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SPECIAL SECTION  
ADOLESCENT HEALTH – PART II

GUEST EDITOR: PATRICIA FLANAGAN, MD



P. Flanagan, MD

**16 Perspectives and Approaches to the Dynamic and Developmental Issues in Adolescent Health Care: Addressing the Needs of Specific Populations of Youth**

PATRICIA FLANAGAN, MD  
 GUEST EDITOR



A. Donaldson, MD

**17 Advances in Adolescent and Young Adult Eating Disorder Care in Rhode Island**

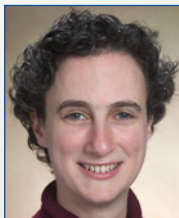
ABIGAIL DONALDSON, MD  
 ALLISON HALL, LICSW  
 CHRISTINA TORTOLANI, PhD



D. DerMarderosian, MD

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

DIANE DERMARDEROSIAN, MD  
 HEATHER A. CHAPMAN, MD  
 MARGARET K. KOZEL, MD  
 FRANCINE R. PINGITORE, PhD, PCNS-BC  
 MICHELLE L. RICKERBY, MD



E. Lowenhaupt, MD

**24 Health Care Needs of Incarcerated Adolescents**

KRISTYN GERGELIS, MD  
 JONATHAN KOLE, MD  
 ELIZABETH A. LOWENHAUPT, MD



C. Barron, MD

**27 Sex Trafficking Assessment and Resources (STAR) for Pediatric Attendings in Rhode Island**

CHRISTINE E. BARRON, MD  
 JESSICA L. MOORE, BA  
 GRAYSON BAIRD, PhD  
 AMY P. GOLDBERG, MD



A. Janicka, MD

**31 Transgender and Gender Nonconforming Youth: Psychosocial and Medical Considerations**

AGNIESZKA JANICKA, MD  
 MICHELLE FORCIER, MD



M. Forcier, MD



**On the cover**

Brochure: "My Life, My Health," a series of three checklists available at the Rhode Island Dept. of Health website. [http://health.ri.gov/programs/detail.php?pgm\\_id=89](http://health.ri.gov/programs/detail.php?pgm_id=89)

# Perspectives and Approaches to the Dynamic and Developmental Issues in Adolescent Health Care: Addressing the Needs of Specific Populations of Youth

PATRICIA FLANAGAN, MD  
GUEST EDITOR

In this month's Rhode Island Medical Journal we continue the focus on Adolescent Health first presented in the August issue, which can be accessed here:

<http://www.rimed.org/rimedicaljournal/2016/08/2016-08-15-adolescent-health-complete.pdf>

It is important to note that health behaviors beginning in adolescence continue into adulthood, making this a unique time in a life-course for interventions that will have a lasting impact.

Providing health care for teens requires an understanding of adolescent psycho-social, psycho-sexual,

and cognitive development. Brain maturation from age 10 to age 24 is dramatic, is variable in timing and tempo, and is not always in synchrony with the dynamic physical maturation that happens throughout adolescence. The capacity of a 12-year-old to communicate his or her concerns and symptoms, to understand the ramifications of actions or behaviors, and to fully engage in healthcare decision making certainly can vary widely but is also drastically different from a 16-year-old or a 21-year-old. Helping young people navigate adolescence with the tools, knowledge and motivation to stay healthy requires building a developmental scaffolding. Partnering with parents, schools, and communities allows teens to experiment, to grow, to take risks and make good choices.



This month, we look at specific conditions and the health needs of specific populations of youth. **DR. ABIGAIL DONALDSON** and her team present an update on the care of individuals with eating disorders. **DR. DIANE DERMARDER-OSIAN** and colleagues write about an integrated approach to psychiatric care for children and youth with medical conditions. She describes a unique, team-based integrated care model provided both in an in-patient setting and in a partial hospital setting. **DRS. KRISTYN GERGELIS, JONATHAN KOLE** and **ELIZABETH LOWENHAUPT** write about the healthcare needs of incarcerated youth and **DRS. AGNIESZKA JANICKA** and **MICHELLE FORCIER** discuss transgender and gender non-conforming youth. **DR. CHRISTINE BARRON** and colleagues present their research on RI pediatricians and their training, screening, and knowledge about domestic sex trafficking of minors.

Quality health care that recognizes the dynamic developmental nature of adolescence can help youth stay safe and make good behavioral choices. It can be attuned to some of the potential pitfalls and roadblocks to healthy adolescence as well as motivations for positive health-affirming decisions. It can be a great opportunity to cultivate a strong foundation for adult health.

## Guest Editor

Patricia Flanagan, MD, is Professor and Vice Chair of Pediatrics, The Warren Alpert Medical School of Brown University, Providence, RI.

# Advances in Adolescent and Young Adult Eating Disorder Care in Rhode Island

ABIGAIL DONALDSON, MD; ALLISON HALL, LICSW; CHRISTINA TORTOLANI, PHD

**KEYWORDS:** Eating disorder, nutritional deficiency, treatment for anorexia, treatment for bulimia

## INTRODUCTION

Medical providers in primary care practice are at the forefront of diagnosis and management of adolescents and young adults with eating disorders (ED). As a result, they play a critical role in establishing an interdisciplinary treatment plan that will help stabilize patients and move them towards recovery. While ED are prevalent among adolescents and young adults in the United States<sup>1</sup> and are among the most common chronic illnesses of adolescence, they can present a diagnostic challenge in the primary care setting. Diagnostic criteria for ED were recently modified in the Diagnostic and Statistical Manual, 5th Edition,<sup>2</sup> allowing clinicians to more accurately identify a variety of ED including anorexia nervosa, bulimia nervosa, binge eating disorder, avoidant-restrictive food intake disorder, and feeding or eating disorder not elsewhere classified (Table 1). Clinicians are increasingly recognizing ED in previously overlooked groups, including males,<sup>3</sup> transgender individuals,<sup>4,5</sup> and overweight/obese adolescents.<sup>6</sup>

This article briefly describes strategies to identify ED in the primary care setting. We include treatment options available for adolescents and young adults with ED in Rhode Island, and summarize the inpatient treatment approach at Hasbro Children’s Hospital for ED patients in medical crisis. We provide an overview of Family Based Treatment, a new evidence-based treatment approach for adolescents and young adults with ED.<sup>7</sup>

### Identification of Eating Disorders in the primary care setting

Given the high prevalence of ED in the second and third decades of life, pediatric and young adult providers should stay alert to signs and symptoms that might indicate an ED (Table 2). Eating disorders can be difficult to diagnose for many reasons, including the secretive nature of the illness and wide variability

