

# PRAXIS

Where Reflection & Practice Meet

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# PRAXIS

## Where Reflection & Practice Meet

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The School of Social Work at Loyola University Chicago created *Praxis: Where Reflection & Practice Meet* to give voice to the scholarly work of students and alumni. Our mission is to encourage and support the development of social work knowledge that will enhance the lives of the clients we serve, embody the humanistic values of our profession, and promote social justice and care for vulnerable populations. *Praxis* respects and welcomes all viewpoints.

### Editorial Policy

*Praxis* is published by students in the School of Social Work at Loyola University Chicago. The editorial board is composed of masters and doctoral social work students. The board encourages students and alumni of the School of Social Work to submit papers that provide insight into clinical, policy, research, education and other areas relevant to social work practice. Submissions are accepted throughout the year and the priority deadline for the annual Fall publication is the last day of January editorial board and edits accepted papers with permission from the authors. Papers should be no longer than 20 double-spaced pages and submitted as a Microsoft Word document file (.doc). All identifying information, including contact information, should be on a separate page. Responsibility for accuracy of information contained in written submissions rests solely with the authors. Opinions expressed in the journal are those of the authors and do not necessarily reflect the views of the School of Social Work or the Editorial Board.

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## EDITORIAL

### The Whole Picture of the Social Work Profession: Practice, Programming, and Policy

When I began my social work journey, as a freshman undergraduate student, my desire was the same as most new social work students – I wanted to help people, I wanted to make a difference, I wanted to change the world. It is, in fact, the genuine desire to “help people” that leads nearly all of us into the field. And, nearly all of us carry out that goal through some form of direct practice. I did the same. Yet, somewhere over the course of the past decade I have found for myself a new niche in the field of social work. It happened almost without my notice and with very little conscious thought on my part at all. Today, I still want to “help people”, but the means by which I feel personally compelled to do so have shifted dramatically. I have become a social work academic and consultant much more committed to policy work and organizational analysis and development than to clinical social work practice.

My experience in the field has given me a unique understanding of how policies affect clients and a strident desire to be a voice for change. My experience has also left me with powerful insights into the ways communities can be organized and empowered to make a difference in their own futures, and I have had opportunities to be privy to such inspiring work as a consultant. My experience and reputation in the field has recently afforded me several opportunities to begin to expand my professional career into the world of consultation, serving non-profits as a grant writer, program evaluator, and strategic planning leader. While this is not the niche I would have expected to fill when I began my quest to “help people” as a social worker, I am invigorated by the work I do today.

Over the past two years, I have had the opportunity to teach several policy and macro-level courses in Loyola University’s social work program, both at the graduate and undergraduate levels. These classes have been the most enjoyable part of my teaching experience thus far. As I share from my experience and passion in macro social work practice, I am continually approached after class by students eager to continue the dialogue. They often say things like, “I’m really interested in how you talk about

communities and policy. This is just not something we talk much about in other social work classes.” Other students have asked for my assistance in identifying places where they can do macro level social work internships, stating that such placements are often few and far between.

While these conversations with students are some of the most rewarding for me personally, they have also led me to reflect upon what these responses say about the picture social work students are receiving of the social work profession today. I stress in my courses that the silos of micro, mezzo, and macro social work practice should not be viewed as mutually exclusive categories. I caution students who make statements like, “I’m only interested in clinical social work practice.” I urge them to consider all of the ways that even the most clinical of social work practitioners will often encounter issues of a more macro nature. It is my sincere hope that those of us in social work academia will be cognizant of the task before us to present the whole picture of the social work profession to our students –a picture which includes equal parts practice, programming, and policy.

As I look over the articles included in this edition of *Praxis*, I am encouraged by the diversity of topics students have written on. This edition includes examples of student work and critical thinking in all three areas of social work practice –practice, programming, and policy. Articles range in topic from practice articles on memory loss and bipolar diagnosis to program articles presenting new models of group work to policy articles analyzing a range of hot topics. Given my personal commitment to presenting the whole picture of the social work profession as well as comments I have heard from students, I am proud of the range of articles we have chosen to publish this year and believe *Praxis* is doing our part to represent social work in its entirety.

Allison M. Tan, MSSA  
Doctoral Candidate  
Editor-in-Chief

## Analysis of Bipolar Disorder in Children and Adolescents:

### Changing the Diagnostic Criteria

By: W. Edward Brown

#### Abstract

*The last two decades have seen a massive shift in our understanding of bipolar disorder in terms of how it presents in children and adolescents. It has gone from being considered a very rare disorder to one that is diagnosed frequently. Surprisingly, few journal articles have questioned the nature of or reasons behind this paradigm shift. This article hopes to begin to fill that gap by providing a critique of several studies on childhood bipolar disorder. This article makes the case that clinicians, through overeager research, have informally changed the diagnostic criteria they use, resulting in the present over diagnosis of bipolar disorder in children and adolescents.*

#### Introduction

Bipolar disorder was once thought to be extremely rare in children and adolescents. One of the first texts on bipolar disorder that mentioned children was Kraepelin's 1921 text *Manic-Depressive Insanity and Paranoia*. In one of the chapters, Kraepelin stated findings of four cases of bipolar onset before age 10 (out of 903 children), or 0.4% (as cited in Wozniak et al., 1995). This view of the rarity of the disorder in children and adolescents was prevalent for the next 75 years.

In the 1980s, a few professionals began to question the traditional wisdom and began studying manic symptoms in children. G.A. Carlson's 1983 paper held that manic symptoms presented differently in children as opposed to adults (as cited in Wozniak et al., 1995). Instead of long periods of elation, he found that children were more prone to irritability and prolonged, aggressive temper outbursts. He believed that his findings should be studied more, especially implications for bipolar disorder (as cited in Wozniak et al., 1995).

For awhile, Carlson's and similar studies had limited impact on the mental health community. As late as 1990, Goodwin and Jamison reviewed 898 cases from 1977 to 1985 and found only three cases of bipolar onset before the age of 10. The *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed., text re.; *DSM-IV-TR*, American Psychiatric Association, 2000) has not changed its definition or list of required symptoms for a manic episode in children and the common perception remained unchanged.

This state of affairs received a big jolt in 1995 when Wozniak et al. published a report that found 43 children under the age of twelve, out of a sample of 262 or 16%, with manic symptoms. Since this watershed report was published, there has been a severe increase in the diagnosis of children and adolescents with bipolar disorder. In 1995, 25 children out of every 100,000 in the United States were diagnosed with bipolar disorder (Moreno et al., 2007). In 2003, that number increased to 1,003 children out of every 100,000, which is a 4,012% increase in diagnosis in a mere eight years (Moreno et al., 2007). To understand this massive shift in our diagnostics, it is important to understand the definition of bipolar disorder and how it relates to children.

#### Defining Bipolar Disorder

##### *The DSM-IV-TR Criteria*

To receive a diagnosis of bipolar disorder a person must experience changes in mood from one extreme to another (example: manic to depressed), usually with a normal state in between. If a person is experiencing rapid cycling, they will have had four or more mood episodes in a year (*DSM-IV-TR*, 2000).

A manic episode must last for at least a week (or until there is a hospitalization) and includes at least three (four if irritability is normal mood) of the

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following: grandiosity, decreased need for sleep, pressure to keep talking, flight of ideas, distractibility, “increase in goal-directed activity,” or “excessive involvement in pleasurable activities that have a high potential for painful consequences” (*DSM-IV-TR*, 2000, p. 362).

A major depressive episode must last for at least two weeks and contain at least five of nine possible symptoms. The symptoms include: depressed mood (may be irritability in children), decreased interest, weight loss (or failure to make weight in children), insomnia, change in psychomotor function, fatigue, feeling worthless or excessive or inappropriate guilt, having a harder time to think, or thinking about death (*DSM-IV-TR*, 2000). Besides noting the special exceptions for children, the *DSM-IV-TR* (2000) also makes note that somatic complaints, irritability, and social withdrawal are especially common with prepubertal patients.

It may be possible for a mixed episode to occur. A mixed episode is when the criteria for a manic episode and a major depressive episode are met, with the exception of the duration requirement, almost every day for a minimum of one week (*DSM-IV-TR*, p. 365).

The *DSM-IV-TR* (2000) also states that bipolar disorder is found in between 0.4% to 1.6% of the population. It states that onset usually occurs in a person’s early 20s and is more frequently diagnosed in women (*DSM-IV-TR*, 2000).

### ***Critiquing the DSM-IV-TR***

One notices that some symptoms are listed in the *DSM-IV-TR* (2000) under both manic and depressive episodes. The overlapping symptoms include change in sleep patterns and irritability. A lack of interest in things could also look very similar to distractibility, depending on how a person presents with the symptom. This overlap of symptoms means that a clinician needs to pay very close attention to a person’s mood state to determine when the mood changes. This can be especially difficult if the client’s usual functioning level does not require much sleep or the client is generally irritable. The clinician would then need to compensate and find other symptoms to meet the requirements.

The symptoms for a manic episode and attention deficit hyperactivity disorder (ADHD) also overlap. The symptoms of distractibility, flight of ideas,

and pressured talking are listed as symptoms for both disorders (*DSM-IV-TR*, 2000). Irritability and excessive involvement in pleasurable but risky activities, depending on the client’s presentation, could also be a symptom for either disorder (*DSM-IV-TR*, 2000; Kowatch, Youngstrom, Danielyan, & Findling, 2005). At the very end of their paper, Kowatch, Youngstrom, Danielyan, and Findling (2005) note that “irritability is not specific to mania” citing that it could be symptomatic of depression, ADHD, conduct disorder, oppositional defiance disorder, anxiety disorders, and other disorders (p. 493). It should not be surprising, then, to find that bipolar disorder is often comorbid with ADHD (*DSM-IV-TR*, 2000; Geller et al., 2000; Geller et al. 2002; Axelson et al., 2006).

Another interesting item in the *DSM-IV-TR* diagnostic requirements is the fact that they defined a major depressive episode for a child, but they did no such thing for a manic episode (*DSM-IV-TR*, 2000; Wozniak et al., 1995; Geller et al., 1998; Axelson et al., 2006; Danner et al., 2009). Many researchers believe that mania, just like depression, presents itself differently in children than in adults (Wozniak et al., 1995; Geller et al., 1998; Axelson et al., 2006; Danner et al., 2009). Several researchers claim that in the past bipolar disorder was under-diagnosed in children because clinicians were looking for the adult symptoms of mania (Wozniak et al., 1995; Geller et al., 1998; Faedda, Baldessarini, Glovinsky, & Austin, 2004; Axelson et al., 2006).

### **New Manic Definitions**

Since several vocal researchers believe that the *DSM-IV* does not define mania well for children, they have gone on to make their own definitions of mania in childhood (Wozniak et al., 1995; Geller et al., 1998; Faedda et al., 2004; Axelson et al., 2006). Faedda, Baldessarini, Glovinsky, and Austin (2004) gave the harshest condemnation of the *DSM-IV-TR* in their defense for changing diagnostic requirements for bipolar youth. They argued that many adults do not exhibit many of the symptoms for a bipolar diagnosis (Faedda et al., 2004). They also claimed that the *DSM-IV-TR* was not based on empiricism, so it would be acceptable to change the definition (Faedda et al., 2004). A specific example of those diagnosed with bipolar disorder not exhibiting symptoms is that elation and grandiosity, the centerpiece for one study leading to

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the diagnosis criteria in the *DSM-IV-TR*, does not occur in all adults with bipolar disorder, meaning that it is possible that bipolar disorder is being under-diagnosed (Kowatch et al., 2004). Appendix A, found after the References in this article, demonstrates the major differences and results between the various studies discussed herein.

### ***Irritability and outbursts***

Wozniak et al. (1995) followed the advice from Carlson (1983, as cited in Wozniak, et al., 1995) and decided to focus on irritability and prolonged, aggressive temper outbursts to diagnose a manic episode. They also removed the three overlapping symptoms between mania and ADHD and reassessed the client to make sure the diagnosis was correct (Wozniak et al., 1995). They found a 16% prevalence rate in their sample of 262 (Wozniak et al., 1995). Of the 43 manic children, 42 of them also had ADHD and nearly 30 of them reported symptom onset before age five (Wozniak et al., 1995). Thirty-six or 84% of the manic children were boys (Wozniak et al., 1995).

### ***Euphoria***

Geller et al. (1998) argued that, for many youth, irritability is their normal personality trait. They decided that a bipolar diagnosis must include an episode of euphoria, which would help make sure they did not mistakenly diagnose ADHD. They also increased the necessary duration period from one to two weeks in order to make their study stronger (Geller et al., 1998). Their study used 93 youth, who were diagnosed with bipolar disorder based off the criteria created, rather than the *DSM-IV* criteria (Geller et al., 1998; Geller et al. 2000; Geller et al. 2002). Of those, 57 (61%) were boys (Geller et al., 1998; Geller et al. 2000; Geller et al. 2002). The comorbidity with ADHD was 92% overall, but when you break it down by gender 56 (98%) of the boys had a comorbid diagnosis versus 25 (69%) of the girls (Geller et al., 2000; Tillman et al. 2003). This study found that rapid cycling, as defined by the *DSM-IV*, never occurred (Geller et al., 2002). They found that ultra-rapid cycling, defined as a mood episode occurring 5 to 364 times a year, occurred in 10% of the patients and continuous cycling, more than 365 times a year, occurred in 77% of the sample (Geller et al., 2000; Geller et al. 2002).

### ***Bipolar disorder not otherwise specified***

Another clinical study chose to change the *DSM-IV-TR* criteria even more. Axelson et al. (2006) chose to concentrate on bipolar disorder not otherwise specified for their youth. In this study, bipolar disorder was defined as at least two *DSM-IV-TR* manic symptoms, three if irritability was the standard mood, which is one less symptom than the *DSM-IV-TR* specifies (Axelson et al., 2006; *DSM-IV-TR*, 2000). They also decided that there needed to be a clear change in functioning and redefined duration of a mood or symptom as lasting at least four hours in a day for at least four days, which do not have to be consecutive (Axelson et al., 2006). He studied 438 youth diagnosed with bipolar disorder from a university clinic or by their criteria (Axelson et al., 2006). Fifty-three percent of their sample was male with the average age of onset around nine years old (Axelson et al., 2006). Their study found a comorbidity with ADHD of 60% (Axelson et al., 2006).

