



# PA CASSP

## Newsletter

### Pennsylvania Child and Adolescent Service System Program

*A comprehensive system of care for children, adolescents and their families*

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## Youth Suicide Prevention in Primary Care

*Matthew B. Wintersteen, Ph.D. and the Garrett Lee Smith Grant Project Team*

Every 2 hours and 11 minutes, a person under the age of 25 dies by suicide in this country – 12 young people every day. In 2007, suicide ranked as the third leading cause of death for young people ages 10-24, with only accidents and homicides occurring more frequently. Pennsylvania has also been struggling with the effects of youth suicide. Between 2003-2005, 514 youths committed suicide in Pennsylvania. Youth suicides have occurred in every county this decade. Of the 19 counties with population densities great enough to calculate suicide rates, 15 percent have rates at least twice the national average.

In September 2003, Garrett Smith, son of former Oregon Senator Gordon Smith died by suicide. Garrett was 21 years old and preparing to go on a mission trip when he reported on a general health screen that he suffered from depression. His parents asked him about this, and he denied any desire for counseling. Soon after, he ended his life. In hindsight, warning signs for suicide were evident but no one knew exactly how to assess for risk and provide effective intervention. Recently Sharon Smith, Garrett's mother, indicated that education and routine screening in primary care are among the most important considerations for the future of suicide prevention.

Following Garrett's death, Congress passed the Garrett Lee Smith Memorial Act, which appropriated \$82 million to the

Substance Abuse and Mental Health Services Administration (SAMHSA) to fund state, tribal and college grants with the explicit goal of reducing youth suicide nationally.

In 2008, Pennsylvania was awarded a Garrett Lee Smith grant from SAMHSA. We became the first state in the country to use these funds to specifically target youth suicide prevention in primary care. Aimed at reaching providers of youth ages 14-24 years, we targeted three northeastern Pennsylvania counties (Lackawanna, Luzerne, and Schuylkill) with suicide rates well above the national and state averages. Currently, seven primary care practices in the three counties are now directly linked as project participants, and an additional five practices are waiting to come on board. Below, we describe the objectives and progress toward each.

### **Objective #1: Create a task force of a broad range of stakeholders.**

**Progress:** All three counties now have a suicide prevention task force, including members from the health professions. State agencies are collaborating with several state medical and nursing associations, as well as building partnerships with regional public insurers. Through these collaborations, we have promoted webinars on suicide prevention and spoken at several state conferences for health providers. The Pennsylvania Youth Suicide Prevention Initiative Web site

([www.payspi.org](http://www.payspi.org)) includes project progress reports, information for all Pennsylvania counties, and resources for adolescents, parents and professionals. We completed a survey of over 600 health care providers across Pennsylvania addressing their experience with suicide, their comfort with suicide risk assessment, routine screening for psychosocial problems and other related topics.

### **Objective #2: Provide a youth suicide "gatekeeper" training program to participating pediatricians, family physicians and nurse practitioners in the designated counties.**

**Progress:** We adapted a primary care training developed by the American Association of Suicidology (AAS), "Recognizing and Responding to Suicide Risk in Primary Care," for providers of youth and young adults. This training has been offered to all participating practices, and is available to others by contacting AAS at [www.suicidology.org](http://www.suicidology.org). A similar on-line suicide prevention training curriculum designed for nurses and nurse practitioners is also being developed.

### **Objective #3: Provide medical practitioners in the three counties free access to a screening tool for patients to self-report and to assess for suicide and related risk factors.**

**Progress:** All participating practices now have access to the web-based Behavioral Health Screen (BHS), a broad psychosocial

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# The Role of Primary Care in Youth Suicide Prevention

Seven years ago, the newsletter topic was "The Relationship Between Physical and Mental Health in Children" (September 2003). In my introduction to that edition, I quoted from the Surgeon General's 1999 report on mental health, noting that there is "an inextricably intertwined relationship between our mental health and our physical well-being." However, despite that clear relationship, the primary and behavioral health care systems by and large still operate separately.

The rationale for better collaboration between and even integration of the two systems – especially on behalf of children and adolescents – include these facts:

- At well-child visits, almost one-fourth of parents told their pediatrician about a psycho-social concern related to their child.
- More than 70 percent of adolescents see a physician at least once a year, making primary care the entry point for many adolescents who need behavioral health services.
- In one report, pediatricians indicated their belief that 16 percent of the adolescents they saw in the previous year were depressed and five percent were at risk for suicide.