Table 1. DSM V diagnostic criteria for Eating Disorders

<b>Anorexia Nervosa</b>	Restriction of food intake leading to weight loss, or maintenance of weight < 85% of ideal body weight (BMI<17.5) Fear of fatness or weight gain Distorted body image <i>Restricting type:</i> no binge behavior <i>Binge/Purge type:</i> binge purge behavior in setting of low weight or weight loss
<b>Bulimia Nervosa</b>	Binge eating (at least once per week for at least 3 months) • Discrete period of time (2h) • Definitely more food consumed than appropriate (>2000 kcal) Sense of lack of control with eating behavior Purging/other compensatory behaviors to avoid weight gain/promote weight loss
<b>Binge Eating Disorder</b>	Recurring episodes of binge eating Must meet at least three of the following: • Eating more quickly than “normal” • Eating until so full that it is uncomfortable • Eating large amounts when not hungry • Eating alone because of embarrassment about volume • Feeling negative emotions about binge (disgust, depression, guilt) Distressed emotions around eating Binges occur at least once per week for at least 3 months No recurrent behaviors to avoid weight gain
<b>Avoidant/ Restrictive Food Intake Disorder</b>	An eating or feeding disturbance as manifested by persistent failure to meet appropriate nutritional and/or energy needs associated with at least one of the following: • Significant weight loss, or failure to gain developmentally appropriate weight • Significant nutritional deficiency • Dependence on enteral feeding or oral nutritional supplements • Marked interference with psychosocial functioning. The eating disturbance does not occur exclusively during the course of anorexia nervosa or bulimia nervosa, and there is no associated body image disturbance The disturbance is not better explained by • lack of available food • associated culturally sanctioned practice • attributable to/better explained by concurrent medical or psychiatric condition
<b>Feeding or Eating Disorders Not Elsewhere Classified</b>	Sub-threshold Anorexia Nervosa/Bulimia Nervosa “Atypical” eating disorders

American Psychiatric Association DSM-5

**Table 2.** Signs/symptoms that could suggest ED

Crossing growth curves
Functional GI disorders
Presyncope or syncope
Unexplained hypokalemia or other electrolyte disturbance
BMI ≤ 17.5 kg/m <sup>2</sup>
Abrupt change in dietary or exercise habits
Secretive behavior around food
Hyperglycemia in a type I diabetic easily controlled in the hospital

**Table 3.** SCOFF questionnaire for eating disorder screening

Do you make yourself Sick (vomit) because you feel uncomfortably full?
Do you worry you have lost Control over how much you eat?
Have you lost more than One stone (14lbs) over the last 3 months?
Do you believe yourself to be Fat when others say you are thin?
Would you say that Food dominates your life?
2 or more positive responses suggest further exploration into ED is indicated

Morgan et al., 1999

in associated behaviors. For instance, while weight loss in an overweight or obese patient may be medically appropriate, literature suggests that overweight/obese individuals are at particularly high risk for developing an ED.<sup>6</sup> In a healthcare environment strongly focused on helping patients lose weight and avoid obesity, clinicians can find it hard to determine which patients are engaged in healthy weight-loss behaviors and which are adopting life-threatening strategies. In addition to using clinical judgment, providers can apply a simple, five-question validated screening tool to determine whether further evaluation is warranted (Table 3).<sup>8</sup> When in doubt, close monitoring of patients over time can help establish a trajectory of weight change when an ED is suspected. More frequent follow-up can also help build trust between patient and provider, encouraging honesty in disclosure of unhealthy attitudes and behaviors. Connecting the family to a dietician and a family counselor familiar with eating disorders may be sufficient to treat ED.

**Eating disorder treatment options in Rhode Island**

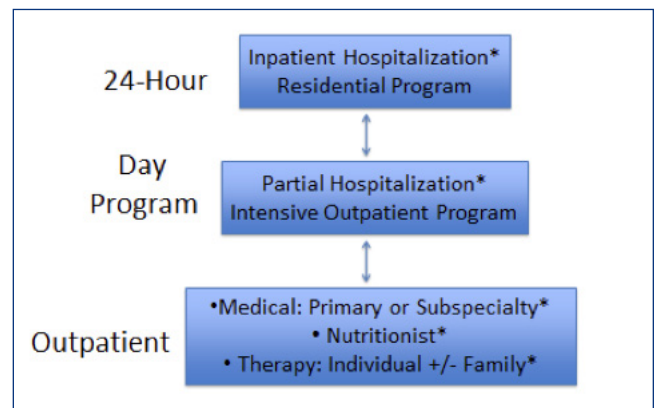
Many clinicians in Rhode Island effectively diagnose and treat adolescents and young adults with ED within the primary care setting. For patients requiring subspecialty support or access to a higher level of care, there are multiple levels of care available in our state. The Hasbro Eating Disorders Program (HEDP) offers multidisciplinary outpatient and inpatient medical and nutritional services, in addition to care coordination. For patients who have more complicated psychiatric pathology related to their ED or a co-morbid condition, the Hasbro Behavioral Health Inpatient Unit and Partial Hospital Program offer more intensive psychiatric management along with medical and nutritional support for medically stable

patients with ED (Figure 1). As patients move between these levels of care, close coordination and communication between teams help facilitate seamless transitions across the continuum. While these services meet the needs of many individuals struggling with ED, it is important to note that in Rhode Island, we do not have access to local, long-term residential or intensive outpatient ED treatment settings. However, there are multiple programs in neighboring states who serve this need.

**Inpatient Hospitalization**

The Society for Adolescent Health and Medicine revised their guideline statement on hospitalization of eating disordered patients in 2015.<sup>7</sup> Despite having clear admission criteria articulated in this guideline (Figure 2), treatment

**Figure 1.** Overview of different levels of ED care



\*Indicates treatment currently available in Rhode Island

**Figure 2.** Society for Adolescent Health and Medicine hospital admission criteria for ED

Electrolyte disturbance
Cardiac dysrhythmia
Acute medical complications (syncope, seizures, pancreatitis, etc)
Severe malnutrition (<75% goal weight)
Other physiologic instability • HR <50bpm awake, 45bpm asleep • BP < 80/50 mmHg • Temp < 97 F • Orthostatic changes in pulse (>20 bpm) or BP (>10 mmHg)
Food refusal
Dehydration
Arrested growth/development
Uncontrolled binging/purging
Failure of outpatient treatment
Co-morbid conditions that complicate outpatient care (depression, OCD, family dysfunction, etc)
Acute psychiatric emergency (self-harm, suicidality)

Society for Adolescent Health and Medicine, 2015

of ED patients in the medical inpatient setting without an interdisciplinary team which includes eating disorder trained nursing staff can be a challenge. In Rhode Island and the surrounding area, adolescent and young adult patients can access inpatient medical services at Hasbro Children’s Hospital (HCH).

The HEDP admits over 100 ED patients to the hospital each year for medical stabilization of complications related to ED. The average inpatient length of stay is 7 days, during which time patients receive daily care from the medical, psychiatry, social work, nutrition, and nursing teams. Patients can also access Child Life and academic services during their hospitalization.