### ***Mood changes***

Another group kept hardly any of the *DSM-IV-TR* criteria (Faedda et al., 2004). Instead, they were interested in mood changes from the baseline (Faedda et al., 2004). In this study, mood changes must have occurred repeatedly or intermittently and they must have been associated with clinically significant disability or functional impairment (Faedda et al., 2004). They waived the *DSM-IV-TR* duration requirement completely (Faedda et al., 2004). The symptoms that were discovered to occur most frequently were mood instability, irritability, dysphoric onset, and sleep disturbance (rather than needing less sleep) (Faedda et al., 2004). Of the 82 children purported to have bipolar disorder, 54 (65%) were boys (Faedda et al., 2004). Using the same definitions as Geller and colleagues (2002) for cycling patterns, this study found that 7% experienced rapid cycling, 12% experienced ultra-rapid cycling, and 66% experienced continuous cycling (Faedda et al., 2004). Of note is that this study claims the average age symptoms first occurred was 2.8 years old; participants first received treatment at an average age of 6.8 and were first diagnosed with bipolar disorder at an average age of 9.6 (Faedda et al., 2004). The first symptom reported at such a young age was sleep disturbance, as remembered by the parents (Faedda et al., 2004). It is uncertain what diagnostic criteria was used when the children were first

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diagnosed with bipolar disorder; however, because they were in the study, they all met the extra requirements of Faedda et al. (2004).

### ***Complications in Defining Bipolar Disorder***

The wide variety and competing clinical criteria for bipolar disorder create a major problem in understanding the prevalence of bipolar disorder. Kowatch et al. (2005) performed a meta-analysis on seven studies, including some of those described above, to see how consistent the studies were with their criteria. It was decided that, overall, the various studies were very consistent in defining and diagnosing bipolar disorder based on similarities of the symptoms for mania (Kowatch et al., 2005). Appendix B shows the distribution of symptoms for the seven studies.

Note that while the weighted means in all the studies are very similar, they have a very wide range, which this author feels detracts from the argument of consistency. Kowatch et al. (2005) did note that the only symptom constant throughout all cases was pressured speech, with the appearance of other symptoms dependent upon age. For instance, they found that the younger a person was, the more reported distractibility, irritability, and poor judgment occurred (Kowatch et al., 2005).

Knowledge of young children leads to an expectation of this result. Those who interact frequently with young children know that young children do not have good attention spans, are prone to irritability (especially around age two and three), and often exhibit poor judgment. In fact, those mannerisms appear to be relatively normal developmental behaviors (Lesser and Pope, 2011). Without being a part of the research team, one is left to trust that those behaviors were elevated from normal levels and significantly impaired functioning.

### **Continuity of Symptoms from Youth to Adulthood**

Obviously, if one changes the diagnostic measurements for bipolar disorder, than one is going to come up with different results than the standard body of knowledge as recorded in the *DSM-IV-TR*. One of the complications of this penchant is that there is no continuity between adolescent bipolar disorder and adult bipolar disorder (Wright, 2004; Moreno et al., 2007; Danner et al., 2009). For instance, from 1999 to 2003, Moreno et al. (2007) found that about two-thirds of adults diagnosed as bipolar were women, which is

similar to what the *DSM-IV-TR* (2000) says should occur in terms of gender-diagnosis relationships. During that same time, two-thirds of youth diagnosed with bipolar disorder were boys (Moreno et al., 2007). Similarly, co-morbidity of bipolar disorder with ADHD is higher in children than in adults (Moreno et al., 2007). Ultra-rapid and continuous cycling were also common occurrences with childhood bipolar disorder (Geller et al., 2000; Geller et al. 2002; Faedda, 2004). In adults, ultra-rapid and continuous cycling is considered very rare except in cases of hospitalization for bipolar disorder (Geller et al., 2000; Geller et al. 2002; Faedda, 2004; Kramlinger & Post, 1996; Moreno et al., 2007). Furthermore, it is not certain how some youth will grow out of symptoms during adolescence (Lewinsohn, Klein, & Seeley, 2000; Wright, 2004; Moreno, et al., 2007). Nor is it understood why medication does not work for many youth (Wong, Murray, Camilleri-Novak, & Stephens, 2004; Wright, 2004; Moreno et al., 2007).

One recent study that followed the *DSM-IV-TR* criteria unsurprisingly had results that were in line with the standard conclusions listed in the *DSM-IV-TR* (Lewinsohn et al., 2000; *DSM-IV-TR*, 2000). Lewinsohn, Klein, and Seeley (2000) tracked 1,507 children through adolescence and followed up with 893 of them at age 24. This study found a total of 1% of adolescents who met the requirement for bipolar disorder, expanding to 2% during young adulthood (Lewinsohn et al., 2000). It was found that 4.4% of adolescents presented with sub-threshold symptoms of bipolar disorder, expanding to 5.3% in young adulthood (Lewinsohn et al., 2000). The study also found that 70% of diagnosed cases were female, in line with statistics in the *DSM-IV-TR* (Lewinsohn et al., 2000; *DSM-IV-TR*, 2000).

### **“Begging the Question”**

Along similar lines, many of the studies appeared to “beg the question” (Wright, 2004). Begging the question is when what should be the conclusion is used as the premise for investigation (Wright, 2004). In this case, many studies asked *how* childhood bipolar disorder is different and answered that it is different (Wright, 2004). To be a little more concrete, several studies (Wozniak et al., 1995; Geller et al., 1998; Geller et al. 2000; Geller et al. 2002; Faedda et al., 2004; Axelson et al., 2006) found youth that fit the researchers' definition of bipolar disorder and then studied the phenomenology of bipolar disorder in those

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youth. The results of their study reinforced their diagnostic material (Faedda et al., 2004; Axelson et al., 2006). These studies generally tell us very little because they do not adequately prove that the youth in the study have bipolar disorder - readers have to take their word for it. This criticism is not to say that all the studies are useless, however.

### Contributions of the New Studies

Although Geller et al. (1998) used the same form described above, their requirements for a manic episode were stricter than the *DSM-IV-TR* and they had two control groups: one of youth with ADHD and another with no diagnoses. The two control groups allowed them to compare symptoms across these three groups, which demonstrated that there were significant differences in these populations (Geller et al., 2002).

Another useful result from this study is that Tillman et al. (2003), using the same data, compared the age of onset for various disorders. It was found that ADHD usually began around five years old, mania close to seven, oppositional defiance disorder a little past seven, and conduct disorder around 10.5 years old (Tillman et al., 2003; Geller et al., 2002). These results could be helpful in proving that what is presently being diagnosed as childhood bipolar disorder is something different from ADHD, important to learn because of overlapping symptoms between the two disorders. These results may also perhaps help establish a standardized criteria for diagnosing bipolar disorder.

### How Biology Informs the Discussion

With all the conflicting information and results from differing sources, who should be believed? A good place to resolve this issue would be information from biology to see if there is a type of abnormality found in individuals with bipolar disorder. If there is a scientific cue, it may be possible to study those individuals to get a universally accepted phenomenology of bipolar disorder in children and adolescents.

The *DSM-IV-TR* acknowledges that there could be a biological component to bipolar disorder. If the parent has bipolar I disorder their child has a 4-24% chance of also being diagnosed bipolar, while the offspring of individuals with bipolar II disorder have a much lower chance (1-5%) of being diagnosed with bipolar disorder (*DSM-IV-TR*, 2000).

### Genetics

Genetically, scientists have begun to find abnormalities on chromosome-18 for people who have a bipolar diagnosis; however, these results have been mixed, and some studies point to other chromosomes being effected (Nurnberger & Foroud, 2000). This could mean that bipolar disorder affects many chromosomes, that it is not genetic, or that some of the people studied were misdiagnosed (Nurnberger & Foroud, 2000).

### Neuroscience

Neuroscience has begun to yield more positive results. Studies of bipolar adults found that those with bipolar disorder had an abnormal (larger or smaller) amygdala compared to individuals without bipolar disorder (Chen et al., 2004). The amygdala is responsible for direct emotional responses, especially regarding fear or anxiety (Chen et al., 2004). The general trend is for the amygdala to decrease with age (Chen et al., 2004). This process starts in adolescence when brain cells start getting pruned; however, one study found that the amygdala increased with age in male adolescents with bipolar disorder (Chen et al., 2004). The sample size was too small to determine if this is a real trend and more studies need to be done to determine if the abnormal amygdala is the result of biology or development (Chen et al., 2004).

In another study on the brain structure of bipolar individuals, Ladouceur et al. (2008) conducted a study comparing the brain-imaging of 20 youth, who were not themselves bipolar but had at least one parent with bipolar disorder, to 22 youth of the same age and gender who did not have a parent with bipolar disorder. The only noticeable difference between the scans was that the group of 20 youth (who had a parent with bipolar disorder) had more gray matter in their left parahippocampus and hippocampus than the control group (Ladouceur et al., 2008). The parahippocampus and hippocampus regulates stress and emotions within the limbic system (Ladouceur et al., 2008). In previous studies, people with bipolar disorder tended to have less gray matter, so the researchers believed this to be a protective factor (Ladouceur et al., 2008).

### Development

In terms of development, a lot happens between the age of two, which is one of the earliest ages symptom identification occurs (Faedda et al., 2004), and 18, which is when many studies set their age limit for pediatric bipolar disorder (Axelson et al., 2006). There



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are many differences in development based on gender (Lesser & Pope, 2011). For example, at entry into kindergarten, girls generally have better fine motor skills and grasp of language than boys do (Tyre, 2006; Lesser & Pope, 2011). Boys at that age tend to be more active, and at times more aggressive, since their brains have been exposed to testosterone since the first trimester in the womb (Tyre, 2006). During elementary school, many youth learn to grasp abstract concepts, which, with the development of language skills, will eventually allow them verbalize their emotions and hopefully diminish episodes of acting out their frustration (Lesser & Pope, 2011). Starting around late elementary school and early middle school, children will begin to individuate from their parents, a process that often creates conflict and may last through high school (Lesser & Pope, 2011). At this time, the limbic system begins to grow, helping to regulate emotions, and the prefrontal cortex begins its final growth spurt, completing around age 11 for girls and 18 months later for boys (Lesser & Pope, 2011; Tyre, 2006; Giedd et al., 1999). This means that boys generally lag behind girls in their ability to make rational decisions. When puberty hits, it increases the amount of chemicals running through the body, which can cause rapid mood swings (Lesser & Pope, 2011). Puberty, along with slower development of the prefrontal cortex, lead to impulsivity, mood changes, grandiosity, exaggeration, and at times a return to concrete thinking (Lewinsohn et al., 2000; Tyre, 2006; Lesser & Pope, 2011).

When looking at development, it is important to remember that every individual is unique and will develop in his or her own time (Lesser & Pope, 2011). Overall, the vast developmental changes that people go through during this time can serve to frustrate diagnosing individuals. This author believes that it is always important to look at the duration and magnitude of the possible symptom to make sure that it is not merely a developmental phase.

### Parallels with ADHD Diagnosis Trends

As stated earlier, the manic episode for adolescent bipolar disorder shares several symptoms with ADHD (*DSM-IV-TR*, 2000; Kowatch et al., 2005). Furthermore, the diagnostic trends are quite similar between bipolar disorder and ADHD in the fact that boys are diagnosed with both disorders more frequently, that adolescent bipolar disorder has a high comorbidity with ADHD, and a few studies appear to indicate that

ADHD is a precursor to bipolar disorder in children and adolescents (Wozniak et al., 1995; *DSM-IV-TR*, 2000; Geller et al., 2000; Geller et al. 2002; Tillman et al., 2003; Wright, 2003; Kowatch et al., 2005; Axelson et al., 2006; Moreno et al., 2007). Some are also questioning whether both disorders are being over-diagnosed. While an in-depth analysis of the reasons for diagnosing ADHD is beyond the scope of this paper, the subject will be briefly discussed here, since it shares many similarities with bipolar disorder.

To many people it appears as though the schools are ill suited to meet the developmental needs of boys (Tyre, 2006; Kimmel, 2006). As discussed above, boys are much more active, with their brains seeped in testosterone since they were in the womb (Tyre, 2006). Their language skills lag behind girls, as does the maturation of their prefrontal cortex and fine motor skills, like holding a pencil (Giedd et al., 1999; Tyre, 2006; Lesser & Pope, 2011). All of this means that sitting quietly at their desk and talking about the reading or math is ill-suited for many boys (Kimmel, 2006). It has been demonstrated that these children, in frustration, are likely to get depressed and begin to act out in class, causing the disruptions (Tyre, 2006; Bauermeister et al., 2007). This will flag them as “trouble” children, leading to a possible referral to special education for emotional difficulties. In many cases, the investigation for special education is an intimidating process for many families, and it is possible for many parents to be cowed or relieved into accepting a diagnosis of ADHD and/or bipolar disorder (Arndt, Konrad, & Test, 2006).

The above intellectual exercise is perhaps not so outlandish. Boys outnumber girls in remedial classes across the country by a rate of two to one, generally due to behavioral concerns (Kimmel, 2006; Tyre, 2006). Wright (2004) also gives anecdotal evidence that of the dozens of children he has seen with a bipolar diagnosis, less than five of them met the *DSM-IV-TR* criteria. The symptoms that most of the youth presented with were symptoms of something deeper that was resolved through therapy and not medication (Wright, 2004).

### Possible Explanations

Why would professionals seek and parents accept what may be natural behaviors given the environmental context? There is certainly the possibility that blaming a disease, like bipolar disorder, takes the responsibility for the behavior out of the parents' and professionals' hands and instead blames it on the

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disorder (Tyre, 2006; Moreno et al., 2007). A mood disorder offers some hope for a speedier treatment through medication. The thinking goes that there will be no need for long-term treatments, behavioral corrections, or the need to adapt the environment because the medicine will solve the problems and it is cheaper (Goodwin, 2003; Kimmel, 2006; Tyre, 2006). Another possibility is that with the increase of people with insurance coverage, the insurance companies have greater power to dictate what can and cannot be treated; so it becomes necessary for more serious diagnoses, like bipolar disorder, to be given in order for insurance to cover treatment (Kimmel, 2006).

A little counter-intuitively, one study found that in-patient units diagnose bipolar more frequently than community mental health clinics, but perhaps this is because they see more severe cases (Danner et al., 2009). A similar study found that psychiatrists at clinics gave the diagnosis more commonly than pediatricians, but that could be for the same reason that pediatricians referred the more complicated cases to psychiatrists (Tillman et al., 2005).

The apologetics within academia claim that an increased awareness of the disorder in children has rectified the previous under-diagnosis of bipolar disorder (Axelson et al., 2006; Faedda et al., 2004; Geller et al., 2002; Tillman et al. 2003; Tillman et al. 2005; Danner et al., 2009; Wozniak et al., 1995; Moreno et al., 2007). They site that the same pattern occurred with major depressive disorder, obsessive compulsive disorder, and panic disorders in youth as well (Danner et al., 2009). Another argument points out that Kraepelin, in his 1921 text, wrote that childhood was defined as people under the age of 10, which is not the case anymore (Wozniak et al., 1995; Danner et al., 2009). Early studies, citing very small percentages of bipolar children, refer to just that specific demographic (Wozniak et al., 1995; Danner et al., 2009). Finally, the apologetics note that each subsequent generation tends to be diagnosed earlier than the previous one (Danner et al., 2009). However, none of these arguments explain why bipolar disorder presents so significantly different in children and adolescents than it does in adults.