Recognizing the reasons why behavioral health care ought to be coordinated with primary care is only the beginning. It is also important to acknowledge the barriers to effective coordination. Some of the barriers are:

- Physicians often lack the skills and resources to handle behavioral health problems. They not only don't know what to do with the information they might obtain from adolescents about their behavioral health concerns; they also don't feel capable of identifying depression or other specific issues.
- Primary care practices generally have time constraints that don't allow providers to spend a lot of time exploring issues in depth with their patients.

- Tools for effective identification of behavioral health problems are inadequate or not available.
- When behavioral health needs are identified and referral would be helpful, there are not sufficient resources available and there is often poor communication with the services to which the youth are referred.

One specific example of how the two systems are becoming more integrated and the barriers to integration are being addressed is the Garrett Lee Smith, GLS, "Youth Suicide Prevention in Primary Care" grant project, being implemented in three Pennsylvania counties: Lackawanna, Luzerne and Schuylkill. This edition of the newsletter provides an overview of the grant project and the importance of screening for suicide risk, testimonials from several primary care practices in the three grant counties about their involvement with the project, and additional examples of efforts to more effectively integrate primary and behavioral health care.

*Harriet S. Bicksler, editor*

## Leadership Team for "Youth Suicide Prevention in Primary Care" Grant Project

**Sherry Peters**, Principal Investigator and Program Director, September 2008 - August 2010

**Stan Mrozowski**, Principal Investigator, beginning September 2010

**Guy Diamond**, Program Director

**Denise Short**, Program Co-Director (currently on leave)

**Doris Arena**, Acting Program Co-Director

**Matt Wintersteen**, Program Co-Director

**Alanna O'Malley**, Research Coordinator, September 2008-June 2010

**Shannon Chaplo**, Research Coordinator, beginning June 2010

# Screening in Primary Care

By Guy Diamond, Ph.D. and Shannon Chaplo

The need to integrate behavioral health services into primary care is central to identifying adolescents at risk for suicide. A cornerstone of this process is the introduction of behavioral health, BH, screening procedures into medical offices and clinics. Screening practices lie on a broad spectrum, from doing a screening when problems are suspected (indicated screening) or with all patients at every visit (universal screening). Whether indicated or universal screening is used, many considerations and challenges confront primary care practices as they begin to integrate behavioral health services into their practices.

In the past, the American Academy of Pediatrics, AAP, only recommended screening at a well visit, but recently the U.S. Preventive Services Task Force released a new position statement in *Pediatrics* (Volume 123, Issue 4, April 2009) encouraging the screening of adolescent patients for depression (and related problems such as suicide) at all visits, provided treatment and follow-up are locally available. The AAP supports suicide screening, but depression is much more prevalent and thus is a more prominent problem for the medical community.

Universal screening with a standard screening tool is highly recommended because of its potential benefits. Universal screening reduces stigma by making it a standard procedure for all patients. Routine screening increases the likelihood it will be completed. Screening tools also help standardize behavioral health screening, allowing confidence that clear and appropriate questions are being asked of all patients. Further, studies suggest that using these tools increases identification of BH issues in general and the likelihood of identifying youth that no one would suspect are struggling.

When selecting a screening tool, several considerations are important. Some tools focus on a single domain (e.g., depression) whereas others focus on multiple domains (e.g., depression, suicide, substance use, anxiety, etc.) providing a

more complete clinical picture. Broader screening takes a bit more time, but subsequently provides more information to better understand the context of the depression or suicidal symptoms. Although the AAP is highly concerned about depression (because it is prevalent and can easily go unnoticed), they recognize the need to screen for a wide range of problems and risk factors. The USPSTF also recommends using valid and reliable screening tools (Diamond, 2010).

An alternative screening tool has been developed by our research team at The Children's Hospital of Philadelphia and used by the Garrett Lee Smith project. The Behavioral Health Screening (BHS) tool is a brief, web-based tool that covers a wide range of behavioral problems. It covers 13 different domains including depression, anxiety, substance use, trauma, psychosis, sexuality, family and social supports. The tool takes about 12 minutes to complete by adolescents before their appointment. The computer then automatically scores the questionnaire and generates a brief report which can be added to an electronic medical record and the data can be collected. The web-based tool solves many of the common challenges related to screening including scoring, integration with medical records, audio files for reading impaired, integration of repeated administrations, and skip-outs to shorten time when patients are non-symptomatic. The tool has very good reliability and validity. Contact Guy Diamond (diamondg@email.chop.edu) for more information about it.