The primary goal during an admission for a medically unstable ED patient is to nourish, closely monitor, and ultimately stabilize the individual for discharge to an alternative level of care (outpatient, partial hospital, residential, or psychiatric inpatient). In addition to the medical complications that may arise during the re-feeding process, the experience of re-feeding often causes significant discomfort. Fluid and electrolytes shift encountered in feeding malnourished youth can be life-threatening. Close monitoring of electrolytes and fluids, and slow judicious refeeding are essential for safety. Chronically malnourished patients often have bradycardia and orthostatic instability which requires close monitoring. For example, starvation leads to decreased intestinal motility, and as nutrition is re-introduced and for days or weeks thereafter, individuals may feel physical fullness, nausea, bloating, and constipation. The re-introduction of nutrition can also prove emotionally challenging, leading to psychological distress as well as refusal to participate in treatment. Family members who witness a loved one in distress are often challenged in supporting a treatment plan that can be difficult and protracted.

The HEDP employs a multidisciplinary approach to care including psychiatric evaluation and daily treatment; extensive nutritional assessment and ongoing education with patients and families; psycho education regarding the function of the eating disorder and available treatments; and support regarding adjustment to illness. Both patients and families are integrally involved in all aspects of care during the hospitalization; this allows them to develop an understanding of the ED disease and to receive the best possible treatment options for discharge. For many patients and families, hospitalization is the first step on their road to recovery from the ED. The knowledge patients and families gain during their hospitalization has the potential to significantly impact treatment compliance following discharge.

**Including Families in Eating Disorder Care**

In their 2015 review of ED practice guidelines, the Society for Adolescent Health and Medicine clearly recommends hospitalization as an acute, short-term period of stabilization, acknowledging that an individual struggling with ED must rely on supports available to them in their home

**Table 4.** Phases of Family Based Treatment

Treatment Phases	Sessions	Task/ Focus of Treatment
Phase 1	Sessions 1–10	Parents in charge of weight restoration
Phase 2	Sessions 11–16	Parents gradually give control over eating back to adolescent
Phase 3	Sessions 17–20	Focus on adolescent development issues

*Lock & LeGrange, 2013*

**Table 5.** Tenets of Family Based Treatment

An agnostic view about the cause of anorexia nervosa
Initial symptom focus (pragmatic)
Non-authoritarian consultative stance as therapist
An ability to separate disorder of anorexia nervosa from the adolescent (externalization)
An emphasis on parental symptom management (empowerment)

*Lock & LeGrange, 2013*

environment to ultimately succeed in recovery.<sup>7</sup> For most adolescents and young adults, this support system is comprised primarily of parents and other close family members.

Family-Based Treatment (FBT) is a promising, evidence-based therapy for the treatment of ED in adolescents. FBT has been found to be effective among children and adolescents who have been ill for less than three years, are under age eighteen, and are medically stable for outpatient treatment.<sup>9</sup> Through its empowering of parents to manage their child’s ED, and its firm, consistent, yet compassionate focus on re-feeding, FBT signifies a paradigm shift in the treatment of ED. FBT informs, prepares and equips parents to become the best resource and strongest tool in their child’s treatment.

Encompassing three phases over six to twelve months (Table 4), FBT helps family members mobilize to take charge of their child’s eating during the initial phases; afterward, the adolescent is gradually given back control. Throughout the treatment, care givers support parents to “fight the eating disorder” with a “food as medicine” approach. By getting the adolescent “back on track” and returned to normal development, care givers and parents treat the ED and prevent relapses. Although FBT was developed for an outpatient setting, its principles (Table 5) have begun to be adapted for use across levels of care, including inpatient, partial hospitalization and intensive outpatient treatment.<sup>10,11,12</sup>

**CONCLUSIONS**

When establishing a treatment plan, patients and families with ED often embark on a long treatment/recovery process marked by both setbacks and success. As with any pediatric chronic illness, treatment ultimately aims to help individuals recover and transition to a healthy adulthood. In Rhode Island, services exist that support many levels of ED care and acuity.

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

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**KEYWORDS:** integrated care, functional impairment, family therapy, somatic symptoms, inter-professional team, med/psych day treatment

## 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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# Health Care Needs of Incarcerated Adolescents

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**KEYWORDS:** juvenile justice, adolescent medicine, incarceration, public health, child and adolescent psychiatry

## INTRODUCTION

Adolescents involved in the juvenile justice system represent a unique pediatric patient population, often hidden from public view. For a multitude of reasons including socioeconomic disparities and poor access to health care, these children have a disproportionate number of physical and mental health needs.<sup>1,2</sup> Many of these conditions are first identified upon entering the juvenile justice system, addressed while youth are incarcerated, and require continued care long after release. Pediatricians and other community providers may encounter these patients in a variety of settings, thus familiarity with their medical needs as well as the basic legal steps faced by the adolescents and their families is essential.

## DEMOGRAPHICS

The United States has the highest rate of juvenile incarceration in the industrialized world, with 2 million adolescents arrested and approximately 60,000 detained each year.<sup>1,3</sup> In Rhode Island in 2013, there were 498 youths – 85% male and 15% female – in the custody of the Rhode Island Training School (RITS), with an average daily population of 101 residents.<sup>4</sup> Minorities are disproportionately represented in the juvenile justice system, both nationally and within Rhode Island. In 2014, 20% of adjudicated youth at the RITS were black and 34% Hispanic, while these ethnicities represent only 6% and 21% respectively of the total child population in Rhode Island.<sup>4</sup> Family and community poverty are also risk factors for juvenile justice involvement; in 2013, over half of the youth at the Training School were from the areas of the state where 64% of Rhode Island's impoverished children live.<sup>4</sup>

## JUVENILE JUSTICE PROCESS

To become involved in the juvenile justice system, a minor first comes into contact with the police, either by arrest or by referral from parents, school or victim. Once arrested, the juvenile is either detained in a secure facility awaiting a court appearance or released to the community, if deemed

both reliable to return for a court date and low risk to society. Once in court, a judgment is made to sustain the charge, release the individual, or divert him/her outside of the court system to court-mandated community service or counseling. Factors such as age, victim impact, severity of offense, and prior police contact determine whether a case is appropriate for diversion.

Once charged with a crime, a juvenile participates in three hearings. The first is a detention hearing to determine whether the youth will remain detained or be released to the community. The second is an adjudication hearing, where a judge determines whether or not the juvenile is guilty of the alleged offense. Juveniles do not have jury trials within the juvenile system, these occur only if their cases are waived into adult court. If found guilty, a dispositional hearing is held to determine how the youth will serve his or her sentence: in a correctional facility, in a residential facility, or at home with electronic monitoring or probation. This process highlights the difference in status between a “detained” juvenile (in temporary custody pending adjudication over an indeterminate period of time) and an “adjudicated” one serving a fixed sentence in a correctional facility.<sup>4,5,6</sup>