### The Case for Over-Diagnosis

It does appear as though bipolar disorder may be getting over-diagnosed in children and adolescents. The fact that many clinicians and researchers have started to create their own standards for bipolar

disorder, ignoring the *DSM-IV-DR*, contributes to the argument that it is being over-diagnosed currently. Furthermore, this jump in diagnosing bipolar disorder has only occurred in North America while the rest of the world still sees it as a very rare disorder in young patients (Goodwin, 2003). Perhaps this is because much of the world still utilizes the *DSM-IV-TR* symptomatology instead of creating new ones.

A further reason that it appears bipolar disorder is being over-diagnosed is the fact that it is being diagnosed primarily in boys during youth and women during adulthood (Moreno et al., 2007; Wright, 2003). This may be evidence of cultural bias in diagnosis, but this author feels it is more evidence of over-diagnosis. Along with the higher rates in boys, there is also a higher comorbidity with ADHD in young cases as opposed to adult cases (Moreno et al., 2007). This then ties into the question of whether ADHD is being over-diagnosed in boys, especially in the schools. How are we certain that what we are labeling as bipolar disorder in children and adolescents is not in fact a completely different disorder with its own unique phenomenology?

### Recommendations for Further Research

This author could not find a single scholarly, peer-reviewed article researching any of the above possible connections. Instead, the citations above come from either speculations at the end of an article or an article published in the news media. Similarly, there are very few articles published that question the nature of the research on bipolar disorder in youth. Most articles build on one another in support of a new standard (Wright, 2004). There is a disjoint between what is happening in academia and what is being reported in the press. Every few years the press raises the specter that our children are being over-diagnosed and over-medicated—a view that, if shared in academic journals, is not often publicized (Wright, 2004).

Thus it becomes imperative for new research to investigate many of these questions. The most pressing questions to study should investigate if there are significant biases in diagnosing bipolar disorder in children and adolescents (examples include: blaming the disease, pressure from insurance companies, environmental/developmental causes, etc). It is just as important for more studies to look at how a manic episode presents in youths – is it truly different than an adult episode? Furthermore, there should be studies, longitudinal and otherwise, to find out why there is no

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apparent continuity between bipolar disorder in adolescents and adults; such studies may come up with a clearer, more universally agreed upon, symptomology of adolescent bipolar disorder.

### Implications for Practice

Understanding current diagnostic trends of bipolar disorder is vital for social workers serving children and adolescents. When working with a young client previously diagnosed with bipolar disorder, it may be necessary to reevaluate the client and take another look at the diagnosis, especially if medication is not working. It may be possible that the individual was diagnosed based on a new formula and not the *DSM-IV-TR*. For clinicians and school social workers, it is important to be aware of the surge in diagnoses and realize that many of the new techniques employ scales that do not use the *DSM-IV-TR* criteria, in order to prevent a misdiagnosis that would have significant negative repercussions for the client. Advocacy for students and families during special education processes

may be vital, and relationships with appropriate clinicians should be developed.

### Conclusion

The symptoms needed for diagnosing bipolar disorder in young clients remain unclear at this time. More research needs to be done in order to create a universal agreement on the phenomenology of childhood bipolar disorder that does not “beg the question” (Moreno et al., 2007).

It may be possible that Wozniak and others are correct in their assertions, but a 4012% increase in diagnosed cases seems a bit unbelievable for an eight year period (Moreno et al., 2007). Until other studies are completed, in a valid and reliable fashion, that support the new phenomenology, clinicians should stick to using the *DSM-IV-TR* criteria for diagnosing bipolar disorder. To do otherwise and create other methods for diagnosis runs the risk of misdiagnosing a client.

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### References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed., text rev.). Washington, DC: Author
- Arndt, S.A., Konrad, M., & Test, D.W. (2006). Effects of the self-directed IEP on student participation in planning meetings. *Remedial and Special Education, 27*(4), 194-207. doi: 10.1177/07419325060270040101
- Axelson, D., Birmaher, B., Strober, M., Gill, M.K., Valeri, S., Chiappetta, L., ... Keller, M. (2006). Phenomenology of children and adolescents with bipolar spectrum disorder. *Archives of General Psychiatry, 63*(10), 1139-1148. doi: 10.1001/archpsyc.63.10.1139
- Bauermeister, J.J., Shrout, P.E., Chávez L., Rubio-Stipec, M., Ramírez, R., Padilla, L., ... Canino, G. (2007). ADHD and gender: are risks and sequela of ADHD the same for boys and girls?. *Journal of Child Psychology and Psychiatry, 48*(8), 831-839. doi: 10.1111/j.1469-7610.2007.01750.x
- Chen, B.K., Sassi, R., Axelson, D., Hatch, J.P., Sanches, M., Nicoletti, M., ... Soares, J.C. (2004). Cross-sectional study of abnormal amygdala development in adolescents and young adults with bipolar disorder. *Biological Psychiatry, 56*(6), 399-405. doi: 10.1016/j.biopsych.2004.06.024

## Analysis of Bipolar Disorder in Children and Adolescents

- Danner, S., Fristad, M.A., Arnold, L.E., Youngstrom, E.A., Birmaher, B., Horwitz, S.M., ... The LAMS Group (2009). Early onset bipolar spectrum disorder: Diagnostic issues. *Clinical Child and Family Psychology Review*, 12, 271-293. doi: 10.1007/s10567-009-0055-2
- Faedda, G.L., Baldessarini, R.J., Glover, I.P., & Austin, N.B. (2004). Pediatric bipolar disorder: Phenomenology and course of illness. *Bipolar Disorders*, 6(4), 305-313. doi: 10.1111/j.1399-5618.2004.00128.x
- Geller, B., Williams, M., Zimmerman, B., Frazier, J., Beringer, L., & Warner, K.L. (1998). Prepubertal and early adolescent bipolarity differentiate from ADHD by manic symptoms, grandiose delusions, ultra-rapid or ultradian cycling. *Journal of Affective Disorders*, 51(2), 81-91. doi: 10.1016/S0165-0327(98)00175-X
- Geller, B., Zimmerman, B., Williams, M., Bolhofner, K., Craney, J.L., DelBello, M.P., ... Soutullo, C.A. (2000). Diagnostic characteristics of 93 cases of a prepubertal and early adolescent bipolar disorder phenotype by gender, puberty and comorbid attention deficit hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology*, 10(3), 157-164. doi:10.1089/10445460050167269
- Geller, B., Zimmerman, B., Williams, M., DelBello, M.P., Bolhofner, K., Craney, J.L., ... Nickelsburg, M.J. (2002). DSM-IV mania symptoms in a prepubertal and early adolescent bipolar disorder phenotype compared to attention-deficit hyperactive and normal controls. *Journal of Child and Adolescent Psychopharmacology*, 12(1), 11-25. doi: 10.1089/10445460252943533
- Giedd J.N., Blumenthal J., Jeffries N.O., Castellanos F.X., Liu H., Zijdenbos A., Rapoport J.L. (1999) Brain development during childhood and adolescence: A longitudinal MRI study. *Nature Neuroscience*, 2(10), 861-863.
- Goodwin, F. & Jameson, K. (1990). *Manic-Depressive Illness*, Oxford University Press, New York.
- Goodwin, G.M. (2003). Evidence-based guidelines for treating bipolar disorder: Recommendations from the British Association for Psychopharmacology. *Journal of Psychopharmacology*, 17(2), 149-173. doi: 10.1177/0269881103017002003
- Kimmel, M. (2006). A war against boys?. *Dissent*, 52(3). Retrieved from <http://www.dissentmagazine.org/article/?article=700>.
- Kowatch, R.A., Youngstrom, E.A., Danielyan, A., & Findling, R.L. (2005). Review and meta-analysis of the phenomenology and clinical character of mania in children and adolescents. *Bipolar Disorders*, 7, 483-496. doi: 10.1111/j.1399-5618.2005.00261.x
- Kramlinger, K.G. & Post, R. (1996). Ultra-rapid and ultradian cycling in bipolar affective illness. *The British Journal of Psychiatry*, 168(3), 314-323. doi: 10.1192/bjp.168.3.314
- Ladouceur, C., Almeida, J., Birmaher, B., Axelson, D.A., Nau, S., Kalas, C., ... Phillips, M.L. (2008). Subcortical gray matter volume abnormalities in healthy bipolar offspring: Potential neuroanatomical risk marker for bipolar offspring?. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47(5), 532-9. doi: 10.1097/CHI.0b013e318167656e
- Lesser, J.C. & Pope, D.S. (2011). *Human behavior and the social environment: Theory and practice* (2<sup>nd</sup> ed.). Boston: Allyn & Bacon.
- Lewinsohn, P.M., Klein, D.N., & Seeley, J.R. (2000). Bipolar disorder during adolescence and young adulthood in a community sample. *Bipolar Disorders*, 2, 281-293. doi: 10.1034/j.1399-5618.2000.20309.x
- Moreno, C., Laje, G., Blanco, C., Jiang, H., Schmidt, A.B., & Olfson, M. (2007). National trends in outpatient diagnosis and treatment of bipolar disorder in youth. *Archives of General Psychiatry*, 64(9), 1032-1039. doi: 10.1001/archpsyc.64.9.1032

## Analysis of Bipolar Disorder in Children and Adolescents

- Nurnberger, J.I. & Foroud, T. (2000). Genetics of bipolar affective disorder. *Current Psychiatry Reports*, 2(2), 147-157. doi: 10.1007/s11920-000-0060-0
- Tillman, R., Geller, B., Bolhofner, K., Craney, J.L., Williams, M., & Zimmerman, B. (2003). Ages of onset and rates of syndromal and subsyndromal comorbid *DSM-IV* diagnoses in a prepubertal and early adolescent bipolar disorder phenotype. *Journal of the American Academy of Child and Adolescent Psychiatry*, 42(12), 1486-1493. doi: 10.1097/00004583-200312000-00016
- Tillman, R., Geller, B., Frazier, J., Beringer, L., Zimmerman, B., Klages, T. Bolhofner, K. (2005). Children with a prepubertal and early adolescent bipolar disorder phenotype from pediatric versus psychiatric facilities *Journal of the American Academy of Child and Adolescent Psychiatry*, 44(8), 776-781. doi: 10.1097/01.chi.0000164588.10200.edu
- Tyre, P. (2006, January 30). The trouble with boys. *Newsweek*, pp. 44–52.
- Wong, I.C.K., Murray, M.L., Camilleri-Novak, D., & Stephens, P. (2004). Increased prescribing trends of paediatric psychotropic medications. *Archives of Disease in Childhood*, 89(12), 1131-1132. doi: 10.1136/adc.2004.050468
- Wozniak J., Biederman J., Kiely K., Ablon J.S., Faraone S.V., Mundy E., Mennin D. (1995). Mania-like symptoms suggestive of childhood-onset bipolar disorder in clinically referred children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 34(7), 867-876. doi: 10.1097/00004583-199507000-00010
- Wright, G. (2004). Special issue on bipolar disorder. *Journal of Child and Adolescent Psychopharmacology*, 14(3), 332-334.

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**Appendix A**

Table showing demographic information and results from the studies mentioned in this paper.

<b>Researchers</b>	<b>Wozniak et al., 1995</b>	<b>Geller et al., 2000</b>	<b>Lewinsohn et al., 2000</b>	<b>Faedda et al., 2004</b>	<b>Axelson et al., 2006</b>	<b>DSM-IV-TR, 2000</b>
<b>Sample Size</b>	262	93	1507	82	438	--
<b>Bipolar Diagnoses</b>	43	93	1%	82	438	0.4-1.6%
<b>Boys (Bipolar)</b>	212 (36)	57 (57)	-- (30%)	54 (54)	-- (53.2%)	--
<b>Girls (Bipolar)</b>	50 (7)	36 (36)	-- (70%)	28 (28)	-- (46.8%)	More common
<b>Mean Ages (Onset Age)</b>	8.8 (4.4)	10.9 (7.3)	16.6 (--)	10.6 (2.8 symptoms start, 9.6 diagnosed)	12.7 (9)	-- (early 20s)
<b>Cycling: Rapid Ultraprapid Continuous</b>	--	0% 10% 77%	--	7.3% 12.2% 65.9%	--	4+ episodes in a year
<b>ADHD Comorbidity</b>	42 (98%)	92% (98% of boys & 69% of girls)	--	59.8%	59.8%	Associated feature
<b>Manic Symptoms Evaluated</b>	Removed overlapping ADHD/BD symptoms (distractibility, flight of ideas, pressured talking) – emphasized irritability	Mania must have euphoria, nor irritability. Doubled duration requirements to two weeks.	DSM III-R criteria	A symptom was a change from the base with clinically significant disability or impairment to clients. No duration requirement.	Only need 2 DSM symptoms unless irritability is one (then need 3). Duration must last 4 hours for at least 4 days	at least 3 (4 if irritability is normal mood) of the following: grandiosity, decreased need for sleep, pressure to keep talking, flight of ideas, distractibility, “increase in goal-directed activity,” or “excessive involvement in pleasurable activities that have a high potential for painful consequences” (p. 362). Duration=1wk

Appendix B

Figure showing the weighted means and ranges of manic symptoms from the meta-analysis of seven different studies. (Taken from Kowatch, et al.. (2005).)

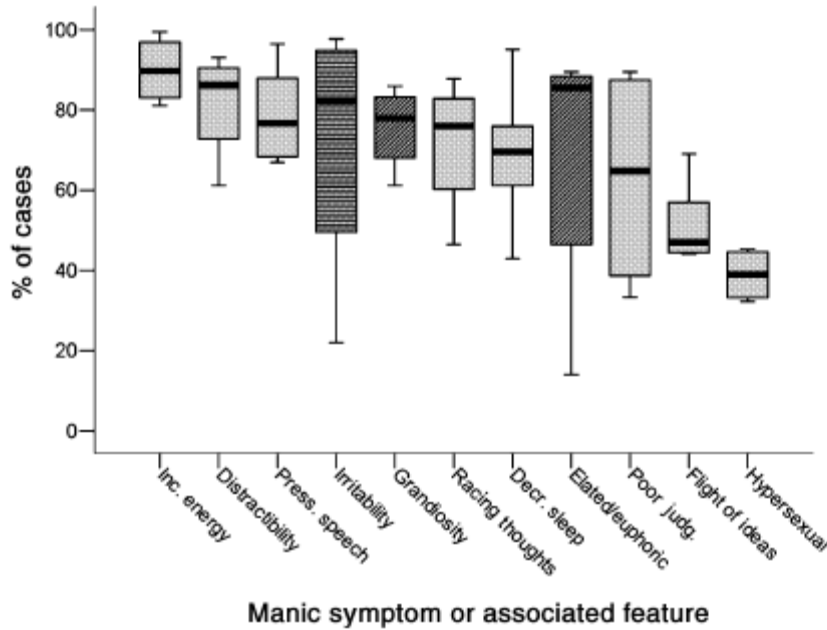


Fig. 1. Unweighted rates of symptoms of mania. Note: Symptoms are arranged in decreasing order of weighted means from Table 3. Irritability, grandiosity, and elated/euphoric mood are shaded due to their controversial status in the literature.