Whether a paper or web-based screening tool is selected, the actual integration of screening into everyday office work flow takes planning, motivation and effort by the primary care practice. A number of issues need to be addressed prior to using any BH screening tool: Is the office ready to increase their attention to behavioral health? Are there internal office procedures for handling troubled youth, especially acutely suicidal youth? Who will administer the screening? Where will it take place? Who will score

and interpret the data and get it into medical records? How will it be introduced to the patient and the parent? Are there strong relationships with local behavioral health providers that help increase patient access to care? The web-based technology can help address some of these challenges, but it presents others: Does the office have a computer that patients can use? Will it be placed in the lobby or on a rolling cart to be wheeled into offices? Is internet access available? Are staff members comfortable using computers? Is there support if technical problems occur? The Garrett Lee Smith project has learned a lot about these challenges and can assist any practice that might be interested in beginning more systematic screening.

Unfortunately, one remaining challenge is that insurance reimbursement for screening remains uncertain. Medicaid has developed codes to bill for screening and prevention, but actual payment for these codes remains questionable. There is strong indication that the new Affordable Health Care Act will create a mandate and procedures for reimbursement and also require insurance companies to pay for evidence-based prevention services that include screening. We think it is only a matter of time before screening will be a billable service. Furthermore, we believe this will usher in a new era of collaboration between medical and behavioral health service providers.

## Reference

Diamond, G.S., Levy, S.A., Bevans, K.B., Fein, J.A., Wintersteen, M.B., Tien, A., & Creed, T.A. (2010). Development, validation and utility of the web-based, Behavioral Health Screen for adolescents in ambulatory care. *Pediatrics*, 126 (e163-e170).

*Guy Diamond, Ph.D., is co-director of the Garrett Lee Smith grant project and director of the Center for Family Intervention Science Associate Professor at the University of Pennsylvania School of Medicine. Shannon Chaplo is research coordinator for the project.*

# Perspectives on Using the Behavioral Health Screen

## Opening Doors for Dialogue

Since Hazelton Professional Services, HPS, began using the Behavioral Health Screen several months ago, about 60 youth ages 14-21 have completed it. Most youth complete the screen during a well visit; they use a portable laptop computer in the exam room before the appointment where they are given plenty of time to answer the questions in private.

Jeffrey Kulsa, a nurse practitioner at HPS, emphasizes how the use of the screening tool opens doors for conversations with youth that probably wouldn't have happened before. When Jeff asks them, the youth assure him they answer the questions truthfully. Depending on what concerns are flagged, he is able to have conversations about difficult topics like sexual activity and substance use. He also finds that teen depression is common, along with significant anxiety due to all the pressures and expectations teenagers face in contemporary culture. He can ask whether teens have support at home or are experiencing stress there as well.

Jeffrey relates several anecdotes that illustrate the value of doing these screens as part of a routine medical appointment:

- One girl already had an appointment scheduled and the screening identified her history of suicide ideation. She made a pact with Jeffrey that she would not hurt herself, but would contact someone if she needed help.
- A boy revealed experience with numerous different sexual partners, leading to a discussion of risky behaviors.
- Another adolescent acknowledged depression and anxiety, as well as thoughts about suicide. Her doctor referred her to a psychiatrist for additional help. Using the screen as a prompt, information regarding depression, anxiety and suicide elicited a more in-depth consultation concerning the issues the adolescent was facing.

When HPS was first approached about implementing the Behavioral

Health Screen, they were ambivalent and met several times as a staff to discuss the idea and work through the challenges. One of those challenges is the additional time required. Jeff says they have adapted their schedule so they don't waste time, and he emphasizes that it's essential to add extra time to the appointment and ask patients to come half an hour early so they can complete the screen before the exam. He now enthusiastically recommends that other practices consider using the screen as well because it creates an opportunity for open dialogue. In face-to-face conversation teens are unlikely to volunteer information about their emo-



tional difficulties or risky behaviors, but using technology they are comfortable with, they are able to reveal information that can not only give them the help they need but also benefit their families.

