due to complications of his illness.*

*JC’s mother had limited financial and social resources and experienced persistent grief and guilt around the loss of her husband as well as JC’s diagnosis. She had not engaged in her own mental health treatment around these losses and stressors, in part because she felt her full attention needed to focus on caring for her family. Her overwhelming guilt left her powerless to set limits with JC and her three younger children. After her husband’s difficult course and his premature death, she found it hard to trust the medical establishment and its prescribed treatments.*

*Given the safety concerns, JC’s gastroenterologist admitted him to the Hasbro Med/Psych Inpatient Unit with the goals of establishing safety and clarifying his medical presentation. While inpatient, JC had close medical monitoring with daily assessment of pain, functioning and bowel patterns. Medications were administered by nursing with ongoing attention to side effects. Safety assessment, medication evaluation, nutrition monitoring with balanced and structured meals were important parts of his plan. Individual and family sessions focused on supporting JC in managing his illness. Additionally, group psychotherapy sessions offered JC an opportunity to share his challenges and explore ways to manage them. With the structure and coaching provided by milieu staff in conjunction with the support and understanding of his peers, JC identified positive coping strategies and was successful in implementing them during his inpatient admission. After 7 days, JC was able to commit to safety, a home safety plan was formulated, and he transitioned to HCPHP*

*In HCPHP, there was ongoing medical monitoring with transition of medication administration to home with parental support. A physical therapy consult was obtained for strengthening and reconditioning. Family work focused on expanding the family network, with extended family and mother’s best friend identified as additional supports. Mother attended family support groups. She was referred to an adult partial hospital program followed by outpatient individual therapy and medication management. Program staff collaborated with JC’s home school through inter-professional phone conferences and a school meeting that included the program teacher, therapist, school guidance counselor and nurse which resulted in the development of a comprehensive 504 plan outlining medical and emotional supports recommended for school. At discharge, JC transitioned back to the Hasbro GI team, including a psychologist embedded into the GI clinic. In addition, a referral was made to the Gateway Med/Psych team for home-based services, and a bridge meeting was conducted prior to discharge.*

At each level of care, JC made progress in self-monitoring, emotional expression, and acceptance of both medical treatment and family support. This movement occurred in parallel to his mother's increasing confidence in limit setting and being open to help from others. As she understood the power of her own guilt, JC's mother could more effectively set appropriate limits around her son's lack of treatment adherence and poor school attendance. In addition, the feedback inter-professional treatment team provided around the range of factors impacting JC's pain – Crohn's Disease flair, medication side effects, emotional distress – deepened her understanding and helped her maintain these limits. This awareness guided important treatment shifts including a reduction in the number of medications prescribed while improving intervention efficacy. Establishing an outpatient plan that mirrored the integrated, patient and family-centered approach was imperative. While achieving safety and supporting improved functioning in the hospital setting are important first steps, transitioning these sustainable gains to home is most critical. This care continuum facilitates ongoing progress in ascertaining and maintaining meaningful therapeutic change within the home environment.

In summary, and as illustrated by the case study, a continuum of integrated medical and psychiatric treatment provides a unique, highly effective approach to treating children and adolescents with co-existing psychiatric and medical conditions. Utilizing the most effective, evidence-based principles of integrated care and family-centered approaches, these programs offer the kind of complex, individualized, treatment that this population needs.<sup>10</sup> In an effort to replicate this care continuum, teams from around the country have visited Hasbro to gain a broader understanding of the treatment philosophy and logistical considerations required. While more difficult, it is also possible to adopt an integrated, patient and family-centered approach in more traditional settings. In doing so, key concepts to consider include understanding family relationships and illness beliefs including their impact on illness experience, appreciating patients and families as the experts regarding their illness experience, supporting family-based decision making, recognizing broader contexts, collaborating with all members of the treatment team and valuing the patient and family as essential partners.

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