## Memory Loss and Preservation of Self: A Call for Social Work

By: Mia Gentiles

### Abstract

*This article identifies a demand for therapeutic social work responses to dementia care as the need rises with the aging population in the United States. Existing cognitive and behavioral interventions are defined and explored for both their utility and their shortcomings. Using a narrative lens to understand the dementia experience, this article highlights the need to place emotional care at the forefront for individuals with dementia. This piece advocates for the use of constructive, narrative models to preserve sense of self in the care of clients with dementia and calls for the field of social work to respond to this growing need. Emphasis is placed on the value of the perspective of individuals in the early stages of dementia, to learn about their disease experience, and to gather input in the planning of care models and systemic change.*

### Introduction

With dementia plaguing older adults in the United States and a sizable portion of the population approaching the ages at most risk of being diagnosed, social workers should aim to understand the meaning of the loss experience for individuals and families affected by the disease. Alzheimer's disease, the most common form of dementia characterized by memory loss, is one of the most feared and costly diseases in this country (Alzheimer's Association, 2011a). Emphasis on individuality in American culture fuels the universal dread of memory loss related to dementia, for fear that the disease will dilute individual identity (Basting, 2003). Through examination of journal writings and qualitative research responses of individuals with the disease, a further understanding of the impact of the disease for those diagnosed will be established. Using this understanding as the backdrop, this piece will explore cognitive and behavioral interventions to support dementia patients and their families. The utility of narrative approaches will be highlighted for their ability to explore patients' loss experiences and promote individuality. Today there is a call for social workers to

shape practice that uses the narrative experience and the input of dementia patients to advocate for program and treatment improvements that promote individual strengths and identities.

### The Dementia Experience: Loss of Identity in Their Own Words

Upon diagnosis the social response to a person with dementia immediately impacts that person's sense of identity. According to Langdon, Eagle, and Warner (2007), once dementia was identified as part of a person's life journey, participants became acutely aware that their social worlds were responding to them differently than prior to the diagnosis. Persons with the disease depicted the sense of no longer belonging as early as onset, a time when the very words *dementia* and *Alzheimer's disease* are problematic because of their connotations (Langdon, Eagle, & Warner, 2007). Due to noticeable changes in social responses, many described their hesitation to share their diagnosis for fear of their public worlds making conclusions about their capabilities (Langdon et al., 2007).

Accompanied with changes in a person's social world at diagnosis, the person's deepest sense of self can also waver. At the time of diagnosis there is often an inner conflict for persons to protect themselves from the implications of the disease and to accept the disease and its impending changes on level of functioning (Clare, 2003). Often viewed as denial of diagnosis, reluctance to acknowledge the diagnosis may be part of a self-maintaining stance (Clare, 2003). In addition to the desire to maintain a sense of self, those who are diagnosed experience multiple losses, "of status as a contributing social partner, loss of social and familial roles, declining abilities, and changing mood" (Ryan, Bannister, & Anas, 2009, p. 147).

Loss of social status and role were described by those with memory loss as the most devastating aspect of living with dementia. Although individuals are willing to acknowledge that the disease causes changes, what was devastating was "the sense of being no longer



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of use to the world” (Langdon, Eagle, & Warner, 2007, p. 996).

According to Swenson (2004), even an experienced social worker equates the loss of the person’s abilities with loss of personhood in her description of care giving for a family member (Swenson, 2004). Society views the person as diminished at the very start of the formal disease path. Unfortunately, this happens long before the end of life.

The degree to which societal fears of the disease fuel a profound sense of loss and force individuals to consider new classifications of their deepest self are clear in the words of persons with dementia. The societal response to dementia leads one woman to wonder, “If I am no longer a woman, why do I still feel I’m one?” (Basting, 2003, p. 94). The devastating impact is experienced as “living halfway...you will never be what you once were” (Basting, 2003, p. 94). These messages convey the serious damage to an individual’s sense of self.

### Overview of Cognitive Interventions and Behavioral Management

Interventions to address memory loss have focused on assistance with the prolongation of functioning. Because the cure for Alzheimer’s disease and related dementias is currently out of reach, social workers play a role in supporting patients and families and should plan for ongoing modifications toward competence in treating memory loss and its effects within an individual’s social environment.

Through the use of ongoing repetition and testing facilitated by a neuropsychologist, cognitive techniques focus on optimizing functioning to help patients enjoy independence and meaningfulness. (Van der Linden, Juillerat, & Adam, 2003). Within this cognitive intervention model, efforts to improve communication, reduce apathy, and assist with disorientation of clients with dementia have been implemented (Van der Linden et al., 2003). Included within these initiatives are practical interventions for caregivers to foster stronger communication between caregiver and patient, along with external memory aids to assist patients with communicating personal facts and life history to maintain quality of life through adaptive approaches to the effects of memory loss.

The Spaced Retrieval Technique (SRT) assists with the practical challenges that accompany memory

loss: maintaining the recall necessary to complete daily tasks. For example, the SRT is used not to help a client with Alzheimer’s Disease learn the steps necessary to use a cell phone, but instead to help him or her learn a single piece of information, such as to immediately look at the back of a cell phone when holding one, where explicit instructions for its use will be attached (Vance, Struzick, & Farr, 2010). Although the effectiveness of SRT becomes compromised as the severity of a patient’s dementia increases, this technique offers a way to prolong functioning and autonomy (Vance et al., 2010). An additional cognitive technique, Reality Orientation (RO) attempts to relieve the confusion of memory loss by offering information to help individuals regain a sense of control through increased awareness of time, place, and person (Spector, Davies, Woods, & Orrell, 2000).

The Progressively Lowered Stress Threshold model (PLST) focuses attention on environmental triggers that lead to behavioral problems. PLST is a framework social workers can use to help families respond to the difficult behaviors resulting from dementia, such as agitation, confusion, and wandering social workers can assist in helping families work toward management of behaviors (Toseland & Parker, 2006). PLST is a framework for responding to the difficult behaviors resulting from dementia, such as agitation, confusion, and wandering. Within PLST, challenging behaviors are explained through stress-related triggers in the person’s environment (Hall & Buckwalter, 1987). This theoretical approach to management of behaviors of persons with dementia is utilized in current care methods, with the underlying understanding that anxiousness and confusion presented outwardly signify fear within (Hall Buckwalter, 1987). Management of environmental stimuli along with unconditional positive regard are the crux of behavior management within this model (Hall & Buckwalter, 1987).

Current interventions focus on helping older adults maintain the ability to complete tasks independently for as long as a disease characteristic of progressive decline in functioning allows. Cognitive rehabilitation and its related interventions attempt to train the mind in adaptive strategies to fulfill day-to-day cognitive demands. While reality orientation and the use of a cognitive rehabilitative perspective offer increased functioning for some clients, the use of these interventions should be carefully considered for appropriateness of fit. Application of these techniques

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with some individuals may have adverse effects, because the implications of these interventions may lead to feelings of incorrectness and stress (Hall & Buckwalter, 1987). Although strategies to maintain cognitive capacity may enrich an individual's life through continued abilities and higher level of functioning when successful, they do not directly address the emotional aspects of the disease and loss of self identity described in the words of those diagnosed.

Similarly, the Progressively Lowered Stress Threshold offers a behavioral framework for addressing agitation, confusion, and fear. By framing the experiences of persons with dementia using this theory, practitioners, long-term care facility staff, and families become adept at maintaining a safe, stable environment. Although a safe environment is vital to help individuals feel stable and calm, the opportunity to process their challenged sense of self is absent in this framework. Assistance in management of behaviors is an important component for helping clients and families, but it can often take center stage and lead attention away from the emotional implications for clients with dementia. Therapeutic interactions using a narrative framework move away from pathologizing individuals with dementia to guide them toward a new way to consider their personal identity.

### Looking through a Narrative Lens

Narrative therapy for individuals with memory loss follows a social constructionist framework to help process a subjective, emotional, and ultimately personal experience. Creating a narrative in which clients and family members learn to blame the disease, rather than the person will foster externalization of the problem (Young, 2010). Narrative therapy with individuals with memory loss allows for them to deconstruct the societal values represented by the linear, productive notions prevalent in American thought (Young, 2010). The use of narrative to help a client in the early stages of dementia gain insight into his or her life as more than simply a chronological series of events along the human developmental line opens the space to continue participation in the joy that often comes with telling one's stories. Maintenance of identity can be reached through a "shift from the events or plot of a life story, to the person or character in the story, and to the story's meanings or themes" (Young, 2010, p. 201). This shift of focus from memory, time, and productivity to life themes and character traits leads individuals with

memory loss to identify their life's meaning (Young, 2010).

### Written Narratives: Benefits and Strengths

The concept of narrative in written form as an activity for processing the experience of dementia helps individuals connect to positive experiences despite the often devastating effects of diagnosis. Written narratives allow individuals with dementia to maintain social functioning and purpose at a time when these aspects of identity are in jeopardy. Engagement in writing fosters a sense of purpose and empowerment within a world where the opportunity to direct activities is lacking (Ryan, Bannister, & Anas, 2009). This activity in turn fosters self-esteem where the disease in its socialized form tends to diminish an individual's positive self-regard. Through close examination of twelve written narratives of persons with dementia, Ryan, Bannister and Anas (2009) find that writers "shatter stereotypes of incompetence" (p. 154) and demonstrate potential for growth and acceptance.

Descriptions of memory loss in journals include examples of individual strength. Authors offer a model for focus on the present, a place in which an author's "narrative voice lives in the present moment" (Basting, 2003, p. 94). An inherent challenge in the modern western world to maintain presence is overcome by these authors; their voices demonstrate an invaluable strength. The use of humor as a tool is also demonstrated within journal entries of clients, and humor offers strength in their lives. Finally, the need for purpose demonstrated within these journals is indicative of the desire to be useful in society (Basting, 2003). In addition to sharing their journey through journal writing to educate others with Alzheimer's Disease, writers sought activities to foster purpose in helping others, such as participation in research and the founding of support groups (Basting, 2003). These strengths, the ability to reflect in the present, use of sense of humor, and increased satisfaction through purposefulness in society, offer an opportunity for clinicians to work therapeutically with clients with dementia to identify and to maintain a life packed with meaning.

### Limitations and Directions for Research

Cognitive rehabilitative therapies to some extent have been deemed beneficial, if implemented properly with a person with consideration for the timing

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of the intervention and the person's disease stage. Continued examination of these interventions will offer clarity of their utility and ways to maximize their success in improving quality of life. More importantly, the emotional effect of participation in such interventions calls for further investigation. Interventions to help an individual compensate for cognitive decline have an inherent risk of damaging self-esteem in the process. In research, formal assessment of depression and/or self-esteem before, during, and after treatment periods can build professional knowledge to help individuals who experience cognitive decline maintain life satisfaction for as long as possible.

Individuals in the early stages of dementia have the ability to describe their experiences in ways that are coherent, meaningful, and insightful (Langdon, Eagle, & Warner, 2007). The individual response to the disease experience has been and should continue to be examined. Qualitative research should continue to clarify the circumstances of the disease experience. Those who have traveled into the world of memory loss can guide the rest of us, including those in helping professions, along the path of the experience as it unfolds.

### Limitations for Social Work Practice

The words of persons with dementia indicate that we must not give up on understanding the impact of the disease experience on the individual. In order to maximize the level of support offered to individuals with dementia, clinicians must "be sensitive to the psychological needs of the person with Alzheimer's as demonstrated in a way in which they describe their subjective experience, and must be ready to respond in a way that enhances well-being" (Clare, 2003, p. 1027). With a great degree of association between early memory loss and depression (Van der Linden, Juillerat, & Adam, 2003), the use of holistic interventions that enhance self-esteem and maintain sense of self may help to minimize depressive symptoms for individuals with dementia in the early to moderate stages and at time of diagnosis when the person faces tremendous anticipated losses of memory, self, social roles, and a hopeful future in old age. As older adults with dementia shared in their journals, a sense of usefulness and helping others acts as their motivation for writing and in turn, becomes a key component in improving self-esteem. The written words of these individuals demonstrate that the Western

cultural emphasis on purposefulness does not vanish upon diagnosis.

Young (2010) poignantly illustrates in her description of interventions in Narrative Therapy that individuals with dementia have the ability to identify their preferred sense of self. This is evident in her therapeutic work with Ronald, who identified problem solving and his profession as an engineer as his preferred identity and later went on to be "less angry about the limits his dementia created...he had begun to focus on solving problems around the house" (Young, 2010, p. 198). Regardless of whether tasks lead to completed projects or are limited in their usefulness to family members, Ronald's work helped him continue to identify himself as a problem solver and as a result, feel better about his place in the world. Talents, experiences, and life themes should be identified and utilized to grow a positive sense of self and positive experiences.

### Accessibility of Narrative Approaches

The field of social work should work toward responsiveness to the thoughts of these writers with dementia and the many individuals existing in a world quite separate from published academic writing; these individuals lived productive lives and are now grasping for purpose and usefulness. Design of programs to raise self-esteem and increase purposefulness is within our realm of possibility. With the input of clients who participate in these programs or spend their days grasping for ways to engage with the world as it becomes increasingly more difficult to absorb and comprehend, feedback can be solicited, programs can be modified and improved, and the seeds for research design planted. Individuals with dementia in its early stages retain the capacity to share rich information about their experiences and needs. An in-depth exploration of this information should also be included in consideration of policy-level decisions.