*This article was based on a phone interview by the editor with Jeff Kulsa, nurse practitioner, and Barbara Biacco, Hazelton Professional Services, Hazelton.*

## Using the Screen with Children in Foster Care

*By Kathy Wallace*

After trainings for staff and procedural meetings, the Garrett Lee Smith Project, GLS, started using the Behavioral Health Screen at Dr. Linda Thomas's office in early spring this year. As the co-coordinator, I was looking forward to working

with this enthusiastic office that was very committed to working on the project. The first day, two teens in the foster care system came to the doctor's office for a routine check-up. We know that children in the foster care system are at risk and may have experienced trauma and transitions. All children in this system have case workers who are responsible for the child's life planning and monitoring; many of them also have private foster care agency case managers and mental health case managers.

The teen girls each came to the office with two case workers: a county case worker and a private agency case worker. Both children were living in the same foster home with an experienced caring foster parent. They both had past experience with behavioral health support and currently one was in active therapy, seeing her therapist once every two weeks.

In the screening that day, both girls were identified as being very depressed and the one who was seeing a therapist was actively having suicidal thoughts. After talking to them, the physician and I encouraged the foster parent to set up an appointment with a behavioral health agency for the girl who was depressed and helped coordinate that appointment. A more intensive intervention occurred for the adolescent with suicidal ideation. This child had many losses in her life and was feeling hopeless, but denied any present intent or plan for suicide. The office arranged for the screening report to be faxed to her present therapist and made an appointment for her as soon as possible.

I also contacted her private foster care case worker and her state case worker. The support plan had to include the foster care parent and we had much work to do with her to help her understand that the girl was indeed feeling hopeless and not just seeking attention. It worked out well that day with everyone supporting the child. We were also able to present a "gatekeeper training" for all foster care parents and case workers in the private agency. The GLS project high-

lighted the importance of the primary care physician in the “chain” of care for children who are at risk in the foster care system.

*Kathy Wallace is Director of Advocacy and Community Mental Health Services at the Advocacy Alliance, and the Garrett Lee Smith grant project coordinator for Lackawanna County.*

## Responding to a Suicide Note

*By Linda Wagner*

In June I was contacted by a local primary practice and asked to assist them in registering a 16-year-old adolescent they were seeing that afternoon. The patient’s guardian had reported that she found a suicide note the 16-year-old had written and she was very concerned. The girl and her guardian came for her appointment and the Behavioral Health Screening tool was explained to them. The staff encouraged her to complete the tool. The screening assessment was positive for active suicidal thoughts, as well as previous thoughts and attempts over the past few months. The girl also screened positive for severe depression, significant anxiety and was at risk for post-traumatic stress disorder. A staff person determined that the girl needed to be evaluated by crisis intervention for immediate hospitalization. She and her guardian agreed and she was taken to the local emergency room where she was met by a mobile crisis unit and hospitalized.

Clearly, this was a good outcome for this 16-year-old girl, but what impressed me most was the guardian’s decision to call her primary care provider and schedule an appointment in order to discuss the girl’s suicide note. I was also impressed that the center called me to assist in the process because they knew they would want the girl to complete the screen. Without the attention given to the adolescent and the center’s willingness to engage the local behavioral health system, the outcome may have been very different for this young person.

*Linda Wagner is the Garrett Lee Smith grant project coordinator for Schuylkill Luzerne County.*

## I Had to Do Something About Youth Suicide

*The following is condensed from an interview by Matt Wintersteen with Carol Bilinski, M.D., Blue Mountain Pediatrics, Schuylkill Haven.*

### **To give us some context, please tell us about the structure of your practice.**

I am a solo practitioner and have been in practice 16 years. I started the practice right out of residency because I wanted to come back and serve the area where I had lived most of my life. I really wanted to serve a more rural population. I have been pleased to be in practice this long. Five full-time people are working for me now. We have two licensed practical nurses, two medical assistants and my office manager. We know our patients well and have very little staff turnover.

### **What was your interest in getting involved with the Garrett Lee Smith suicide prevention project in Schuylkill County?**

Some parents of the children in my practice were victims of suicide or a murder-suicide. In one family, both parents died in a murder-suicide. When I found out that Schuylkill County was number one in the state for suicides, I felt like I had to do something.

