Social workers have important contributions to make in working with people coping with genetic conditions. The rapid pace of medical advances and increased treatment options for phenylketonuria (PKU), for example, have challenged the clinical interdisciplinary team to offer more comprehensive assessments and further program development. In addition to the metabolic abnormality, many psychosocial concerns are visible in this patient population and have often required further evaluation and referral to a mental health specialist. Unfortunately, comprehensive mental health screenings targeting emotional and behavioral concerns are not routinely implemented during outpatient appointments within our metabolic genetic population. In this report we illustrate the integral role that social work provided in the introduction and implementation of mental health screening questionnaires in the PKU Clinic at Children’s Memorial Hospital.

People with PKU have a form of hyperphenylalaninemia, a rare inherited metabolic disorder. PKU is caused by a mutation in the gene coding for phenylalanine hydroxylase (PAH), a liver enzyme, leading to elevated levels of the amino acid phenylalanine (Phe). Individuals with severe forms of PKU have a complete absence or profound deficiency of PAH enzyme activity and typically have very high Phe levels (> 1200 mol/L or > 20 mg/dL). A partial PAH deficiency results in a lower degree of blood Phe elevation (Hoeks & Janssens, 2009). A normal Phe level is 60 to 120 mol/L or 1 to 2 mg/dL. If this problem is not found and treated early in infancy, PKU can cause severe developmental delays, including mental retardation, microcephaly, delayed speech, seizures, and behavioral abnormalities.

Newborn screening for PKU began in the early 1960s and became the prototype for identifying similar genetic conditions that require early treatment. Screening infants shortly after birth helped to prevent the severe cognitive and developmental impairments that resulted from not being diagnosed. When identified at birth, PKU is treated with Phe-free, protein supplemental medical foods, and a Phe-restricted diet to avert severe brain damage and developmental delays. Foods high in protein, such as meat, poultry, fish, dairy products, eggs, beans, and nuts, are eliminated. A prescription medicine for PKU called Kuvan® (sapropterin dihydrochloride) received Food and Drug Administration approval in 2007.
can be used to lower Phe levels in combination with a Phe-restricted diet. It may also lead to improvement in the neurocognitive symptoms of PKU.

RATIONALE
A Phe-restricted dietary regimen has prevented severe neurological injury in many patients with PKU. However, studies have shown that children with PKU may be at increased risk for school problems and attentional disorders. Recent research conducted by Anastasoaie et al., (2008) revealed that patients whose disease is treated from early infancy with or without diet may still be vulnerable and experience neurocognitive, behavioral, and psychosocial challenges. Adults may experience problems with concentration, organization, and moodiness, which are components of executive function (EF) (Hoeks, den Heijer, & Janseen, 2009). Additional EF domains include planning, inhibitory control, attentional flexibility, and working memory (Anderson et al., 2002). These processes affect goal setting, problem solving, and skills needed to live independently and to manage a Phe-restricted diet.

In the early years of PKU therapy, treatment was typically discontinued around age six and patients were allowed to return to an unrestricted diet. Years later, when the data revealed declining I.Q.s and other neurocognitive sequelae in patients off diet, most physicians advised patients that it would be in their best interest to return to a Phe-restricted diet. However, some patients chose not to, or were unable to do so. For the past two decades, physicians have agreed that blood Phe levels need to be controlled throughout the lifetime of patients with PKU.

Despite recommendations to continue the PKU diet for life, however, compliance with treatment continues to be a problem. As patients get older, an increasing number experience difficulty maintaining the Phe-restricted diet and eventually lose contact with the PKU clinic. These patients may gradually develop behavioral, emotional, and executive functioning difficulties. Overall findings from a collaborative study on PKU in adulthood correlated high Phe levels after age 6 with abnormalities in psychological, educational, and occupational performance (Koch et al., 2002).

In response to these concerns, the clinical team working with the PKU population introduced a quality improvement initiative. A Diversified Approach to PKU Treatment (ADAPT) was integrated into the PKU clinic program. This program was planned and designed in collaboration with two other PKU centers. ADAPT is designed to identify these issues in patients with PKU more proactively and systematically by incorporating screening for executive function and psychiatric distress (Leviton, Vespa, & Burton, 2011).