Program planning, modifications, and the study of interventions should demonstrate consideration of the need for interventions that caregivers and individuals with dementia can benefit from at home, that can be modified to work for persons outside of the dominant culture, and for the oppressed and impoverished. Informal caregivers of patients with Alzheimer's disease and dementia are estimated at 15 million providing over 17 billion hours of unpaid care (Alzheimer's Association, 2011b). This skyrocketing rate of informal caregivers for individuals with dementia in this country

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demonstrates the potential impact of interventions and can be understood and applied in the family home to improve quality of life in the home environment. The tool of journal writing was identified as a universal activity for those of diverse levels of education, income, or cultural background (Ryan, Bannister, & Anas, 2009). The utility of journal writing may be a start, but home-based, multicultural interventions should become a focus for social workers in the years to come.

### Conclusion

With social work's clinical lens, relationship building, and empathic approach to listen and to identify meaning, the tools are already in our professional toolbox to move toward helping individuals with

dementia maintain their identity through programmatic change and support services. Further, using a strengths-based approach, practitioners remain cognizant of diagnosed individuals' continued usefulness to society and their potential to guide change in helping strategies. With the rising population of older adults in the years to come, social work implementation of interventions to raise self-esteem is, and will remain in great demand. As scientists continue to search for effective medical interventions and hopefully cures, the field of social work needs to prepare an emotionally supportive response to individuals affected by the predicted rising disease epidemic.

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### References

- Alzheimer's Association. (2011a). *Alzheimer News* 1/04/11. Retrieved from [http://www.alz.org/news\\_and\\_events\\_Obama\\_signs\\_NAPA.asp](http://www.alz.org/news_and_events_Obama_signs_NAPA.asp)
- Alzheimer's Association (2011b). *Alzheimer's Facts and Figures*. Retrieved from: [http://www.alz.org/alzheimers\\_disease\\_facts\\_and\\_figures.asp](http://www.alz.org/alzheimers_disease_facts_and_figures.asp)
- Basting, A.. (2003). Looking back from loss: Views of the self in Alzheimer's disease. *Journal of Aging Studies*, 17(1). 87–99. doi: 10.1016/S0890-4065(02)00092-0
- Clare, L. (2003). Managing threats to self: Awareness in early stage Alzheimer's disease. *Social Science & Medicine*, 57(6). 1017–1029. doi: 10.1016/S0277-9536(02)00476-8
- Hall, G. & Buckwalter, K. (1987). Progressively Lowered Stress Threshold: A conceptual model for care of adults with Alzheimer's Disease. *Archives of Psychiatric Nursing*, 1(6), 399–406.
- Langdon, S., Eagle, A., & Warner, J. (2007). Making sense of dementia in the social world: A qualitative study. *Social Science & Medicine*, 64(4). 989–1000. doi: 10.1016/j.socscimed.2006.10.029
- Ryan, E. B., Bannister, K., & Anas, A. (2007). The dementia narrative: Writing to reclaim social identity. *Journal of Aging Studies*, 23. 145–157. doi: 10.1016/j.jaging.2007.12.018

## Memory Loss and Preservation of Self

- Spector, A., Davies, S., Woods, B., & Orrell, M. (2000). Reality orientation for Dementia: A systematic review of the evidence of effectiveness from randomized controlled trials. *The Gerontologist*, 40(2), 206–212.
- Swenson, C. (2004). Dementia diary: A personal and professional journal. *Social Work*, 49(3), 451–460.
- Toseland, R. & Parker, M. (2006). Older adults suffering from significant dementia, In B. Berkman & S. D'Ambruso (Eds.), *Handbook of social work health and aging*. (pp. 117–127). Boston: Oxford Press.
- Van der Linden, M., Juillerat, A., & Adam, S. (2003). Cognitive intervention. In R. Mulligan, M. Van der Linden, & A. Juillerat (Eds.), *The clinical management of early Alzheimer's disease: A handbook* (pp. 169–233). London: Lawrence Erlbaum Associates.
- Vance, D., Struzick, T., Farr, K. (2010). Spaced Retrieval Technique—A cognitive tool for social workers and their clients. *Journal of Gerontological Social Work*, 53(2). 148–158. doi: 10.1080/01634370903409745
- Young, E. (2010). Narrative therapy and elders with memory loss. *Clinical Social Work*, 38(2). 193–202. doi: 10.1007/s10615-008-0146-4

## Aggression Replacement Training

# Aggression Replacement Training: An Alternative to Suspensions and Expulsions for Behavioral Issues in the School Setting

By: Scarlett Stoppa, Cassie Kuzmanoff, and Sally Chavez

### Abstract

*This article considers the adverse effects school suspensions and expulsions have on the students who are suspended or expelled, the schools they attend, and the community as a whole. Empirically supported alternatives to suspensions and expulsions are suggested that are effective for reducing behavioral issues and dropout rates and are culturally competent as interventions with African American male adolescents, which happens to be the population most frequently suspended in Chicago, Illinois. One alternative, the Aggression Replacement Training (ART) program, is a cognitive behavioral intervention that targets chronically aggressive children and adolescents. This multi-modal program is evaluated for both its effectiveness at reducing behavioral issues and dropout rates in middle schools and high schools and its cultural competency for use with African American male adolescents. Suggestions for tailoring the program to better serve the target population are made.*

### Introduction

In the United States, low high school graduation rates are prevalent, with the lowest achievements seen in cities. Chicago ranks particularly low among U.S. city graduation rates, and within Chicago, black males experience the lowest graduation rates. Conversely, in Chicago, black males experience the highest suspension rates. The institution in 1994 of zero-tolerance policies in schools was originally intended to eradicate school violence, but these policies exacerbate the very problems they aim to reduce, and have resulted in increased suspensions and misuse and abuse of suspensions and expulsions by school administrators, including discriminatory practices and practices that demonstrate a lack of cultural competency, particularly with African American adolescents.

Suspensions and expulsions have been demonstrated to be a risk factor for dropout. Rather than addressing behavioral issues and employing interventions to limit behavioral issues, some schools yield under the pressure of the federal mandates for academic achievement and use their discipline policies as an exit strategy to exclude students who present problem behavior and, subsequently, poor academic achievement. Looking beyond individual struggles inherent for those without a high school diploma, dropouts reduce our country's competitive edge and are a huge financial drain on our economy.

More effective methods of intervention for students with behavioral issues must be implemented, in order to reduce dropout. Aggression Replacement Training (ART) is an empirically supported intervention program designed to alter aggressive behaviors in adolescents. It may also be a viable alternative to suspensions and expulsions for the populations seen most at risk for dropping out as a result of being suspended and expelled, particularly African American male adolescents. To determine ART's effectiveness as an alternative to suspensions and expulsions, it must be demonstrated that ART serves to reduce behavioral issues and dropout rates in middle schools and high schools. The empirically-supported behavioral-issue intervention approaches it incorporates will be explored. Additionally, this article will suggest improvements to the ART program based on effective evidence-based practices. These suggested improvements include: cultural awareness training for working with target populations (particularly concerning African American teen males); positive African American adult male role models in the implementation of ART; parental involvement; ART graduates to serve as peer mentors to new ART students; and implementing ART as a school-wide initiative to be taught in schools with high dropout rates in order to broaden its capabilities of helping a population in need.

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### Effect of Current Interventions in U.S. High School Dropout Crisis

High school dropout rates in the U.S. are profoundly high. In 2008, 7,000 students dropped out every day and only about 70 percent of students graduated from high school with a regular high school diploma (America's Promise Alliance [APA], 2008; McIntosh, Flannery, Sugai, Braun, & Cochrane, 2008; U.S. Committee on Education & the Workforce, Democrats, 2009). Within the U.S, cities experience a particularly low graduation rate. According to America's Promise Alliance, the 50 largest urban districts reported a 52% graduation rate, and the City of Chicago School District ranked 31st out of 50, with a graduation rate of 51.5% (2008).

Worthy of note, according to a press release by the U.S. Committee of Education and the Workforce Democrats, 2,000 U.S. high schools produce over half of all dropouts, and poor minority children attend these so-called "dropout factories" at significantly higher rates (2009). In Illinois, "more than half of African American students...attend high schools in which the majority of students do not graduate on time, if at all." (Balfanz & Legters, 2004, p. 2). According to official Chicago Public Schools 2007 graduation data, the school district experienced a 55% graduation rate (46% of males and 64% of females). The lowest graduation rate was seen in black males at 40% (Karpuk, 2008).

Individuals who do not graduate high school experience many difficulties, including lower incomes, frequent unemployment, higher than average rates of health problems, prison and death row incarceration, substance abuse, and dependence on government social assistance programs (McIntosh et al., 2008). Looking beyond the individual-level difficulties, dropouts cost the U.S. much more than they earn. Students who do not complete high school cost taxpayers billions of dollars in lost revenues, welfare, unemployment, crime prevention, and prosecution (McIntosh et al., 2008). According to a recent report by Columbia University's Center for Benefit-Cost Studies of Education at Teachers College, "Cutting the dropout rate in half would yield \$45 billion annually in new federal tax revenues or cost savings." (U.S. Committee on Education and the Workforce, Democrats, 2009, para. 6).

### History of Misuse of Zero-Tolerance Policies

The Gun-Free Schools Act of 1994 required schools to "institute a zero-tolerance policy for students . . . who bring a firearm on campus" (Martinez, 2009, p. 154). The intended effect of zero-tolerance policy was to eradicate violence in schools. However, by 1999, some school districts had widened their zero-tolerance policies to include drugs, alcohol, fights, swearing, truancy, insubordination, disruption, disobedience, disrespect, and even dress-code violation (Martinez, 2009; Morrison, Anthony, Storino, & Dillon, 2001). In a study of one urban school district, the majority of discipline referrals represented student behaviors that threatened teachers' authority rather than dangerous or serious infractions of the school's disciplinary code (Dupper, Theriot, & Craun, 2009). Fenning and Rose (2007) assert that federal mandates to prove increased academic achievement in schools is linked to school administrators' suspension and expulsion of children who present with problem behavior, and thus, may disrupt academic achievement. Curiously, one national study comparing zero- and non-zero-tolerance schools found that more zero-tolerance schools had a violent incident that required police intervention (Bruenlin, Cimmarusti, Bryant-Edwards & Hetherington, 2002).

While no specific studies have determined greater feelings of safety and improvement in student behavior as related to zero-tolerance policies (Martinez, 2009). Fenning and Rose (2007) discovered that suspension and expulsion actually increased violence and behavioral issues. Other studies have revealed that (a) suspension rates have increased (Martinez, 2009), (b) suspensions lead to higher dropout rates (Dupper et al., 2009; Evenson, Justinger, Pelschek, & Schulz, 2009), and (c) suspended students are more likely to have significant problems outside of school (Arcia, 2007; Christie, Nelson, & Jolivette, 2004; Dupper et al., 2009; Freeman, 2007; McGinnis, 2003), including engagement in or becoming victims of violent crimes (Evenson et al., 2009). Lastly, researchers assert that school administrators use the policies inappropriately (Martinez, 2009), including engagement in discriminatory practices.

According to Browne, Losen, and Wald (2001) "zero-tolerance policies were supposed to remove (or at least minimize) discretion and therefore ensure objectivity and the unbiased application of discipline." (p. 73). Rather, students in urban schools, African

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American or Hispanic, male, and/or of low socioeconomic status are disproportionately suspended (Arcia, 2007; Christie et. al., 2004; Evenson et. al. 2009; Freeman, 2007; McGinnis, 2003). Additionally, “students of color disproportionately receive harsh punishment under zero-tolerance policies, due in large part to the expansion of these policies to cover a range of nonviolent behaviors that are not objectively defined.” (p. 74). Cartledge and Loe (2001) stated that African American students receive more severe punishment than their White counterparts for the same infractions, and since the implementation of zero-tolerance programs are expelled at as much as five times the rate of White students (before zero-tolerance African American students were expelled at two to three times the rate of White students). Furthermore, Fenning and Rose (2007) found in a school discipline review that “African American youth did not receive more referrals for severe behavior. On the contrary, they received disproportionately more referrals for subjective and nonviolent offenses, such as disrespect, excessive noise and tardiness” (p. 537). Proactive consequences, such as teaching students alternative behaviors, are seldom employed, even for nonviolent behaviors.

Narrowing the purview again to Chicago, Chicago Public Schools suspend an average of 13 per 100 students (Catalyst Chicago, 2009). Additionally, 25 percent of black male students in Chicago Public Schools were suspended at least once in 2008; that rate is double the district average (Karp, 2009).

### Effects of Suspensions and Expulsions

Studies and statistics support that suspensions and expulsions result in increased problem behavior (McGinnis, 2003), lower academic achievement (Townsend, 2000; McGinnis, 2003; Arcia, 2007), including lower standardized test scores (Christie et al., 2004; Rausch & Skiba, 2004; Arcia, 2006) and higher dropout rates (Epp & Epp, 2001; McGinnis, 2003; Christie et al., 2004; Freeman, 2007; Suh, Suh, & Houston, 2007). Suh, Suh, and Houston (2007) targeted suspension as one of the independent variables for dropout risk assessed by the National Longitudinal Survey of Youth 1997. Twenty variables were targeted “on the basis of high correlation and statistical significance with respect to school dropout behavior” (p. 197). History of suspensions was specifically chosen because this predictor because of its wide use in research showing a stronger correlation with dropout

rates. Suspended students were those who had been suspended from school at least once ( $n=1,486$ ; 925 boys and 561 girls). Suh et al. (2007) discovered that “sixteen out of 19 predictors were significant for suspended students compared with 11 predictors for nonsuspended students” (p. 200), which indicated magnified dropout risk for students demonstrating behavioral issues, targeted for suspension, or both.

Arcia (2006), researching suspension's effect on academic achievement, discovered through a 3-year retrospective analysis of a large urban school district in the Southeast that the “difference in [reading achievement] scores between suspended and nonsuspended students increased with increases in days in suspension” (p. 363) with lowest achievement experienced by students with highest suspension rates. Arcia (2006) found that “the percentages of students who dropped out increased substantially with increases in suspension” (p. 366).

Recalling the discriminatory practices sometimes employed in school's suspension/expulsion decisions, “denial of access to learning opportunities that [occur] when students are not in school...[result in] a widening achievement gap...between African American students and their white peers” (Townsend, 2000, p. 382). Additionally, Fenning and Rose (2007) describe how exclusionary discipline consequences has been linked to entrance to prison, which they describe as a “school-to-prison-pipeline for these most vulnerable students” (p. 536).

### African American Teen Male Culture and Educators' Cultural Competency

Teachers' reactionary responses to what they deem to be behavioral issues may result from a lack of cultural education about the African American teenage male experience and cultural communication patterns. The urban African American male subculture often socializes boys to suppress their feelings, which are viewed as effeminate. This cultural norm promotes resiliency; however, many such adolescents lack appropriate outlets for expression of personal angst and express suffering by engaging in delinquency, acting-out, hostility, or physical aggression – actions that can result in suspension or expulsion in schools (Day-Vines, & Day-Hairston, 2005).