### **What elements of the project are you particularly enthusiastic about?**

I now have a concrete way to evaluate kids. I’ve been surprised that some children who I had no idea had any thoughts of suicide or had any other issues revealed their thoughts when they took the test (Behavioral Health Screen). We were glad we could get them into counseling.

### **In what ways has your participation in the project benefitted your practice?**

I think it has benefitted us a lot because there are definitely children we would not have realized were having serious issues. When they took the test, we became aware of significant concerns and were able to get them into therapy.

### **Have you noticed any changes in the way you or your staff interact with patients as a result of your participation?**

We all are so much more aware of how suicide can cross every economic

boundary. All of the children, regardless of what I am thinking before they come in the door, can have potentially serious issues with depression, anxiety and even suicidal thoughts. We had been trying to address these, but this gave us a concrete way to find out more than we normally can during a 15 or 20-minute well visit.

### **Do you have any specific success stories you would like to share?**

Often when I initially talked to some children and asked them how everything was going, they seemed to be fine. Then I would ask them to take the test and after that they were tearful and very upset. We spent a lot more time talking and I found out they were struggling with many issues. It felt good to get help for them before things got worse. I think we have always been good about talking to our kids, but the screen has opened doors for those who had not said anything before and were then able to openly admit, “Yeah, I’m struggling greatly.”

### **What has been your biggest challenge related to participation in the project?**

The biggest issue is that sometimes when a problem is identified, there isn’t anywhere to go with it because there are limited mental health services in our county. When I talk with other pediatricians they say, “Why do you want to open that can of worms?” I tell them, “Because it can save someone’s life!” But I don’t think they know where to find services for their patients once they find out that something is wrong. In that respect, Linda Wagner (Schuylkill County’s project coordinator) has been tremendously helpful in finding services for teens who are identified by the screen as needing them.

### **Are you involved in any other suicide prevention efforts?**

Yes. I joined the Child Death Review Team for our county this past year. I had been asked to join multiple times before, but I didn’t have the time. Our current plan is to train a number of members in QPR (Question – Persuade – Refer). We have encouraged other physicians to participate in the Garrett Lee Smith project and have tried to set an example for that in our county.

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screening assessment for youth under age 25. Each practice has received a user's manual and formal training on screening administration. See the article on page 3 for more information about the tool.

**Objective #4: Increase the integration, if not co-location, of behavioral health services with medical services.**

**Progress:** This objective clearly identifies one of the greatest challenges. In the three target counties we have been able to identify behavioral health partners to collaborate with each participating practice. While some practices represent many insurance carriers, we have often relied on extraordinarily knowledgeable project coordinators within each county to help navigate systems of care. There has been some discussion of co-located

behavioral health services in one health-care practice, but progress toward this objective is slow.

**Objective #5: Provide clinical training in best practice therapy models for suicidal youth to behavioral health providers who will receive referrals of these at-risk youth.**

**Progress:** Behavioral health providers in the three counties were offered free training in both cognitive behavioral therapy, CBT, and attachment-based family therapy, ABFT, as empirically supported treatment for suicidal youth. A second wave of CBT training is currently ongoing as well as biweekly phone consultation in the ABFT model.

While we have made tremendous progress toward many of our objectives,

more work remains. Our overarching goal is to identify barriers, solutions and resources that would allow us to disseminate this program across the commonwealth. We are encouraged by the enthusiasm of the health professionals and our systems change focus has made us nationally recognized leaders in this area. We look forward to continuing our collaboration in the years ahead.

*Matt Wintersteen, Ph.D. is co-director of the Garrett Lee Smith project and assistant professor in the Department of Psychiatry and Human Behavior at Thomas Jefferson University, Philadelphia.*

## Toward Coordinated Care: The Medical Home

By Molly Gatto

Lizzie, a child with autism, had an Individualized Education Plan (IEP) at school and was placed in a classroom for children with severe mental retardation. Her parents were unhappy because they felt Lizzie was in the wrong school setting; although she was non-verbal, they believed she had the potential to be educated. They had been unsuccessful in working with the school to modify the education plan.