METHOD
Social workers, in coordination with the rest of the clinical team, implemented and executed the screening tests. An introductory letter, sent to all active patients and/or parents, explained the rationale and
all states apply confidentiality laws to HIV test results.

plan for implementation of ADAPT in order to engage them as working partners. Families were encouraged to share their questions and concerns to further support this initiative. Patients with a diagnosis of PKU who are age 5 or older, presenting for a regular clinic visit, are screened for potential areas of vulnerability that can be associated with PKU. The questionnaires specifically addressed areas of EF and psychiatric distress using validated self or parent report instruments. Questionnaires used to address psychiatric concerns include the Pediatric Symptom Checklist in children and the Brief Symptom Inventory in adults. Executive functioning impairment is identified via the Behavior Rating Inventory of Executive Function. Patients who screen positive on either tool are referred to a community-based mental health provider.

• Motivational interviewing techniques were used when discussing feedback and ambivalence when integrating mental health services into the treatment plan.

Patients and families were receptive to mental health screening and, when appropriate, referral to a community-based mental health provider became part of the overall PKU treatment plan. Patients cited the following reasons for refusing a referral to a mental health provider: financial concerns, disbelief that a problem existed, time commitments, or currently in mental health treatment. Screening serves as a catalyst to identify more subtle problems in individuals living with PKU that have affected their self-esteem and ability to self-monitor.

This quality improvement initiative has also enhanced communication and goal setting among the interdisciplinary clinic team and allowed us to develop additional educational services. An example is a staff-led “Boot Camp” for adult patients who could benefit from peer support and group education around their diagnosis of PKU. This initiative emphasized the importance of working with preadolescent and adolescent patients on fostering independence and self-management of PKU treatment. Recognition and treatment of psychiatric distress and cognitive impairment have the potential to improve patients’ ability to adhere to PKU treatment plans, as well as their overall quality of life. Social workers played a critical role in the implementation and execution of this screening process in this clinic.

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NASW Celebrates U.S. Supreme Court Decision to uphold the Affordable Care Act

SocialWorkers.org/pressroom/2012/statement6282012.asp
Knowledge of an array of modalities is essential for social work providers. Likely, treatment teams inclusive of the client or the client’s representative are involved and committed to the modality of choice that is in the best interest of the client. Whether delivered solely or in combination, treatment modality implementation usually occurs after a series of assessments and diagnosis. Prior to determination of the modality of choice, client mental and physical health stability are paramount. The presence of substance use disorders can mimic psychiatric diagnosis. Hence, before treatment is implemented, clients must demonstrate readiness for treatment. All treatment modalities have benefits and challenges. Myriad issues influence the social work provider’s decision making with respect to the best treatment approach for clients. At the outset, it is essential that clinicians inquire about their client’s reason for presentation. Essentially, what is the precipitating event motivating the client’s presentation? This includes whether the client is self-referred, court ordered, or otherwise motivated for treatment. The reason for treatment provides some insight into the client’s willingness to engage in a therapeutic alliance with the clinician. Furthermore, it is reasonable to inquire about what the client hopes to achieve by participating in treatment. Hence, from the initial moments of meeting a client, the social work provider begins gathering information that will culminate in the choice of a treatment approach.

**CLINICAL ASSESSMENT**

The clinical assessment has been referred to by many names, among them (1) social work assessment, (2) bio-psychosocial assessment, and (3) behavioral health assessment. Regardless of semantics, it is vital that clinicians complete an assessment that includes but is not limited to (1) demographics, (2) health status (history of inpatient and outpatient hospitalizations), (3) social supports, (4) income, (5) employment, (6) mental health (medications, benefit, and outcomes), (7) substance abuse history (drug of choice, frequency, amount, treatment history, and completion), (8) trauma history, (9) education, (10) criminal history, (11) diet, (12) spirituality, (13) other psychosocial issues (bereavement, housing, relationships, poverty, and domestic violence), (14) behavior across the life span, and (15) goals for treatment. Clinical assessments need to be user friendly, relevant to the population assessed, and easily translated from identified needs into services delivered (Leon & Armantrout, 2007). At the completion of the assessment, clinicians are encouraged to obtain signed consents for release of information. Information obtained during completion of the clinical assessment assists clinicians with formulation of the best treatment modality for clients.