## HEALTH CARE NEEDS

While juvenile incarceration may provide access to care and respite from unsafe environments, it is also associated with poor adult health outcomes and early mortality.<sup>1,7</sup> It is therefore imperative for providers to assess and optimize the health of these vulnerable patients while in the correctional setting. The U.S. Department of Justice found in a national sample that nearly two-thirds of incarcerated youth reported physical health concerns, consistent with other research suggesting that 46% of youth had a diagnosable medical condition.<sup>1</sup> Dental problems are common; approximately 50% of patients have untreated tooth decay and 6% more urgent conditions such as abscess, jaw fracture, or severe gingivitis.<sup>8</sup> More than 25% of youth in some samples require medical care for trauma-related injuries including lacerations, fractures, and joint limitations, which fits with the high incidence of physical conflict prior to or sometimes during incarceration.<sup>9</sup>

Reproductive health, however, represents the most significant issue for incarcerated youth, as they report higher rates of sexual activity, more lifetime partners, less contraceptive use, and more sexually-transmitted infections (STIs).<sup>1</sup>

A 2011 CDC report found that 13.5% of incarcerated girls and 6.7% of boys had active chlamydial infection, a 4- and 10-fold increase from the female and male community adolescent populations.<sup>10</sup> Detained youth have increased rates of teen parenthood; nationally, 20% of youth in custody are already parents or expecting a child, compared to less than 5% of the general population.<sup>5</sup>

Particular attention should be paid to incarcerated females, as they are “among the sickest and most medically underserved of all adolescent populations.” Specifically, 13% of girls have experienced a head injury and more than 20% were victims of sexual assault in the week preceding detention, while nearly 20% had a history of visiting an ED for asthma. Surveys of nearly 2,000 girls in the Florida and California systems revealed that 88% had between one and three serious health issues that were not adequately addressed (predominantly asthma, STI, or traumatic brain injury).<sup>11</sup>

The American Academy of Pediatrics (AAP) has published recommendations advocating that incarcerated adolescents should receive comparable care to non-incarcerated youth, including preventive services such as thorough history and physical, mental health and substance abuse screening.<sup>2</sup> This recommendation is particularly important in light of the variable quality of care for the incarcerated population nationwide: for example, less than one quarter of juvenile detention facilities screen all youth for STI's.<sup>1</sup> The AAP publication also emphasizes the need for coordination and communication with community providers.<sup>2</sup> Of note, it is estimated that as many as 80% of detained youth lack a primary care provider in their communities, making the outreach to establish outpatient care vitally important.<sup>1</sup>

## MENTAL HEALTH CARE

The American Academy of Child and Adolescent Psychiatry (AACAP) published *Practice Parameters for the Assessment and Treatment of Youth in Juvenile Detention and Correctional Facilities* in 2005, which recommend that all youth entering juvenile justice facilities be screened for mental or substance use disorders, including risk factors for suicide, and receive continued monitoring throughout their stay. Any juvenile with recent suicidality or symptoms of mental health or substance use disorder should be referred for thorough evaluation by a qualified mental health clinician. It is also imperative for mental health clinicians to differentiate their role and potential limits to confidentiality with patients and family members. Finally, it is recommended that all youth referred to mental health services within the juvenile detention or correctional facility have a violence risk assessment.<sup>13</sup>

The prevalence of psychiatric disorders is much greater within the juvenile justice population than in the general pediatric population. The prevalence of mental health disorders in the general adolescent population has been estimated to be 7–17%, compared to 60–80% in detained youth,

the majority of whom have more than one psychiatric disorder.<sup>2,14,15</sup> This may be due to a variety of factors, including limited access to mental health care and the propensity of psychiatric disorders to lead to disruptive or high-risk behavior resulting in legal involvement. *The Survey of Youth in Residential Placement (SYRP)*, conducted by the Office of Juvenile Justice and Delinquency Prevention, found that the majority of detained youth reported anger problems, and over 50% endorsed symptoms of anxiety as well as depression.<sup>16</sup> There are also disparities in rates of ADHD, learning disorders, behavioral problems (including conduct disorder), PTSD and suicidality.<sup>15</sup>

In Rhode Island in 2013, of the 498 youth detained at the RITS, 155 youth were under the care of the RITS psychiatrist; 137 were prescribed psychiatric medications.<sup>4</sup> It has been well documented that girls have higher rates of psychiatric disorders, particularly anxiety, depression and PTSD.<sup>1</sup> This may partially be due to the higher rates of all forms of abuse (physical, sexual and emotional) in female compared to male offenders.<sup>2</sup> Trauma in general is more common in the juvenile justice population; the *SYRP* found that 70% of incarcerated youth reported past traumatic events and 30% reported history of abuse, which itself serves as a risk factor for juvenile justice involvement.<sup>16</sup>

The difference in rates of suicidal ideation and past suicide attempts between youth in the juvenile justice system and the general population is striking. According to the *SYRP*, 20% of youth reported having recent suicidal thoughts, and 22% reported past suicide attempts, which is over four times the rate of the general population.<sup>15,16,13</sup> Unfortunately, completed suicide occurs more than twice as frequently among adolescents in custody than among adolescents in the community. Stressors contributing to increased suicidality in detained youth include awaiting court decisions, sentencing, separation from family and community, receipt of bad news, history of abuse, substance use, and lack of parental visits.<sup>1,13,15</sup>

## SUBSTANCE ABUSE

Substance use disorders are also more prevalent in the juvenile justice population.<sup>16</sup> In 2010, the rates of substance abuse among incarcerated youth were over five times greater than the general population.<sup>6</sup> According to the *SYRP*, youth offenders report using drugs at a higher rate and more frequently than the general population; 68% report having problems related to substance use.<sup>16</sup> The AACAP recommends that any youth with a positive initial drug screen upon entering a juvenile justice facility receive an immediate assessment for possible alcohol or drug withdrawal, followed by a more thorough evaluation within two weeks of admission.<sup>6</sup> Substance use itself is a risk factor for involvement in the juvenile justice system, and is also associated with more serious delinquency, developing antisocial personality disorders later in life and engaging in riskier behaviors.<sup>2</sup>

## CHALLENGES TO HEALTH CARE

Providing health care to adolescents in the correctional setting is rewarding and essential in light of the many medical and psychiatric needs of the population, but can be challenging for a variety of reasons. Juvenile detention and correctional facilities run on strict daily schedules with time for school, meals and other programming, which can create time conflicts for medical and psychiatric appointments. Patients must be escorted to clinic by correctional officers for supervision and safety, which requires sufficient staffing.<sup>1</sup> Length of stay in a juvenile detention or correctional facility is often unpredictable, which significantly impacts treatment planning. The absence of parents may limit the information gathered on initial history as well as access to consent for medical treatment. In addition, adolescents may find it difficult to differentiate health providers from the correctional system, leading to their reluctance to share details about history or symptoms.<sup>15</sup> Clinicians must also be mindful of the potential for exaggeration or malingering of symptoms by juveniles for secondary gain, such as transfer to medical facility or to obtain certain medications that can be diverted. These facilities may also have limited access to emergency and subspecialty care, as well as a shortage of health care providers willing and appropriately trained to treat this specialty population.<sup>15</sup>

## CONCLUSION

Adolescents in the juvenile justice system represent a population with greater health care needs than many of their peers. Involvement in the legal system, and specifically incarceration in a correctional facility, may present a unique opportunity to address these needs, which then persist after release into the community. Delivery of comprehensive, high quality medical and mental health care both during and after incarceration is critical to prevent the worsening of clinical conditions and more serious legal consequences in the future. Community-based pediatricians and primary care providers can make a difference by continuing to treat ongoing health issues and providing more frequent follow-up for youth who have been released. Outpatient providers should obtain medical records and discharge summaries from detention facilities and continue to evaluate and support management of any ongoing risk behaviors after release.<sup>15</sup> Understanding the legal system and the implications for juveniles will help provide a foundation for treating these adolescents; continuing to advocate for ongoing development of preventative and diversionary programs that limit juvenile arrests and detention will also minimize the poor health outcomes and impaired social functioning associated with juvenile incarceration, thereby supporting the overall well-being of adolescents and ultimately adults in this country.