Lizzie's primary care physician is a participant in the Pennsylvania Medical Home Initiative's "Educating Practices in Community Integrated Care," or EPIC IC, program. Through the program, the practice learned of resources to help the family obtain a more appropriate educational setting. The practice worked with the family to identify the best resource. A community care coordinator observed Lizzie in her home and at school and made arrangements to have her tested by a psychologist outside of the area. The testing showed that she was in fact able to be educated in a meaningful way. The IEP was modified and Lizzie made great strides in learning and even began speaking.

### Educating Practices in Community Integrated

Care, or EPIC IC, is a medical home development project funded by the Pennsylvania Department of Health. The mission of the program is to enhance the quality of life for children and youth with special health care needs through recognition and support of families as the central caregivers for their child, effective community-based coordination, communication and improved primary health care.

A medical home is not a building, house or hospital, but rather an approach to providing health services in a high-quality and cost-effective manner. A medical home is defined as health care that includes provision of preventative care, assurance of ambulatory and inpatient care for acute illness 24 hours daily, provision of care over an extended period of time, identification of the need for subspecialty consultation and referrals, interaction with school and community agencies, maintenance of a central record and database with all pertinent medical information, and coordination of care.



The EPIC IC has established a training program for primary care providers and their office staffs on how to create a medical home for children and youth with special health care needs. Creating a medical home is organized around the seven core principles: accessible, family-centered, comprehensive, continuous, coordinated, compassionate and culturally competent. Many practices across the state have actively engaged in a process of quality improvement in the care of their patients with special needs. Teams are comprised of clinicians, staff members and family representatives. These teams attend bi-yearly educational conferences and participate in monthly conference calls on the medical home concept, community resources, clinical updates, family involvement and other topics. Each practice team actively implements a quality improvement cycle based on the needs identified for their special needs population.

Participation includes developing a registry of patients with special health care needs including mental and behavioral health diagnoses. To enhance knowl-

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# Nurse Practitioners as Key Health Professionals

By Susan Van Cleve, D.N.P., C.R.N.P.

Pediatric and Family Nurse Practitioners, NPs, are ideally suited to meet the growing need for providing mental health care to children and adolescents in pediatric primary care settings. With additional education and clinical practice experience in mental health assessment and management, NPs who work in primary care are in excellent positions to provide enhanced mental health services to children and adolescents. They provide coordination of care and services with a family-centered perspective and are identified providers to children and adolescents as part of the pediatric health care/medical home. NPs are uniquely qualified because they provide parent and child teaching and support as well as medical care including diagnosing, prescribing, and evaluating outcomes for children and adolescents. In addition, NPs with additional education/experience may provide brief psychotherapeutic interventions including cognitive behavioral therapy, behavioral management, counseling, and group education.

Several national initiatives have taken place to assure that NPs develop the added competencies to respond adequately to the demand for quality mental

health care within the primary care setting. The National Association of Pediatric Nurse Practitioners (NAPNAP) launched a national program, KySS: Keep Your Children/Yourself Safe and Secure and published a *Guide to Mental Health Screening, Early Intervention and Health Promotion* (Melnyk & Moldenhauer, 2006) focused on preventing and reducing psychosocial morbidities in children and adolescents. Online continuing education programs help primary care and school health providers enhance their knowledge and skills related to evidence-based screening, assessment and management of common mental health disorders in children and adolescents. Many national conferences and continuing education programs are helping NPs increase their knowledge and skills in mental health care for children and adolescents and are offering intensive workshops on anxiety, depression, ADHD and psychopharmacology (<http://www.napnap.org/Events/Annual-Conference>).

Nurse practitioners are key health care professionals to meet the growing demand for integrating mental health services into pediatric primary care settings. Because they are recognized as pri-

mary care providers with established relationships with families, they are excellent candidates to provide mental health screening, early identification and intervention, diagnose common mental health problems and initiate treatment, including pharmacotherapeutic interventions. They can coordinate and collaborate with physician colleagues and monitor outcomes. Most importantly, children and adolescents in the U.S. will have access to quality mental health care within their pediatric health care home.

## Reference

Melnyk, B.M. & Moldenhauer, Z. (2006). *The KySS Guide to Child and Adolescent Mental Health Screening, Early Intervention and Health Promotion*. National Association of Pediatric Nurse Practitioners: Cherry Hill, NJ.