Educators and others working with youth in schools also need to understand that due to different cultural norms in communication styles, African



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American students may speak to each other and school personnel in a loud, intense, seemingly confrontational manner, yet without any underlying feelings of anger. Rather than attempting to eradicate this culturally appropriate communication style, social skills instruction for these students needs to “affirm...and empower them to achieve maximally within their own subculture as well as the main-streamed school environment” (Cartledge and Loe, 2001, p. 41).

It is important to understand relationship dynamics and their significance within the African American community. For instance, if African American male adolescents do not have a trusting relationship with an authority figure, they will often react defensively when confronted about their behavior, and are very sensitive to feelings that they have been “disrespected.” Considering that African Americans have been historically oppressed and marginalized, a struggle for actual and perceived respect is to be expected.

To exhibit that respect and increase student involvement in school, family and fictive kin also are integral. When parents and families are actively involved in their children’s education, African American students experience higher education achievement (Day-Vines & Day-Hairston, 2005). Additionally, a positive impact on student behavior was seen when interventions involved African American adult males and “members of the African American community such as church and social and civic organizations” (Day-Vines & Day-Hairston, 2005, p. 240). If those working with minorities in schools are not of the same ethnicity, cultural awareness sessions are recommended (Day-Vines and Day-Hairston, 2005) and when they result in culturally responsive instruction and behavior management they “can mitigate school suspensions and expulsions of African American children and youth” (Townsend, 2000, p. 361).

### **Empirically Supported Interventions to Reduce Student Behavioral Issues**

#### ***Relational Support***

There is strong evidence supporting interventions for behavioral issues that work to strengthen connections and relationships (Day-Vines & Day-Hairston, 2005; Suh et al., 2007; Evenson et al., 2009; Sherrod, Getch, & Daigle, 2009), whether peer-to-peer, teacher-student, (with particular emphasis on reciprocal trust, teacher approach to discipline, and student trust of

the teacher as an authority figure) (Gregory & Ripski, 2008; Dupper et al., 2009; Evenson et al., 2009), parent-student (Day-Vines & Day-Hairston 2005; Sherrod et al., 2009) or mentor-mentee (Morrison et al., 2001; Christie et al., 2004; Day-Vines & Day-Hairston, 2005; Converse, 2009).

One study that coupled a school-wide initiative with support groups for targeted students saw 60% of support group students reduce their discipline referrals to zero (Sherrod et al., 2009, p. 421). Another intervention example utilizing relationship support is Positive Behavioral Support (PBS), which is a strengths-based approach that integrates “valued outcomes, behavioral and biomedical science, empirically validated procedures, and systems change to enhance quality of life and minimize or prevent problem behaviors” (Sherrod et al., p. 421). Instead of being a curricula or program, PBS is a framework for addressing the full continuum of student needs, from those with mild issues that can be addressed in large or small groups, to those with behaviors that are intensive enough to need individual interventions. This is a model that is meant to increase the ability of schools to meet all student needs (Sugai & Horner, 2002, as cited in McGinnis, 2003).

#### ***Skills Training***

Often students who exhibit behavioral issues simply haven’t had the necessary support to learn and integrate appropriate social behaviors. Life and social skills training is well supported as an intervention for behavioral issues (Hudley & Graham, 1993; Morrison et al., 2001; Dupper et al., 2009; Evenson et al., 2009). Some programs that have proved effective include On-Campus Intervention Program (OCIP), which combines behavioral counseling with life skills training, and Consistency Management and Cooperative Discipline (CMCD), which emphasizes collaboration and a person-centered approach to strengths-based classroom management (Dupper et al., 2009).

#### ***Goal-setting and Thinking of the Future***

Common sense indicates that a positive outlook for the future minimizes inappropriate behavior. Empirical evidence proves this to be true (Christie et al., 2004; Suh et al., 2007; Evenson et al., 2009). In addition to GPA, Suh et al. (2007) found that “optimistic outlook on future had the largest coefficient among 19 predictors and was the most significant factor in

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reducing dropout rate” (p. 201). To that end, it is important that school administrators approach policies and program planning with a “positive attitude” and a “long-term vision for students” (Kearney, 2009, p. 37).

### Service Integration and Multi-systems Models

When behavioral problems are risk factors for dropout, the most effective interventions utilize careful, individualized functional and biopsychosocial assessments and intervention planning utilizing the service integration model and including interventions in multiple systems (Epp & Epp, 2001; Morrison et al., 2001; McGinnis, 2003; Christie et al., 2004; Rausch & Skiba, 2004; Suh et al, 2007.; Evenson et al., 2009).

### Aggression Replacement Training (ART): Precursors

In 1987, Glick and Goldstein asserted that “juvenile delinquency currently affects every sector of society and has infiltrated families, schools, and communities with little regard for socioeconomic, religious, or cultural factors” (p. 365). The authors explained that the resources that were available for delinquent youth during this time were not proven to be effective with aggressive youth because they assumed “that clients have somewhere within themselves, as yet unexpressed, the effective, satisfying, nonaggressive, or healthy behaviors whose expression is a goal of counseling” (p. 356). Due to the lack of empirical evidence proving the efficacy of these three approaches, Glick and Goldstein describe Psychological Skills Training, a new intervention of the 1970s, which came from social learning theory, “particularly from the work conducted and stimulated by Albert Bandura” (p. 356). Other events in the 1970s that prompted this movement towards psychological skills training included deinstitutionalization in mental health and inadequate resources available to the lower class.

This psychological skills training approach is educational, and “the trainer of this method assumes that he or she is dealing with an individual lacking, deficient, or, at best, weak in the skills necessary for effective and satisfying interpersonal functioning” (Glick & Goldstein, 1987, p. 356). The continued research of Goldstein and colleagues revealed that there was a need for a new intervention focusing on aggressive youth. As Glick and Goldstein stated (1987), “Many of these young people are skilled in fighting,

bullying, intimidating, harassing, or manipulating others; however, they are inadequate in more socially desirable behaviors such as negotiating differences, dealing appropriately with accusations, and responding effectively to failure, teasing, rejection, or anger” (p. 357). The authors developed Aggression Replacement Training (ART) specifically to intervene with this target population.

### What Is ART?

Aggression Replacement Training (ART) is a multimodal, psychoeducational intervention designed to alter aggressive behaviors in adolescents (Amendola & Oliver, 2010; Glick & Goldstein, 1987; Goldstein & Glick, 1994). Counselors, teachers, childcare workers, and others who have direct care responsibilities to clients commonly labeled as “juvenile delinquent” or “aggressive” teach ART (Glick & Goldstein, 1987). The program takes 10-weeks, is implemented in schools, and targets a demographic of adolescents age 12-17 (Goldstein & Glick, 1994, p. 13). In addition to the many reasons schools have for reducing aggressive behavior in adolescents, it is worth noting that these behavioral issues “portend such adult problems as drunken driving, antisocial personality, alcoholism, marital problems, and psychiatric disorders” (Nugent, Bruley, & Allen, 1999, p. 466).

### Preliminary ART Research Studies

To test the efficacy of the original ART program with the designated target population, Glick and Goldstein (1987) did an initial study at the Annsville Youth Center, a New York State Division for Youth residential facility for boys ages 14 to 17 “who [had] committed such crimes as assault, burglary, and auto theft, possession of stolen property, criminal trespass and drug use. At the time that the evaluation was conducted, 60 adolescents were in residence. They were 50% Black, 40% white, 8% Hispanic, and 1% Native American” (p. 357). Twenty-four members participated in the ART program for 10 weeks. Members were assigned to a brief instruction control group to control for the effects of trainee motivation; and 12 members were in the no-treatment control group. The researchers then formed new ART groups for the 36 members that were in the control groups. “Both of the statistical comparisons conducted to test for replication effects yielded positive results. Specifically, both the number and the severity of behavioral incidents

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decreased significantly from the first phase to the second phase of the study (taken from the incident reports)” (Glick & Goldstein, 1987, p. 360).

Glick and Goldstein (1987) conducted a second study at the MacCormick Secure Center, another facility for male juvenile offenders. The goal was to replicate the study with youth who commit more serious offenses. In this study, “the median age of the participants was 18 years; there were 30 Blacks, 18 Hispanics, 2 Orientals, and 1 White” (p. 360). In both studies the participants showed “significant changes on skills whose constituent behaviors required a reduction in negative, acting out behaviors (complaining, fighting, accusing)” (Glick & Goldstein, 1987, p. 361). In contrast to the Annsville results, the MacCormick subjects who took part in “moral education sessions grew significantly in moral reasoning” (p. 361). Overall, the research showed that ART, when implemented in a residential facility, was an effective program for White, Black, Hispanic, and Asian delinquent youths. The authors concluded that further research was required, including implementation in other settings, such as schools.

### Efficacy of ART

Aggression Replacement Training (ART) has been shown effective in regular evaluation in the school setting (Goldstein & Glick, 1994; Whitfield, 1999; U.S. Department of Education, 2001; McGinnis, 2003; Roth & Striepling-Goldstein, 2003) as well as in runaway shelters (Nugent et al., 1999). Roth and Striepling-Goldstein (2003) believe that “we must meet our students where they are: underdeveloped in life social skills, underdeveloped in anger and emotional control, and immature in moral reasoning” (p. 138). In their 2003 article, the authors discuss the difficulties related to providing services to challenging youth; the common restraints in the schools such as time, deadlines, and spare resources; and whether established interventions are effective and useful. Roth and Striepling-Golstein (2003) state that “ART has been broadly researched over the years with consistently profound outcomes: fewer school suspensions, lower recidivism, and fewer juvenile arrests” (p.139). The authors discuss the use of ART as a prevention initiative in elementary and middle schools. They state, “The investment is in creating and maintaining the pro-social behaviors to ensure that all students are developmentally equipped with the interpersonal skills to be effective in small and large

groups” (p. 139). The ability to learn and apply these pro-social skills “are viewed as lifelong lessons and are often supported with practice in win/win problem solving, conflict resolution, and effective listening” (Striepling-Golstein, 2003, p. 139). Finally, the authors discuss some of the aspects of ART that are instrumental to its success and implementation such as, “the structure of ART as restorative instead of punitive; the flexibility of ART and the fit to specific needs of youth; to negotiate and renegotiate the curriculum with the participants to increase motivation, commitment, and especially as a way to increase our response to the real life challenges of youth” (pp. 140-141).

According to McGinnis (2003) “there is evidence to support that the ART program results in skill acquisition, increased anger control, and enhanced moral reasoning” (p. 142). A decrease in aggressive incidents and impulsivity and an increase in coping incidents, self-control, and prosocial behaviors was found in one literature review (Jones, 1990); as well as an overall reduction of acting-out behaviors and an increased level of community functioning, even when applied in settings with chronically aggressive adolescents (Amendola & Oliver, 2010; Goldstein, Glick, & Gibbs, 1998). With an eye to improving the program’s efficacy, McGinnis (2003) states:

parental participation in an evening ART class for parents could be required. This class teaches parents the ART skills so they can reinforce and model the skills their child is learning. When parents attend classes, the length of the student’s suspension is often reduced (p. 164).

The staff can also learn to become models by participating in “Staff development for teachers and others in the school environment (custodians, support staff), which is also important in order to support the target student’s attempt at implementing ART in real life school classrooms and hallways” (McGinnis, 2003, p. 165). Of great importance, according to McGinnis, is the support of the district and its’ policies for the implementation of ART. For full efficacy, ART needs to be a school-wide collaborative effort.

According to the U.S. Dept. of Education’s review of exemplary and promising programs for schools (2001), ART shows evidence of efficacy, quality, educational significance, and usefulness to others (p. 6). The study showed that ART often meets its goal of improving psychological skill competence, moral reasoning, social problem-solving skills, and anger control (p. 42). ART was also determined to be a

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great professional resource and to be worth its cost financially (U.S. Dept. of Education, 2001). The ART book used for trainings costs \$24 and an unlimited number of participants can attend the two-day training at a one-time cost of \$5,000 (U.S. Dept. of Education, 2001, p. 42). The price of the program seems fair and necessary based on evaluation of its quality. Lastly, those who have presented the program for youth with behavior issues found “congruence between the level of program effort (intensity, duration) and the identified goals and expected outcomes” (U.S. Dept. of Education, 2001, p. 43).

In *Evaluating School Social Work* (1999) Gary Whitfield concluded that (a) the ART program is shown to be a promising intervention, (b) further studies should be replicated of the research being conducted with adolescents, and (c) research thus far supports the “use of ART in social work practice in both short-and long-term” settings (p. 481).

### Efficacy of ART’s Curriculum Components

Schools around the country are examining cognitive-based programs such as ART and are determining that “providing students with activities” like the moral reasoning and skill streaming portions of ART “may increase awareness” of the challenges faces by youth with behavioral issues (Paone, 2008). According to Kohlberg (as found in Paone, 2008), moral reasoning in the lives of young adolescents provides the “formation of an underlying system of values on which” all future decisions of “right and wrong are based” (p. 124). Programs such as ART allow student participants the “opportunity to try new behaviors” in order to further “develop meaningful relationships at school, at home, with adults, and with their peers” (Paone, 2008, p. 134).

According to Tamaki (1994), adolescents “exhibit an inflated sense of responsibility and a strong need for adult approval” and because of this need, “the peer group becomes a powerful influence” (p. 3). Therefore, adolescents who do not receive the proper direction and support often become “impulsive, lack planning skills, decision-making skills, problem-solving skills, negotiating skills, and the ability to appropriately control and deal with anger” (Tamake, 2008, p. 3)

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Programs such as ART utilize adult teachers and skill streaming to help teach adolescent students who may be lacking in healthy or significant adult support the skills necessary to make better life choices.

According to Leeman (1993), the mediating variables moral reasoning and anger control help youth develop “moral judgment and social skills” necessary to react healthfully in a “socially stressful situation” (p. 284). According to the preliminary analyses of ART and similar programs, both social skills and moral judgment “correlate with pre-incarceration misconduct and with all measures of institutional misconduct” (p.286). Additionally, gang members who completed the ART program in runaway shelters showed that they had “demonstrated significant improvement” in moral judgment and a variety of social skills (Nugent et al., 1999, p. 467).

### Conclusion and Recommended Modifications to the ART Program

Though ART is already considered a promising program for effective intervention in the lives of juvenile delinquents, we propose a few evidence-based enhancements to further strengthen its efficacy as an alternative to suspensions and expulsions in the school setting. First of all, ART facilitators should receive cultural awareness training for working with target populations, particularly African American teen males. Due to the shortage of positive African American adult male role models in Chicago, it is recommended that adult African American males implement ART programs, when possible. Another crucial aspect is to require parental involvement. Setting up ART graduates to serve as peer mentors to new ART students would likely increase successful completion of the program. Lastly, implementing ART as a school-wide initiative to be taught in schools that experience high dropout rates would broaden its capabilities of helping a population in need by creating a safer and healthier system-wide culture.