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# Sex Trafficking Assessment and Resources (STAR) for Pediatric Attendings in Rhode Island

CHRISTINE E. BARRON, MD; JESSICA L. MOORE, BA; GRAYSON BAIRD, PhD; AMY P. GOLDBERG, MD

## ABSTRACT

**BACKGROUND:** Domestic minor sex trafficking (DMST) victims have unique medical and mental health needs and present frequently for medical attention. Little is known about the reported training, screening, comfort and knowledge of DMST among pediatricians in Rhode Island who likely encounter these patient victims without knowing.

**METHODS:** An anonymous electronic survey sent to Rhode Island Hospital staff physicians from November 2014 through January 2015.

**RESULTS:** Of the 109 participants, the majority reported no training, screened no patients for DMST in the past year, did not know any resources available and had limited knowledge and comfort with this pediatric patient population.

**CONCLUSIONS:** Rhode Island pediatricians of various specialties do not feel adequately prepared to identify and respond to a DMST patient population. These findings inform the need for increased training and education on DMST in our medical community.

**KEYWORDS:** domestic minor sex trafficking; commercial sexual exploitation of children; victim; training

## INTRODUCTION

The commercial sexual exploitation of children (CSEC) has become an increasingly recognized manifestation of child sexual abuse. It has profound physical and mental health effects for children domestically and abroad. CSEC is defined as the “recruitment, harboring, transportation, provision, or obtaining of a person for the purpose of a commercial sex act” in exchange for an item of value, such as money, food, shelter or drugs.<sup>1</sup> Sexual acts include trafficking for sexual purposes, prostitution, sex tourism, pornography, stripping, and survival sex.<sup>2</sup>

When CSEC involves United States citizens or legal residents being victimized on U.S. territory, this is known as domestic minor sex trafficking (DMST).<sup>3</sup> It is conservatively estimated that at least 100,000 American juveniles are victimized through sex trafficking each year,<sup>4,5</sup> and over 325,000 U.S. children are at risk.<sup>4,6</sup> Rhode Island’s geographic

proximity to two major metropolitan areas (New York City and Boston) and easy access to a major interstate highway increases the likelihood of sex trafficking. While the Interstate 95 corridor has traditionally been used for drug trafficking, it also is used for human trafficking and specifically to sex traffic both local and non-local youth in and out of Rhode Island.

In response to the prevalence of this issue in our state, the RI human trafficking task force (HTTF) comprised of community service providers, criminal justice, medical and child welfare professionals was initiated in 2013 to develop a statewide plan to address all aspects of sex trafficking. The Lawrence A. Aubin Sr. Child Protection Program (The Aubin Center) at Hasbro Children’s Hospital is a part of this multidisciplinary team and is the only child protection program in the state of Rhode Island where patients are evaluated by board-certified child abuse pediatricians. Aubin Center physicians, medical support staff and social workers collaborate with referring medical and non-medical providers to address the complex healthcare and psycho-social needs of these youth.

Over the past few years, the Aubin Center has seen a significant increase in the number of patients referred for the evaluation of DMST in the outpatient clinic and emergency department. Due to the physically and emotionally abusive nature of sex trafficking, victims seek medical care frequently and have adverse health consequences (e.g. injuries, substance abuse, unsafe sexual practice).<sup>7,8</sup> Therefore, pediatricians and other clinicians have the unique opportunity to identify and effectively intervene on behalf of these vulnerable youth.

Previous studies have identified low levels of knowledge, comfort and training of providers in regard to child abuse,<sup>9,10</sup> and more recently child sex trafficking,<sup>11,12,13</sup> but have not specifically examined pediatricians practicing in RI. The objective of the present study was to describe the reported training, screening, comfort and knowledge of DMST among pediatric physicians in Rhode Island. Our goal was to identify the impediments to the care of DMST patients in our medical community in order to inform education and training needs.

## METHODS

We developed an anonymous survey modeled on a previously established survey that assessed the knowledge,

training and comfort medical providers face when interacting with child abuse patients,<sup>9</sup> and from clinical experience. Experts in survey development and experienced physicians in DMST reviewed the survey. Research Electronic Data Capture (REDCap) software, a free, secure, Web-based application, was used to create and distribute the survey.<sup>14</sup>

The survey was titled “Sex Trafficking Assessment and Resources Survey (STAR)”. Participation in the study was voluntary and anonymous. The survey was distributed from November 2014 through January 2015 via e-mail to all pediatric attending physicians listed in the Rhode Island Hospital staff services and/or the department of pediatrics at Rhode Island Hospital. Surveys were targeted specifically to pediatricians who had completed their training; therefore, medical students, residents and fellows were excluded. All research procedures were approved by the Rhode Island Hospital Institutional Review Board. Descriptive statistics were calculated and the averages were computed using SAS Software 9.4. (SAS Inc., Cary, NC).

**RESULTS**

The survey was sent to 267 pediatric attending physicians in Rhode Island and a total of 109 responded (response rate 41%). **Table 1** describes the demographics of participants.

**Figure 1** depicts the responses to three questions that assessed participants’ experience with DMST and knowledge of re-sources available for these patients. The majority of participants reported limited experience.

**Figure 2** displays the average responses in regard to the knowledge of and discomfort with patients who may be involved in sex trafficking.

**DISCUSSION**

The findings from the current study reveal that Rhode Island pediatric attending physicians of various specialties do not feel adequately prepared to identify and respond to a DMST patient population. The majority of participants reported limited knowledge, training and comfort in regard to screening, managing, and identifying resources for high-risk and involved patients. These findings are problematic, as previous studies indicate the severity of health consequences and outcomes associated with sex trafficking.<sup>7,8</sup> Our survey highlights the potential need for education and training among all pediatricians in RI to subsequently inform effective patient care.