*Susan Van Cleve, D.N.P., C.R.N.P., is a pediatric nurse practitioner who recently started a subspecialty practice in behavioral pediatrics at Pediatrics South in Pittsburgh. She is also associate professor in the School of Nursing and Health Sciences at Robert Morris University.*

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edge of resources available for patients with mental and behavioral health diagnoses, a statewide conference was held in April 2009. One outcome of the conference was the formation of a mental health workgroup. This workgroup includes individuals from pediatric and family medical practices, mental health providers, non-profit and community organizations, mental health insurance organizations and state agencies, as well as

parents and caregivers of children and youth with mental health conditions. The group hopes to be able to encourage and enable change by bringing together stakeholders in mental and behavioral health who can work together to provide coordinated and effective care for individuals like Lizzie.

Lizzie's verbal skills increased because she was in a more appropriate education

setting. Her mother commented that she was happy when Lizzie and her sibling began to squabble – something she never thought would happen and may not have without the assistance of her primary care physician and the medical home initiative.

*Molly Gatto, M.H.A., is program director of EPIC IC, an initiative of the Pennsylvania Chapter of American Academy of Pediatrics.*

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## A Diagnosis is Not a Life Sentence

*While not specifically connected to suicide prevention and primary care, the following story illustrates how better coordination in and between the physical and mental health systems could help identify problems and relieve suffering sooner. Rachel Kallem, age 25, responded to written questions from the editor. Her answers have been edited for length.*

### **Describe the mental health problems you have dealt with, either in the past or currently.**

I was diagnosed with Bipolar Disorder when I was 17 years old. While it was reassuring to some degree to have a diagnosis (my problem had a name and so could be treated), it was also distressing because I felt like I was genuinely “crazy” now that I had a label. However, there wasn’t much relief from my symptoms at first, because many of the psychiatrists and therapists I worked with did not respect me as an expert on myself, and would be incredibly patronizing when explaining my disability and my treatment options.

I was so distraught over my diagnosis that as a way to cope I developed a severe eating disorder. My anorexia and bulimia were devastating, but I felt like if I could not control my moods, I could at least control when and what I ate. I spiraled out of control, I did not take my medication, I did not eat, and I was emotionally and physically wasting away. My parents were at a complete loss – they were literally seeing their daughter disappear and did not know how to help me.

I was suffering and my mental illness was defining my existence. I soon lost the distinction between “Rachel” and “Bipolar

Disorder.” I did not accept my illness or understand myself. I thought my illness condemned me, made me an outcast, and that there was no hope of ever living the life I wanted. I had dreams, but when I was diagnosed, I lost hope. Luckily, my family remained supportive and they never let me give up on myself. Through education and determination they helped me get my life back on track. I finally saw my worth, and realized that I deserved a better life – a life of recovery, a life lived on MY terms.



### **Where did you go for help? For example, did you go to or think about going to your family doctor? If not, why not?**

My family and I did not go to our family doctor but sought the expertise of psychiatrists and therapists. My parents were desperate for answers, help and guidance, and thought that these individuals would help. While I do not doubt the professionals’ knowledge, I do doubt their ability to work with youth and young adults and educate families in a language they understand. I think the concept of recovery was not introduced to my family early enough, and thus we were left feeling imprisoned by my mental health diagnosis.

### **Have you ever discussed mental health problems with your family doctor? Why or why not?**

I never had these discussions with my family doctor because when I was growing up our managed care organization would assign us a different doctor every time I went in for an appointment. I was never able to build a relationship with a medical professional and thus did not feel comfortable talking to them about such sensitive issues.

### **What do you think is the biggest issue for youth with mental health problems who may also be thinking about suicide?**

I think stigma is a huge isolating factor that keeps youth from discussing their mental health challenges and feelings. We are indoctrinated with this idea of “normalcy” and “fitting in” and thus we are afraid to be true to ourselves. The truth is, no one fits in completely, and there is no “normal” out there – we are all unique and we are all beautiful BECAUSE of our differences. I think we need to educate youth and families about mental illness and teach them that a diagnosis is not a terminal life sentence. A disability does not dictate your ability to succeed; it just means you might have to do things differently.

### **What gives you hope?**

I have hope because I finally love myself. I have inherent worth and deserve to live the best life possible. I hope to finish graduate school and continue working in education advocacy, helping youth with mental health needs access an education.

*Rachel Kallem is a young adult working as an education advocate.*