**Physical health.** Before initiating any type of treatment modality, it is important to verify the client’s health status. Behavioral health social work providers need to know the date of the client’s most recent health exam. If the client has not had a physical exam in more than a year, it is recommended that the client be referred for an exam. In some instances, it is beneficial for behavioral health social work providers to provide referral sources commensurate with the client’s income and needs, should the client have limited or no health insurance benefits. A client’s health status provides a wealth of knowledge about mobility, availability, and other barriers to treatment.

**Mental health/suicidal ideation.** During clinical assessment, it is vital that clinicians identify psychosis, any previous history of suicidal ideas or gestures, and medication use (dosage, duration of use, compliance, benefits, or concerns). In addition, behavioral health social work providers are encouraged to identify self-injurious behaviors (cutting, binging, or purging) that suggest elevated risk as a prelude to treatment. It is useful to recognize any recent hospital admissions to inpatient psychiatric units or outpatient medical services (location, duration, interventions, and techniques).
outcomes). If any of these issues are present, it is necessary to assess the client’s mental stability before beginning any treatment intervention/modality. Identification of mental instability prior to beginning a new treatment intervention allows behavioral health social work providers to demonstrate concern for clients by making referrals to hospitals or other needed services.

**Substance use disorders.**
Social work providers are encouraged to inquire about active substance use disorders by asking clients about the last use of drugs, frequency of use, duration of use, treatment episodes, completion of treatment, and actions taken to maintain abstinence. Clients diagnosed with mental illness often have or are at risk of developing a substance use disorder. When mental illness or physical illness occurs simultaneously with a substance use disorder, it is referred to as comorbid or dual diagnosis (National Institute of Drug Abuse, 2009). Clients are encouraged to report substance use disorders and avoid using nonprescription drugs concurrent with psychotropic medications to avoid continuing or worsening symptoms. Some mental health disorders and substance use disorders have similar symptoms. Before a definitive mental health diagnosis can be made, clients may require hospitalization in a safe environment where symptoms can be identified and managed with medications by a trained psychiatrist and treatment team. Clients prescribed psychotropic medications should avoid using nonprescription drugs owing to the increased risk of self-harm.

**Psychosocial issues.** Clients face many issues endemic to the current financial crisis, including employment loss, housing loss, domestic issues, budgeting, adult children returning home, homelessness, and child placement in the child welfare system. When issues arise that are outside of the social work provider’s scope of practice, clients should be referred to competent service providers who are able to meet clients’ needs. Social work providers are also encouraged to consult with colleagues and engage in continuing education.

**Client readiness for treatment.** Clients can provide insight into their readiness to develop a therapeutic alliance with clinicians by demonstrating willingness to schedule sessions and complying with appointment times. Other indications of motivation for treatment include contracting for safety, signing all releases, adhering to payment schedules, rescheduling appointments in a timely manner in the event of emergencies, communicating effectively regarding goals and progress in therapy, and completing any homework assignments. Clients provide verbal and behavioral cues suggestive of treatment approaches that might be congruent with their needs.

**Previous treatment experiences.** Insight into a client’s experiences with and reactions to previous treatment approaches can be gleaned during the assessment period. Many clients are educated consumers and are Internet savvy, so they may know about their diagnosis and be willing to provide what medications have been most effective for them. Social work providers are encouraged to gauge client reports of previous experiences when determining future treatment approaches.

**TREATMENT APPROACHES**

**PHARMACOLOGY-ONLY APPROACH**
Often clients are resistant to individual therapy, group therapy, or pharmacological interventions. The availability of a wide range of psychotropic medications creates a plethora of opportunities for clients to receive medications that are less toxic and have fewer side effects than those previously available. New
psychotropic medications provide multiple opportunities for clients to work with their physicians to find the most effective medication(s) to control unwanted symptoms and side effects (e.g., dry mouth, weight gain, delusions, and nightmares). Pharmacology-only interventions may be consistent with the client’s wishes but trigger lasting or temporary side effects (Bolton, Sareen, & Reiss, 2006). Clients seeking pharmacological interventions should be educated about these side effects so that they can make an informed decision relative to the risks and the benefits of pharmacological interventions.