## Aggression Replacement Training

**Scarlett Stoppa** has a BS in Communications from Arkansas State University, an MA in Creative Writing from Boston University, and earned her MSW, schools specialization, from Loyola University in May 2011. Her first placement was at Youth Guidance, a Chicago agency that creates and implements school-based programs for at-risk children and adolescents. Her second placement was in the Learning Center, a specialized placement setting within New Trier Township High School for students with significant emotional and behavioral disabilities. She also served on the editorial board for *C.R.I.M.E.: Replacing Violence with Compassion, Respect, Inspiration, Motivation, and Empathy*, a book written and edited by the CRIME teens, a youth-led violence prevention program run through Loyola's School of Social Work

**Cassandra L. Kuzmanoff** earned her MSW at Loyola University Chicago School of Social Work with an emphasis in Mental Health in May 2010. Cassandra completed both field placements in child welfare at One Hope United. Upon graduation, Cassandra worked as a case manager for One Hope United in addition to facilitating visits and custody exchanges for families impacted by domestic violence at the Family Visitation Center of Lake County. In May 2011, Cassandra accepted a position as a Family Therapist with A Safe Place/Lake County Crisis Center. Cassandra continues to work primarily with victims of domestic violence - women and children who have been physically, verbally, or emotionally abused. Cassandra facilitates individual sessions, children's groups, and parenting support groups. In addition to working with victims of domestic violence, Cassandra hopes to work with the eating disordered population in the future and she will be attending the National Eating Disorder Association Conference in Los Angeles, CA in October 2011.

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## References

- Amendola, M., & Oliver, R. (2010). Aggression Replacement Training® stands the test of time. *Reclaiming Children and Youth, 19*(2), 47-50.
- America's Promise Alliance. (2008, April). Cities in crisis: A special analytic report on high school graduation. Retrieved May 2, 2010, from <http://www.americaspromise.org/Our-Work/Dropout-Prevention/Cities-in-Crisis.aspx>
- Arcia, E. (2006). Achievement and enrollment status of suspended students: Outcomes in a large, multicultural school district. *Education and Urban Society, 38*(3), 359.
- Arcia, E. (2007). A comparison of Elementary/K-8 and middle schools' suspension rates. *Urban Education, 32*(5), 456.
- Balfanz, R., & Legters, N. (2004). *Locating the dropout crisis. Which high schools produce the nation's dropouts? Where are they located? Who attends them?* (Report 70). Baltimore, MD: Center for Research on the Education of Students Placed At Risk, Publications Department, CRESPAR/Johns Hopkins University. (ERIC Document Reproduction Service No. ED484525)
- Browne, J. A., Losen, D. J., & Wald, J. (2001). Zero tolerance: Unfair, with little recourse. *New Directions for Youth Development, 92*, 73-99.
- Bruenlin, D., Cimmarusti, R., Bryant-Edwards, T., & Hetherington, J. (2002). Conflict resolution as an alternative to suspension for violent behavior. *The Journal of Educational Research, 95*(6), 349-357.

## Aggression Replacement Training

- Cartledge, G., & Loe, S. (2001). Cultural diversity and social skill instruction. *Exceptionality*, 9(1 & 2), 33-46.
- Catalyst Chicago. (2009). *Chicago tops the list on discipline*. Retrieved May 2, 2010, from <http://www.catalyst-chicago.org/assets/20090619/images/maingraphic3.jpg>
- Christie, C., Nelson, M. C., & Jolivet, K. (2004). School characteristics related to the use of suspension. *Education and Treatment of Children*, 27(4), 509.
- Converse, N. (2009). Evaluation of a school-based mentoring program for at-risk middle school youth. *Remedial and Special Education*, 30(1), 33.
- Day-Vines, N., & Day-Hairston, B. (2005). Culturally congruent strategies for addressing the behavioral needs of urban African American male adolescents. *Professional School Counseling*, 8(3), p. 236-243.
- Dupper, D. R., Theriot, M. T., & Craun, S. W. (2009). Reducing out-of-school suspensions: Practice guidelines for school social workers. *Children & Schools*, 31(1), 6-14.
- Epp, J. R., & Epp, W. (2001). Easy exit: School policies and student attrition. *Journal of Education for Students Placed at Risk*, 6(3), 231-247.
- Evenson, A., Justinger, B., Pelischeck, E., & Schulz, S. (2009). Zero tolerance policies and the public schools: When suspension is no longer effective. *The National Association of School Psychologists, Communiqué* 37(5), 5-7.
- Fenning, P., & Rose, J. (2007). Overrepresentation of African American students in exclusionary discipline: The role of school policy. *Urban Education*, 42(6), 536-559.
- Freeman, S. M., (2007). Upholding students' due process rights: Why students are in need of better representation at, and alternatives to, school suspension hearings. *Family Court Review*, 45(4), 638-656.
- Glick, B., & Goldstein, A. P. (1987). Aggression replacement training. *Journal of Counseling & Development*, 65(7), 356.
- Goldstein, A.P., & Glick, B. (1994). Aggression replacement training: Curriculum and evaluation. *Simulation & Gaming*, 25(1), 9-26.
- Gregory, A., & Ripski, M. B. (2008). Adolescent trust in teachers: Implications for behavior in the high school classroom. *School Psychology Review*, 37(3), 337.
- Hudley, C., & Graham, S. (1993). An attributional intervention to reduce peer-directed aggression among African-American boys. *Child Development*, 64, 124-138.
- Karp, S. (2009). *Black male conundrum*. Retrieved May 2, 2010, from <http://www.catalyst-chicago.org/news/index.php?item=2593&cat=23>
- Karpuk, B. (2008). *Chicago public schools: What percent of students even graduate?* Retrieved May 2, 2010, from <http://newsburglar.com/2008/06/06/united-states-high-school-graduation-rates-and-chicago-public-schools/>
- Kearney, L. (2009). Five steps to improving student behavior. *Momentum*, 40(1), 36.
- Leeman, L.W. (1993). Evaluation of a multi-component group treatment program for juvenile delinquents. *Aggressive Behavior*, 19, 281-292.
- Martinez, S. (2009). A system gone berserk: How are zero-tolerance policies really affecting schools? *Preventing School Failure*, 53(3), 153-158.

## Aggression Replacement Training

- McGinnis, E. (2003). Aggression replacement training: A viable alternative. *Reclaiming Children & Youth, 12*(3), 161-166.
- McIntosh, K., Flannery, K. B., Sugai, G., Braun, D. H., & Cochrane, K. L. (2008). Relationships between academics and problem behavior in the transition from middle school to high school. *Journal of Positive Behavior Interventions, 10*(4), 243.
- Morrison, G. M., Anthony, S., Storino, M., & Dillon, C. (2001). An examination of the disciplinary histories and the individual and educational characteristics of students who participate in an in-school suspension program. *Education and Treatment of Children, 24*(3), 276-293.
- Nugent, W.R., Bruley, C., & Allen, P. (1999). The effects of aggression replacement training on male and female antisocial behavior in a runaway shelter. *Research on Social Work Practice, 9*(4), 466-482.
- Paone, T. (2008). A school-based group activity therapy intervention with at-risk high school students as it relates to their moral reasoning. *International Journal of Play Therapy, 17*(2), 122-137.
- Rausch, M. K., & Skiba, R. (2004). Unplanned outcomes: Suspensions and expulsions in Indiana. *Education Policy Briefs 2*(2).
- Roth, B. S., & Striepling-Goldstein, B. S. (2003). School-based aggression replacement training. *Reclaiming Children & Youth, 12*(3), 138-141.
- Sherrod, M. D., Getch, Y. Q., & Daigle, J. Z. (2009). The impact of positive behavior support to decrease discipline referrals with elementary students. *Professional School Counseling, 12*(6), 421-427
- Suh, S., Suh, J., & Houston, I. (2007). Predictors of categorical at-risk high school dropouts. *Journal of Counseling & Development, 85*(2), 196-203.
- Tamaki, S. (1994). *Adolescent anger control*. Retrieved from Saskatchewan School Trustees Association. (SSTA-RCR-94-6).
- Townsend, B. (2000). The disproportionate discipline of African American learners: Reducing school suspensions and expulsions. *Exceptional Children, 66*(3), 381-391.
- U.S. Committee on Education and the Workforce, Democrats. (2009.) *High school dropout crisis threatens economic growth and competitiveness, witnesses tell house panel*. Retrieved on July 25, 2011, from <http://democrats.edworkforce.house.gov/newsroom/2009/05/high-school-dropout-crisis-thr.shtml>
- United States Department of Education (2001). *Exemplary and promising safe, disciplined, and drug-free schools programs*. Retrieved May 2, 2010, from <http://www2.ed.gov/admins/lead/safety/exemplary01/exemplary01.pdf>
- Whitfield, G. (1999). Validating school social work: An evaluation of a cognitive-behavioral approach to reduce school violence. *Research on School Social Work Practice, 9*(4), 399-426.

## The Olmstead Decision and the Winding Road toward Community-Based Care

By: Jamie Floersch, Torrie Kramer, Christine Nelson, Lauren Rosenthal, & Lauren Spira

### Abstract

*The U.S. Supreme Court's June 19, 1999 ruling in *Olmstead v. L.C.* (98-586) 527 US 581 declared that the unnecessary institutionalization of people with disabilities violates the integration regulation of Title II of the Americans with Disabilities Act of 1990 (ADA), which requires that a "public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities" (*Olmstead v. L.C.*, 1999, pp. 6). At the time of its passage, the *Olmstead* decision was hailed by the national disability community as a civil rights victory, signaling the way toward making community-based care the new standard for long-term care for people with disabilities (*Desonia*, 2003). However, in the years following the ruling, the path toward this goal has been riddled with obstacles. Ambiguity in the Supreme Court's ruling, states' resistance and difficulties in implementing *Olmstead's* mandates, and Medicaid's long-standing bias toward institutionalization of people with disabilities have presented mixed signals, road blocks, and detours along the way (*Desonia*, 2003). This article will review *Olmstead's* goals and the difficulties in achieving these goals over the last decade. It will also review recent efforts to set long-term care for people with disabilities on the course toward community-based care and illustrate the importance of these efforts for the social work profession.*

### Introduction

Evidence shows that community-based care is more cost effective than institutional care, and many people with disabilities thrive in community living arrangements (Bazelon Center for Mental Health Law, 2009). Despite legislative efforts to advance community-based care, it is estimated that over 1.6 million people with disabilities in the United States live

in state-run institutions, with the majority living in skilled nursing facilities (Cottrell, 2005; Mann, 2010). According to a 2009 report from the Bazelon Center, "nearly all" of the approximately 500,000 people with mental disabilities other than dementia residing in nursing homes and other segregated settings in the United States could "live independently in the community with adequate supportive services" (p. 1). In addition to those who currently reside in institutional settings, approximately 2 million more people with disabilities who live in their homes are thought to be at risk of eventual institutionalization due to lack of access to supportive services necessary to maintain home-based care (Cottrell, 2005). Social workers have a role and a duty to help ensure that the *Olmstead* decision's goal of community integration for people with disabilities is achieved. As the National Association of Social Workers' Code of Ethics states, social workers should pursue social justice "particularly with and on behalf of vulnerable and oppressed individuals and groups of people," and should "seek to enhance clients' capacity and opportunity to change and to address their own needs" (National Association of Social Workers [NASW], 2010). People with disabilities represent a vulnerable group of individuals, capable of great levels of self-determination and independence when provided with the appropriate supports.

### The Olmstead Decision

The case of *Olmstead v. L.C.* reached the Supreme Court when the Georgia Department of Human Resources appealed a decision by a lower court that it had violated the ADA's integration mandate by failing to provide community-based care to the plaintiffs, Lois Curtis and Elaine Wilson of Georgia (Bazelon Center, 2009). Both women were dually diagnosed - one with a developmental disability, one with mental retardation, both with mental illness - and



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assessed as fit for placement in community-based care by their treatment teams. Despite their qualifications for community-based care, both were forced to live in state-run psychiatric hospitals due to the lack of availability of less-restrictive alternatives (Cottrell, 2005).

The Supreme Court ruled in favor of the plaintiffs, affirming that states are required to provide individuals with disabilities access to community-based care when the following conditions are met: (a) “the State’s treatment professionals have determined that community placement is appropriate,” (b) “the transfer from institutional care to a less restrictive setting is not opposed by the affected individual,” and (c) “the placement can be reasonably accommodated [by the state], taking into account the resources available to the State and the needs of others with mental disabilities” (*Olmstead v. L.C.*, 1999, pp. 22). Given the last condition, the court acknowledged that states provide a range of services to people with mental disabilities and must be able to distribute those services equitably. For example, in the *Olmstead* case, the immediate transfer of the plaintiffs to community-based care would amount to inequity in services for other individuals waiting for placement in community-based settings (*Olmstead v. L.C.*, 1999). Therefore, the court ruled that when immediate transfer of those seeking community-based care is not a viable option, states could meet the “reasonable modifications requirement” as set forth in the ADA, by demonstrating that they have an effective plan for placing qualified persons in community settings with a waiting list for such services that moves at a “reasonable pace” and is not motivated by the state’s wish to keep its institutions at full capacity (Rosenbaum, 2001).

Following the Supreme Court’s decision, both Lois Curtis and Elaine Wilson were moved to community-based settings. Ms. Curtis, now a successful folk artist, lives in a home in Atlanta, where she receives supportive services (Bazelon Center, 2009). Ms. Wilson also lived independently in a supported apartment where, according to her attorney, “she blossomed,” taking an interest in cooking, church, and advocacy for people with disabilities. Ms. Wilson died in 2004 of heart and lung problems at the age of 53 (“Elaine Wilson,” 2004).

## Evolving Attitudes and Approaches to Caring for People with Disabilities

The ADA and the *Olmstead* decision reflect society’s continually evolving attitudes toward those with disabilities, from early beliefs of disability as personal pathology to a more advanced view of disability as a functional limitation, and the community integration of individuals with disabilities as a social responsibility (Yong, 2007).