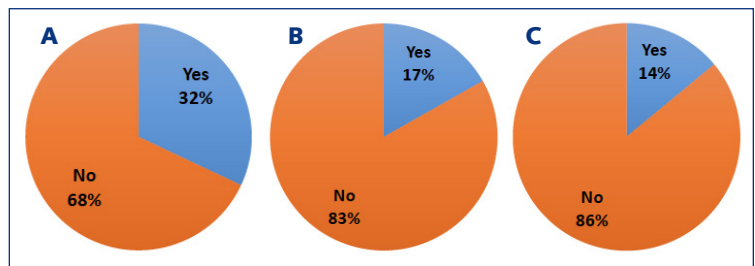
Patients seek medical attention but are often not identified because they infrequently self-disclose involvement to providers and do not consistently present with evidence of involvement (e.g. found trafficking by law enforcement).<sup>4,15,16</sup> Therefore, at-risk or victimized patients are treated solely for their immediate health issues (e.g. drug/alcohol abuse, STIs), only to be at continued risk for DMST

**Table 1.** Respondent Demographics and Experience

	n (%)
<b>Completed survey</b>	109 (41)
Female	67 (61)
Male	39 (36)
Unknown	3 (3)
<b>Medical Specialty</b>	
General Pediatrics	49 (45)
Pediatric Subspecialists	42 (39)
Internal Medicine Pediatrics	10 (9)
Other	8 (7)
<b>Clinical setting</b>	
Private/Community	42 (39)
Hospital based clinic	29 (27)
Emergency Department	18 (17)
Hospital Inpatient	14 (13)
Other	4 (4)

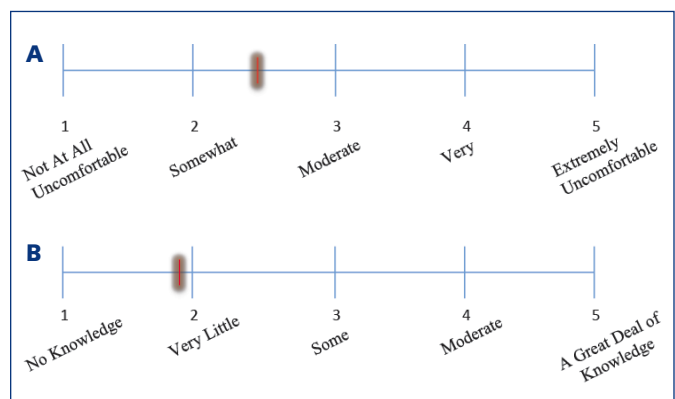
**Figure 1.**

- A. Have you screened any patients for DMST in the past 12 months?
- B. Have you received any training on DMST?
- C. Do you know of resources available for DMST patients?



**Figure 2.**

- A. On a discomfort scale ranging from not at all (1) to extremely uncomfortable (5), on average participants reported somewhat to moderate (2.4) discomfort
- B. On a knowledge scale ranging from no (1) to a great deal of knowledge (5), on average participants reported very little (1.87) knowledge



victimization.<sup>15,16</sup> Youth who are not recognized within a medical setting represent missed opportunities for identification and intervention.

The overwhelming majority of Rhode Island pediatricians (86%) who responded to the survey described having received zero hours of training on DMST. In a recent survey study by Beck and colleagues, 67% of providers with no training were more likely to have lower levels of knowledge on sex trafficking and noted less confidence in their ability to identify victims.<sup>11</sup> In conjunction with limited training, our survey found that the majority of participants had an average of “very little” perceived knowledge and reported “somewhat” to “moderate” discomfort pertaining to the screening, medical management, and identification of resources for DMST patients, and when to report these youth.

A lack of training in, knowledge of and comfort with DMST may hinder appropriate and necessary patient care. The current study found that 68% of RI pediatricians who responded have not screened any patients for DMST in the past year. Moreover, our participants reported having “very little” knowledge of the resources available for DMST patients, and the majority (86%) reported not knowing about any resources. Of the 14% who did identify knowing at least one resource, participants most commonly listed the Aubin Center, followed by DCYF, homeland security, and Day One. To provide for the many medical and non-medical needs of these vulnerable youth, it is imperative for medical providers to be aware of current RI and national resources available (See **Table 2**).

A limitation of this study is that we focused on pediatric physicians in Rhode Island, and therefore findings likely cannot be applied to all medical providers and medical settings in the U.S. In addition, respondents were asked to identify the number of hours they have completed training, but were not asked about the specifics of their training. Future studies should explore differences among pediatric subspecialists regarding knowledge, comfort, training and medical decision making for DMST victims.

These data support the need for a structured standardized approach to training and education about DMST for all pediatricians to improve identification and medical management. Educational programs for sexual abuse, domestic violence and substance abuse might serve as examples of how to train clinicians on DMST. Collaboration between medical providers, investigators, and other community organizations can provide opportunities to educate community partners about the unique medical and mental health needs of this population.

**CONCLUSION**

Over the last few years, DMST in Rhode Island has been increasingly recognized. As with other forms of child maltreatment, a multidisciplinary approach to identify and effectively intervene on behalf of these patients is recommended. As leaders in child advocacy, pediatricians play an essential role in addressing the complex issues faced by victims of DMST. Pediatricians can work to increase recognition of DMST, provide direct care and guidance, and engage in collaborative efforts with medical and non-medical providers. Through clinical based training and education regarding community resources, pediatricians will be more prepared to help address the complex needs of this vulnerable pediatric patient population.

**Acknowledgment**

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**Table 2. Resources Available for DMST Patients**

Rhode Island Resources <sup>a</sup>	National Resources
<ul style="list-style-type: none"> <li>• Aubin Center (401)-444-3996</li> <li>• Day One (401)-421-4100 <a href="http://www.dayoneri.org">http://www.dayoneri.org</a></li> <li>• Department of Child, Youth and Families (DCYF) (401) 528-3502 <a href="http://www.dcyf.ri.gov">http://www.dcyf.ri.gov</a></li> <li>• Family Service of RI (401)-331-1350 <a href="http://www.familyserviceri.org">http://www.familyserviceri.org</a></li> <li>• Gateway Healthcare (401)-724-8400 <a href="http://www.gatewayhealth.org">http://www.gatewayhealth.org</a></li> <li>• Project Renew (401)-272-0220 <a href="http://www.amoshouse.com">http://www.amoshouse.com</a></li> <li>• Project Weber (401)-383-4888 <a href="http://projectweber.org">http://projectweber.org</a></li> <li>• Saint Mary’s Home for Children, The Shepherd Program (401)-353-3900 <a href="http://www.smhfc.org/Outpatient.htm">http://www.smhfc.org/Outpatient.htm</a></li> </ul>	<ul style="list-style-type: none"> <li>• AAP Guidelines <a href="http://pediatrics.aappublications.org/content/pediatrics/135/3/566.full.pdf">http://pediatrics.aappublications.org/content/pediatrics/135/3/566.full.pdf</a></li> <li>• GEMS <a href="http://www.gems-girls.org">http://www.gems-girls.org</a></li> <li>• Homeland Security 1-(800) 973-2867</li> <li>• Love 146 <a href="https://love146.org">https://love146.org</a></li> <li>• My Life My Choice <a href="http://www.fightingexploitation.org">http://www.fightingexploitation.org</a></li> <li>• National Human Trafficking Resource Center (NHTRC) hotline 1-(888)-373-7888 <a href="http://traffickingresourcecenter.org">http://traffickingresourcecenter.org</a></li> <li>• The National Center for Missing and Exploited Children 1-(800)-843-5678 <a href="http://www.missingkids.org/home">http://www.missingkids.org/home</a></li> </ul>

a. RI community agencies listed have established specific resources for victims of DMST