Special concerns. Children ages 12 to 20 who are linked to the juvenile justice (JJ) and child welfare (CW) systems present special concerns. Moses (2008) reported that users of psychotropic medication within these populations are more susceptible to drug treatment misuse (antipsychotics, mood stabilizers, and multiple drugs). Drug treatment misuse is often attributed to the absence of advocates focused on the best interest of the child and limited oversight. Furthermore, the JJ and CW systems have fewer staff, which may increase the likelihood of coercive, excessive, or inappropriate treatments. Other concerns include the tendency of African American and Latino youth to not see the need for medications and to avoid using them, and their desire to work problems out on their own (Leslie et al., 2003).

Challenges when using pharmacology-only therapies. Pharmacology-only interventions likely require periodic lab tests to verify medication compliance and assess toxicity in the client’s system. Pharmacology-only interventions require clients to be responsible for obtaining their prescriptions in a timely manner and reporting problematic or unwanted effects. Pharmacology effectiveness varies among diverse populations. What works effectively in African American clients may be ineffective in Asian populations. Clients are encouraged to educate themselves about medication side effects prior to use and to comply with medication directions. They should note and communicate their level of satisfaction with psychotropic medications to the prescriber. Any unwanted effects of medications should be promptly reported to the prescriber.

Clients are encouraged to be persistent with providers when trying to find the best medication, as there are many psychotropic medications. They should also avoid discontinuing medications without discussing it with their physicians, as some medications may cause adverse withdrawal effects when discontinued abruptly (Potential adverse effects, 2010). Other barriers to use of psychotropic medications may include clients forgetting to take medications and being prescribed multiple medications. Hence, pharmacology-only interventions are viable treatment alternatives, but often require joint efforts of the client (or client’s representative), prescriber, and behavioral health social work provider. Clients often report negative side effects of medications to their therapist. Clients may feel more comfortable reporting undesirable side effects to their behavioral health social work provider rather than their prescriber. Therefore, behavioral health social work providers often mediate for clients and facilitate quality behavioral health service delivery to clients.

THERAPY-ONLY APPROACH
When clients report (1) aberrations with respect to medication side effects and (2) stigma associated with taking psychotropic medications, therapy-only interventions may be in their best interests. However, many clients may not be appropriate for therapy. Alternatives to therapy are requisite when a client has a history of acting out in therapy settings or has a psychotic disorder, which might inhibit the client’s ability to participate in a session or create a danger to self or others. The role of the social work provider always encompasses educating clients and directing them to the most appropriate treatment modality. Other factors that can affect treatment modalities employed include but are not limited to the cost of the modality, availability of the modality, and therapist availability and specialization.

When there are no psychiatric symptoms warranting psychotropic medication use, the client has been concerned about the presenting issue for a limited time, and the issue is not severe, therapy only might be the best modality. For instance, clients presenting for problem solving or assistance with concrete issues might require brief interventions. Motivational, problem-focused, and cognitive behavioral therapies are considered brief therapies. In contrast to problem solving, clients presenting with trauma issues may require exposure therapy that warrants protracted therapy sessions, including extensive assessment, education, cognitive restructuring, development of new coping styles, limit setting, anger management, and safety planning. When clients request therapy, meet the time constraints for therapy, and have prior experience with therapy, they may be best served through therapeutic interventions. Some of the more popular therapeutic interventions include cognitive behavioral therapy, dialectical behavioral therapy, exposure therapy, eye movement desensitization, and reprocessing therapy.

Benefits of therapy. Therapy, whether provided individually or in group format, provides the opportunity for clients to obtain a diverse perspective with regard to problem identification and resolution. Therapeutic group members likely encapsulate myriad life experiences, knowledge, and opinions that can enhance learning and perspective for clients. Groups also foster opportunities for reflection through the reports of group members, as well as possibilities for socialization post group. Of even greater significance is the opportunity for normalization of an issue that was experienced in
isolation to be re-experienced in a way that makes it manageable. Therapeutic individual or group sessions can be beneficial and rewarding for behavioral health clients.