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# Transgender and Gender Nonconforming Youth: Psychosocial and Medical Considerations

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## ABSTRACT

Primary care providers are increasingly called upon to care for youth that are gender nonconforming. While these youth have the same health concerns as their cis-gender peers, gender nonconforming youth face additional challenges. Traditionally, this has been an underserved and marginalized population at significant risk for multiple negative mental and physical health outcomes. Despite the history of disheartening health outcomes, there is hope in interventions that may serve to ameliorate the risks for transgender youth. Studies indicate that with collaborative multidisciplinary interventions by physicians and mental health professionals that promote early identification, emphasize parental support and directly address the patient's gender dysphoria with medical and psychological interventions, transgender youth can reach adulthood without psychological sequelae.

**KEYWORDS:** transgender, gender, dysphoria, transition

## INTRODUCTION

In recent years, growing awareness of and exposure to gender nonconforming children and adults has spurred more public and medical dialogue regarding health and human rights for transgender individuals. Research, the media, and a growing awareness of the needs of the transgender community raise additional questions about the optimal treatment for these individuals.

While the prevalence of gender variant youth is largely debated, recent reports suggest that the prevalence of transgender individuals may be higher than previously estimated. Prior reported prevalence rates have ranged from 1:7,000 to 1:20,000 for transgender females, and from 1:33,000 to 1:50,000 for transgender males.<sup>1</sup> In a recent survey of 18-64 year old Massachusetts residents (n=28,622), 1 in 200 self-identified as transgender.<sup>2</sup> Additionally, gender specialty clinics have witnessed a notable increase in the number of youth presenting with gender nonconformity.<sup>3,4</sup>

Medical and mental health professionals may be a first point of contact for gender diverse youth, playing a critical role in defining treatment trajectories. Thus, it is becoming increasingly necessary that physicians and mental health professionals become familiar with the needs of this

traditionally underserved and vulnerable population. Health care professionals should be able to screen and identify gender nonconforming youth, provide appropriate education to youth and families and facilitate connection with existing referral networks that may aid gender diverse youth and their families.

## GENDER DEVELOPMENT

For most children, gender identity, the internal sense of being male or female is consistent with the physical characteristics of gender assignment at birth. However, a minority of children will experience gender identity that differs from the gender characteristics that initially provide them with an expected gender. It appears that a multifaceted interplay of genetic, neurobiological, prenatal and possibly postnatal hormonal environment, along with cultural and psychological factors work together to determine gender identity.<sup>5</sup>

It is fairly common for children in early childhood to engage in cross-gender play or gender exploration, and children may even express a wish to be a different gender. While most children who engage in gender play do not experience gender dysphoria in adolescence, for some, gender nonconformity persists. Medical and psychological research is only beginning to understand the developmental trajectories of gender identity in gender nonconforming children. One of the main factors identified for persistence into adolescence is the intensity and degree of gender dysphoria in the pre-pubertal years. The children who persist with gender dysphoria into adolescence have more "extreme" signs of gender dysphoria and are consistent, persistent and insistent in cross-gender activities, behavioral preferences, gender identification and dress.

The Diagnostic and Statistical Manual of Mental Disorders (DSM-V) replaced the term Gender Identity Disorder with Gender Dysphoria. This change reflected an effort to depathologize the condition while simultaneously ensuring appropriate access to clinical care. While both diagnosis focus on a condition manifested by a marked incongruence between one's experienced gender and assigned gender, the gender dysphoria diagnosis has the clinical focus on the distress that may occur rather than identity.<sup>19-20</sup>

Some children may not experience a significant amount of gender nonconformity in childhood, but may present with significant gender dysphoria as puberty approaches. Age 10 through 14, the average age of puberty onset, appears to be a crucial period for identification of teens who will experience ongoing gender dysphoria.<sup>6,7</sup> For transgender youth, the growing awareness and concern over secondary sexual characteristics often results in hatred of and disgust with their bodies.<sup>6</sup> Conversations about “becoming a woman” or “becoming a man” can be particularly distressing to these youths as they begin to struggle with more obvious dissonance between their gender identity and physical gender. Either anticipated or existing irreversible physical changes may lead adolescents to feel increasingly hopeless regarding their body and future trajectory. Asserted males may experience extreme distress regarding the growth of breasts and hips and the start of menarche; asserted females may have an intensification of aversion towards their genitals, distress over body and facial hair growth and voice deepening.<sup>6</sup>

Previous studies have consistently identified elevated risk of multiple negative mental health outcomes among transgender youth compared to their cisgender counterparts.<sup>8</sup> In a sample of 360 transgender youth there was a two- to three-fold increased risk of depression, anxiety disorder, suicidal ideation, suicide attempts, non-suicidal self-injury, and both inpatient and outpatient mental health treatment compared to the cisgender controls.<sup>9</sup> A study of transgender youth revealed that 45% had experienced suicidal ideation and 26% had attempted suicide.<sup>10</sup> The effects of chronic brain-body incongruence, resultant anxiety and low self-esteem, lack of family support, discrimination and marginalization in society are hypothesized to contribute to these dishearteningly high rates of psychiatric disorders.

## INTERVENTIONS

Despite the history of significant health and social disadvantage in this population, poorer health outcomes are not inevitable. Recent research demonstrates that a focus on early identification, family support and well-timed interventions addressing both the patient’s gender dysphoria and other components of an adolescent’s psychological and social wellbeing seem to offer long-term health benefits.<sup>11,12</sup>

Ideally, gender variant youth would be identified early, well before puberty, with concurrent medical and mental health involvement. Early identification and anticipatory guidance creates a thoughtfully planned, timely social and medical transition. Guidelines published by World Professional Association for Transgender Health (WPATH) recommend a staged transition. WPATH Standards of Care echo the 2009 Endocrine Society guidelines for puberty suppression for gender dysphoric youth. Guidelines suggest that youth may benefit from puberty suppression with gonadotropin releasing hormone (GnRH) analogs if they have begun puberty with genital development tanner stage 2 or higher,

## TERMINOLOGY

**Asserted gender:** the gender that people communicate to others as their authentic gender in expression and/or identity.

**Cisgender:** adjective used to describe an individual whose natal gender matches their asserted gender identity.

**Gender:** characteristics behaviorally, culturally and psychologically associated with femaleness or maleness.

**Gender expression:** the manner in which a person represents gender to others (including activities, behavior, dress, hairstyles, mannerisms or voice).

**Gender identity:** intrinsic sense of self as male, female or other.

**Gender dysphoria:** distress related to discrepancy between an individual’s gender identity and natal gender (not all gender nonconforming individuals experience gender dysphoria).

**Natal gender:** sex assigned by a physician at child’s birth.

**Transfemale or transmale:** identity label for natal males with asserted female gender identity or natal females with asserted male gender identity.

**Transition:** a process whereby an individual changes their social and/or physical characteristics in order to live in congruence with their authentic gender identity. Transitioning may/may not involve hormonal and/or surgical procedures.

**Cross-gender hormones:** exogenous hormones administered to promote development of secondary sexual characteristics consistent with an individual’s asserted gender identity.

**Gender binary:** classification of gender into two distinct and opposite forms of masculine and feminine, with individuals strictly gendered as either/or, in contrast to gender spectrum which allows for more non-binary or fluid movement along a continuum of gender.

**Gender nonconforming:** adjective used to describe individuals whose gender identity differs from what is normative for their natal gender.

**Social transition:** a process whereby an individual changes their gender expression to align with asserted gender identity which can involve change in appearance (hair, dress, mannerisms etc.), behavior, pronoun, and/or name.

**Transgender:** adjective used to describe individuals whose gender identity differs from their physical sex characteristics. (This term at times is used as synonymous with gender nonconforming.)

demonstrate gender dysphoria with pubertal onset, and have adequate mental health and social support to help them safely transition.<sup>13,14</sup>

Puberty suppression provides additional time for the gender nonconforming youth to explore gender identity without the pressure and distress of ongoing pubertal development. As an added benefit, this “pause” provided by GnRH analogue suppression of continued pubertal development may

provide the family with additional time to adjust. Parents are often reassured that GnRH analogues are fully reversible allowing for endogenous pubertal development to resume once these puberty blockers are stopped. Puberty blockers offer youth significant benefit as they relieve some gender dysphoria by preventing the irreversible physical changes of puberty if started at tanner stage 2. If started later in puberty, GnRH analogues offer more limited benefit but continue to suppress permanent feminization and masculinization characteristics that would require future surgical intervention to alter. Later in adolescence gender affirming hormones can be added.<sup>5</sup> For teens who have already gone through some pubertal changes, stopping continued development of the “wrong” secondary gender characteristics still offers benefit by relieving distress, and facilitating the person’s ability to present in accordance with their gender identity.<sup>5</sup>

Studies indicate that puberty suppression followed by cross-gender hormones may have not just physical benefits for gender nonconforming teens but additional psychological benefit. A study of 70 gender dysphoric adolescents who underwent puberty suppression demonstrated a decrease in behavioral and emotional problems and depressive symptoms and improvement in general function with puberty suppression.<sup>15</sup> In this group of youth, none discontinued puberty suppression and all eventually started on cross-gender hormones.<sup>15</sup> A follow-up study looked at 55 of these youth who had undergone puberty suppression followed by cross gender hormones and gender affirming surgery and evaluated their function in young adulthood. These youth showed a steady improvement in their psychological function over time with rates of clinical symptomatology that were indistinguishable from the general population. Their quality of and satisfaction with life and subjective happiness measures were comparable to same age peers.<sup>12</sup>

These studies support the idea that with early identification, medical treatment and support, transgender youth can reach adulthood with a reduction in psychological sequela.

A growing body of evidence identifies that family support is a significant protective factor that can mitigate the negative psychological sequela. Gender nonconforming youth who described their families as strongly supportive of their gender identity in childhood, went on to have less depressive symptoms, higher self-esteem, higher life satisfaction and lower perceived burden of being transgender.<sup>16,17</sup> A recent study of prepubescent children who had socially transitioned and were supported by their families in their gender identity were found to have normative levels of depression and only minimally elevated levels of anxiety (well below the preclinical range). The authors concluded that allowing children to present in everyday life in accordance with their asserted gender identity was associated with normative levels of depression and anxiety.<sup>18</sup> By supporting their child’s authentic gender self, parents and families of gender nonconforming youth have a crucial opportunity to improve mental health outcomes.

Interventions by healthcare professionals that promote parental support may significantly affect the mental well-being of transgender youth. This approach requires an increased focus on providing support and guidance for parents and families on how best to support their child’s gender identity. When discussing gender identity, parents may feel uncertain as to what the appropriate course of action is and may be paralyzed by many fears about their child’s future. Parents may resist supporting their child’s gender identity due to fears about the difficulties the child may experience in the world beyond their home. Parents frequently voice fears about harassment, peer rejection, physical harm, as well as regret. Highlighting the crucial role of parental support in the mitigation of negative psychological outcomes can provide empowerment for parents who may be overwhelmed by the prospect of their child’s gender identity and transition.

While approaching transition may be a tumultuous time for some families, specially trained mental health professionals can assist in supporting parents through the transition process for the whole family. Assessment of family function and the impact of the child’s gender nonconforming behavior on the family unit is crucial.<sup>8</sup> It is important to acknowledge that parents may be undergoing their own grieving process; experiencing the child’s transition as losing a son/daughter prior to gaining a child of another gender. Processing this perceived loss may be assisted by mental health professionals working with the parents in individual or couples therapy.

Since gender nonconforming youth have lived with their gender dysphoria for an extended period of time, some youth show limited patience with their parents’ slower process of adjustment to disclosure and making a transition plan. Anticipating this lag between youth and parent acceptance is important in making transition plans. Just as gender nonconforming youth may face rejection from their peers and social environment, parents may experience rejection from family members who are not accepting of their child’s asserted identity. It may become necessary for the parents to identify those family members who are supportive of the child’s asserted identity, and protect the child from those family members who may outright reject the child. Parents can also experience increased conflict if their approaches to helping the transgender youth differ, and in those cases marital or co-parenting counseling may be of assistance.

The role of the mental health professional varies with each case. For children who do not have any co-occurring psychiatric difficulties and who are in a supportive and accepting environment, support around gender dysphoria and assistance with safe and thoughtful social and medical transition planning may be sufficient. Before and during the time of transition, mental health providers can function as liaisons with schools in order to advocate for the specific needs of the youth. For children for whom social transition may impact their safety, mental health professionals can work with parents to create a supportive environment in the

home so that the child can experience a sense of acceptance, while a safer plan is developed for outside the home. Given the crucial aspect of parental support, mental health professionals and physicians can help mobilize parents to become greater sources of support and advocacy.

For some youth and families co-occurring psychiatric struggles present additional challenges. Mental health professionals can be an important asset in assessing comorbidities and treating separate psychiatric concerns. As with their cisgender peers, early identification and treatment of adolescent mental health concerns remains essential and predictive of improved long term health outcomes.

**CONCLUSION**

The increased presentation of gender nonconforming youth poses a challenge for healthcare providers to ascertain the safest and best psychological and medical approach for each patient. By working with the youth and their families in a collaborative manner, supportive interventions can aid youth and families adjust to the new landscape of gender nonconformity. Early identification and appropriate psychoeducation, family support, and referrals that lead to well-timed medical and mental health interventions have the potential to offer long-term physical and psychological benefits for this traditionally high-risk population.

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