**Challenges in the use of therapy.** In general, social work providers are responsible for guiding individual and group sessions. Often clients engage in testing or challenging boundaries established by the behavioral health social work provider or group facilitator. Before they begin group or individual therapy sessions, clients need to be educated. Education should include the opportunity for clients to sign contracts and release of information forms, and to understand group rules and processes that can be anticipated in group or individual sessions. Therapy participants may have idiosyncrasies that they want to have acknowledged. They also need to be permitted to express their expectations for treatment. In short, some clients may benefit more from individual sessions versus group sessions or vice versa. Behavioral health social work providers can use diagnosis to gauge how clients might be best served. The behavioral health social work provider or facilitator in conjunction with the group members reserves the right to ask someone who does not comply with the rules to leave the session. Either clients or behavioral health social work providers determine when clients have obtained maximum benefit from treatment.

**COMBINATION APPROACH**
Clients may need to take psychotropic medications when experiencing symptoms that inhibit their functioning at home, work, or in social settings. However, once symptoms are stabilized, it is often beneficial for clients to participate in therapy that will permit them to receive feedback, education, insight, nonthreatening confrontation, and an opportunity to experience new ways of learning, thinking, behaving, and socializing. Group therapies should not be excluded as effective modalities for clients.

**SUMMARY**
Social work providers are intrinsically involved with treatment delivery. They administer clinical services and may participate as members of teams that work in tandem in behavioral health delivery systems. Clients are likely to report pharmacological issues and other complications of treatment interventions to their social work providers. In turn, social work providers need to educate clients about their rights and the role of providers, and be instrumental in reporting pharmacological under- or overuse when applicable. Behavioral health and health encompasses the assessment, treatment, and evaluation of service provision to clients presenting with co-occurring disorders. During assessment and interaction with clients, social work providers must listen for vital information that they can use to gauge the most effective approach in treating clients.

**Pharmacological treatments and best practice therapeutic interventions can be used alone or in combination to facilitate change in client populations. Clients are encouraged to educate themselves about the various therapies available to them and to actively participate in the chosen intervention by reporting problems and benefits throughout treatment. Clients incapable of informed consent require oversight by an interested party in efforts to preempt over- or undertreatment. It is imperative that clients communicate with their prescriber and other members of their treatment team with a goal of enhanced behavioral health.**

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**REFERENCES**

Clinical social workers interested in learning more about treating anorexia nervosa will find this book useful. It reflects an applied approach to anorexia nervosa utilizing the social work profession's general perspective of person in environment. Written by seasoned clinical social worker Dr. Maria Baratta, the book views the disease and its treatment through an additional lens, the feminist sociobehavioral perspective.

Dr. Baratta examines the individual and societal aspects of the eating disorder. The book begins with an overview of anorexia nervosa, including diagnostic features and comorbid disorders according to the DSM-IV-TR. The text also explores the historical development of anorexia nervosa, including a discussion of the cultural elements of the disease (religion and class). Nonpsychiatric explanations are discussed as well, providing the reader with multiple vantage points to evaluate the eating disorder and information to incorporate into clinical judgment and therapeutic process.

Clinical social workers will appreciate the pragmatism with which therapeutic and treatment models are addressed. The topics are covered in a structure intuitive to the therapeutic process, with the brevity often needed in the practice setting. Case studies are included and provide examples of the author's use of clinical interventions and theory. Guidelines for weight management and self-care are the final portion of the book, highlighting concrete and philosophical shifts salient to healthy eating. This information serves as a readily accessible reference for the practitioner.

Dr. Barrata acknowledges in the text's introduction that the focus is the female population. So, to ensure cultural competence, practitioners interested in working with men with anorexia nervosa will need to seek out additional information and resources on how anorexia nervosa affects these women uniquely.

For more information about Skinny Revisited: Rethinking Anorexia Nervosa and Its Treatment and other books published by the NASW Press, please visit www.naswpress.org.

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