Mackelprang and Salsgiver (1996) point out that archeologists have been uncovering evidence of people with disabilities dating back to the Neanderthal Period. In ancient times, people with disabilities were viewed as being possessed by spirits and were treated by drilling a hole into their skull in order to let the evil spirits out and allow the person to heal. During the 18<sup>th</sup> century, the Enlightenment shaped views and treatment of persons with mental illness or disability. It was during this time that institutions began appearing across the country with the mission that professionals could assist to “perfect” people with disabilities and if a cure was not possible, then such persons would be trained to behave in an “acceptable manner” (Mackelprang & Salsgiver, 1996, p. 8). Mackelprang and Salsgiver (1996) report little progress in the 19<sup>th</sup> and 20<sup>th</sup> centuries by way of improving the examination of individuals with disabilities. People with disabilities were still viewed as individuals who could be cured, changed, or perfected. The stigma of disability, even in the mid-to-late 20<sup>th</sup> century, was still so strong that parents of children with disabilities often hid children away in institutions. Until the last ten years of the 20<sup>th</sup> century, treatment of persons with disabilities was solely based on professional intervention for the individual, and the individual had very little input in his or her independent treatment plan (Mackelprang & Salsgiver, 1996).

The emergence of psychotropic drugs to treat mental illness in the 1950s, society’s increasing concerns over civil rights, and the conditions in state-run hospitals in the 1960s helped spur the deinstitutionalization movement. This included the passage of the 1963 Mental Retardation and Community Mental Health Center Construction Act (CMHC), which provided federal funding for construction of community mental health centers. In addition, Medicare and Medicaid were introduced in 1965 and provided coverage for a range of mental health services. From 1955 to 1980, over 400,000 people were moved from

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state-run facilities to community-based settings. Many states began shutting down entire institutions. However, improvement and expansion of supportive services to assist people being moved from institutions into the community were slower to develop. It was not until 1993 that the amount of state-controlled dollars allocated to community-based care outnumbered the amount allocated to institutions. Additionally, promising models of community care were attempted, but rarely evaluated or made part of the standard care, and new technologies were often only provided on a trial basis and did not replace old practices (Koyanagi, 2007).

Given the halting progress toward community integration for people with disabilities, the *Olmstead* case may have been inevitable. Unfortunately, as the Bazelon Center pointed out in 2009, ten years after *Olmstead*'s passage, litigation is still the most effective route for those seeking treatment in the least restrictive setting. As the report stated, "where real progress has occurred, it is largely because states have been sued" (Bazelon Center, 2009, Preface).

### Barriers to Achieving Community Integration

#### *The Language of the Ruling*

One barrier to effective implementation of *Olmstead*'s mandates is ambiguity present in the Supreme Court's ruling. First, though the national disability community established July 26, 2000 - the anniversary of the passage of the ADA - as the deadline by which states should have begun implementing plans to comply with *Olmstead*, the actual ruling did not specify a compliance deadline (Zendell, 2007).

Secondly, *Olmstead* was not explicit about what care setting qualifies as community-based versus institutional. According to a 2010 National Public Radio news investigation titled "A New Nursing Home Population: The Young," from 2000 to 2010, the number of individuals age 31–64 living in nursing homes nationwide rose from 10% of the total nursing home population to 14% (Shapiro, 2010). As stated previously, it is estimated that "nearly all" of the approximately 500,000 people with mental illnesses other than dementia currently living in nursing homes could live independently with the appropriate supports (Bazelon Center, 2009). Moving individuals with disabilities from state hospitals to nursing homes is

considered "transinstitutionalization" because, although nursing homes may be "physically located in the community," residents are, in fact, "quite isolated from mainstream community life" (Bazelon Center, 2010). It is suggested that lobbying by the private nursing home industry has impeded the progression toward community-based care (Bazelon Center, 2009). The largest U.S. provider of nursing home care, HCR Manor Care, earns \$3.6 billion in annual revenues (Service Employees International Union [SEIU], 2007), which is indicative of the plentiful resources available to this industry for lobbying efforts.

A third piece of the ruling largely left open to states' interpretation was the Court's assertion that, though states might not be immediately able to move all qualified individuals into community-based care, they must demonstrate that they have an effective plan for doing so that moves at a "reasonable pace" (Rosenbaum, 2001). Since "reasonable pace" was not defined in the *Olmstead* decision, waiting lists may be long and slow. Although states are technically compliant, few people may move into integrated settings, and the decision's true goals may not be achieved. In an analysis of eight federal court cases involving the "reasonable pace" question that were brought in the three years following the *Olmstead* decision, Rosenbaum, Stewart, and Teitelbaum (2002) found that states' waiting lists for community-based care ranged from three months to more than ten years. The courts agreed that, "waiting periods of many years are outside of the zone of reasonableness," and established 90 days from the time of application for community-based care as a reasonable waiting period (Rosenbaum, Stewart & Teitelbaum, 2002, pp. 5). Nevertheless, waiting lists remain crowded and long. According to Shapiro (2010), there are approximately 400,000 people currently living in nursing homes nationwide who are on waiting lists for state-funded services that would allow them to receive home-based care.

### *Medicaid's Institutional Bias and Other Funding Issues*

States' primary source of funding for long-term care for people with disabilities is Medicaid. As discussed, the Medicaid program was established in the 1965, a time when institutionalization of those with disabilities was the norm and home- and community-

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based care was not well established. Given its beginnings, Medicaid has an historical bias toward institutionalization, tending to cover more services for individuals who reside in state-run, segregated settings versus home- or community-based settings. In the 1980s, Medicaid was reformed to allow “waivers” of the Medicaid laws to fund home- or community-based care. Following the *Olmstead* ruling, the federal Centers for Medicaid and Medicare Services (CMS) issued a series of memos encouraging states to shift Medicaid funds from institutions to home- and community-based services; however, fears that states would be overwhelmed by requests for waivers led to severe limitations on the availability of such waivers; therefore, the growth of community-based care settings has been slow (Desonia, 2003) and Medicaid still has not fully altered its institutional bias (Bazelon Center, 2009).

To pick up where Medicaid left off, the executive branch created grant programs to help states implement the *Olmstead* decision. During the Clinton administration, Congress authorized \$64 million for three grant programs. These programs sought to assist states in developing and implementing plans to comply with *Olmstead*, help transition individuals from institutional settings to community-based settings, and increase the availability of personal care workers. The Bush administration added initiatives to improve the economic status of people with disabilities, provided \$50,000 to each state that requested funding under the Systems Change Grant for Community Living program, and issued the New Freedom Initiative report to remove policy and regulatory barriers that impede people with disabilities from living in community-integrated settings (Desonia, 2003). Still, states are struggling to find enough funds. Although it is cheaper to house people in community settings, states must continue to maintain institutions with high overhead costs. States are therefore unable to divert these funds to create more community living options. Further, recent state budget crises mean a general lack of growth in resources available for financing expansion in Medicaid services (Desonia, 2003).

### **Structural Barriers**

Aside from funding problems, other structural barriers exist in achieving and maintaining community integration. In 2001, President George W. Bush created the Interagency Council on Community Living (ICCL),

which was comprised of six federal agencies and was given the task of identifying barriers to community integration. The ICCL identified healthcare structure and financing, including Medicaid’s institutional bias, as one barrier. Secondly, shortages in affordable housing create a barrier because many people with disabilities rely on public housing, which is often inaccessible and insufficient. Furthermore, personnel shortages create a barrier because many people with disabilities require in-home help to live in a community-integrated setting. However, there is a shortage of skilled in-home workers due to low wages, long hours, and lack of employee benefits. Caregiver and family support service gaps are an additional barrier because people with disabilities may also rely on family to provide in-home support. Burnout in the support network may force the individual back into an institutional living arrangement. Additionally, many people with disabilities live in areas without sufficient public transportation, thus limiting their mobility and independence within in the community. Last but not least, employment disadvantages and disincentives, as well as a lack of access to job training and transitional services, mean people with disabilities have more difficulty finding work to support themselves and integrate themselves in the community (Yong, 2007).

### **Recent Federal Efforts to Clear Obstacles to Community-Based Care**

Per testimony given on June 22, 2010 to the U.S. Senate by Cynthia R. Mann, J.D., Director for the Center for Medicaid and State Operations, over the past 10 years, funding for long-term care services has grown at an average annual rate of 6.3%, while spending on community-based long-term services and supports has increased by an average of 11.8% per year from \$17 billion in 1999 to \$52 billion in 2009. Over half of all Medicaid Long-Term Care beneficiaries now receive services in community settings. However, the demand for community services is continuously expanding. While the number of people served in community settings has grown, there are still over 1.6 million Americans in institutions who would prefer to receive community-based services (Mann, 2010).

In June 2009, President Barack Obama announced “The Year of Community Living,” marking the 10<sup>th</sup> anniversary of the *Olmstead* decision and affirming the principle of community integration on

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which the decision was based. The Community Living Initiative, led by the federal Department of Health and Human Services, was established to begin addressing many of the barriers to community living for people with disabilities (Mann, 2010).

In an effort to correct Medicaid's institutional bias, the Affordable Care Act (ACA), signed into law in March 2010, offers states the option to provide funding for community-based care without the necessity of a waiver and without the requirement of linking the benefit to a current or future need for institutional care. The ACA also identifies a greater range of supportive services as eligible for funding through Medicaid. Additionally, the ACA extended Medicaid's Money Follows the Person (MFP) program through September 2016 and appropriated an additional \$2 billion to the program. The MFP, which was originally passed in 2005 and is set to expire in 2011, allows qualified individuals with disabilities who receive Medicaid and live in institutional settings to use their Medicaid funding to transition to community-based living without having to use one of the state's waiver slots. This benefits the state in that additional waiver slots are not required, and it benefits the individual because they are able to transition to community-based care without having to be placed on a waiting list for waiver funding (Mann, 2010).

The Community Living Initiative also offers technical support to states in their attempts to increase community integration for people with disabilities. The CMS offers states assistance in the creation and administration of Medicaid programs and supports the National Direct Service Workforce (DSW) Resource Center, which provides states and consumers access to information and resources about direct service workers who provide the supportive services that are integral to helping people with disabilities maintain community living arrangements. The CMS also published a guide entitled *Long Term Services and Supports in a Managed Care Delivery System*, to assist states in navigating the various Medicaid structures related to funding for home- and community-based care. Additionally, the CMS established the National Preadmission Screening and Resident Review (PASRR) Technical Assistance Center to help states institute the PASRR, which is a screening test used to ensure that people with mental and developmental disabilities are being served in the most integrated setting appropriate for their needs (Mann, 2010).

Per the Community Living Initiative, the Department of Health and Human Services (HHS) and the Department of Housing and Urban Development (HUD) have teamed up to address the lack of access to affordable housing, which is a persistent barrier to community integration of people with disabilities. With approximately \$40 million in funding from HUD, state public housing authorities will have access to approximately 5,300 housing vouchers to help individuals move from institutions into the community or to maintain their current community living arrangement (Mann, 2010).

### What's Happening in Illinois?

While several challenges exist in states' efforts to comply with the *Olmstead* mandate, and federal policies are attempting to address many of these barriers, it seems that the most persistent and complex barrier is also the most obvious: The lack of existing and available alternatives to institutional care. The state of Illinois' efforts and struggles to increase the number of Permanent Supportive Housing (PSH) units for individuals and families with special needs is indicative of the challenges in many states. In order to increase the number of PSH sites, the state must achieve a delicate balance of incrementally reducing institutional capacity, ensuring that some state-run facilities remain open for those who need them, while also increasing the availability of PSH for those who qualify for community-based care (Illinois Housing Taskforce Supportive Housing Working Group, 2008).

In 2007, the state of Illinois began a project to add 7,700 PHS units to the state by the year 2015. In a report released in 2008, the Supportive Housing Working Group noted several barriers to this goal, including the need for multiple, complex funding sources to create PSH sites, requiring compliance with varying application procedures from federal, state, and private funders. The report also noted the significant upfront costs associated with developing PSH sites, which puts the funding sources at risk of not recouping their costs since state funding is not guaranteed each year, especially given the current state fiscal crisis. Also among the barriers the report mentioned was the stigma that mental illness often carries, which may deter developers from investing in such a site.

It is notable that even if the plans set forth are accomplished, there will very likely still be a significant

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shortage of PSH units available to fill the demand in Illinois. The Supportive Housing Working Group's report (2008) indicated that the plan will make just 2,000 PHS units available for individuals transitioning from institutions for mental disease (IMDs) by the year 2015. The other 5,700 units are slated to be filled by individuals and families who are currently homeless or at risk of becoming homeless. According to an *Olmstead*-related class action lawsuit brought in 2005 in an Illinois district court against then-Governor Rod Blagojevich and other officials of the Illinois Department of Human Services, there were approximately 5,000 people with mental illness living in 26 state-run IMDs in the state of Illinois who had not been properly assessed for transition to community-based care (*Williams v. Blagojevich*, 2005). The court's 2010 ruling in the case declared that the state must evaluate all residents in IMDs over the age of 18 by the year 2013 for qualification for community-based care and must provide Permanent Supportive Housing (PSH) access to those who are qualified for and desire such a placement by the year 2016 (*Williams v. Blagojevich*, 2005). Quick math shows that if just 40% of the 5,000 people currently residing in an IMD are eligible for transition to community-based care, the PSH units available will be filled.

Considering these challenges, federal grants to match states' investments in the creation of supportive housing is critical. Tax incentives to communities that allow PHS sites in their neighborhoods, as well as to private developers who invest in the sites, will be important.

### Social Work's Role: Past, Present, and Future

Given *Olmstead*'s history of slow and faltering progress toward community-based care, individuals with disabilities and their advocates will likely watch the new efforts described here with cautious optimism. Many will have to work to push progress forward. We assert that social workers should join them. According to Mackelprang and Salsgiver (1996, p. 7), at the time of the development and passage of the ADA and the *Olmstead* decision, the social work profession had "done little to promote disability rights." Further, the writers noted that, at that time, the number of students and educators with disabilities in the social work field was low and disability-related articles and presentations

rarely appeared in social work literature or at professional conferences (Mackelprang, 1993). Perhaps most damning is the assertion that, rather than viewing disability as a socially constructed category of oppression, the social work profession continues to see disability as a pathology to be treated through clinical services (Depoy & Gilson, 2008).

The Supreme Court's majority opinion on *Olmstead*, written by Justice Ginsberg, noted that unnecessary institutionalization, ". . . perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life," and, ". . . severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (*Olmstead v. L.C.*, 1999, pp. 16). The isolation of people with disabilities violates social work values on several levels. As set forth in the NASW Code of Ethics, social workers must address social problems and challenge social injustice. Additionally, social workers are to respect the inherent dignity and worth of the person and recognize the central importance of human relationships as an important vehicle for change (NASW, 2010). It is clear that the goal of the *Olmstead* decision, community integration for people with disabilities, is aligned with social work's values of client self-determination and empowerment.

Zendell (2007) asserts that social workers can play a multi-faceted role in the effort to increase community integration for people with disabilities. Perhaps the most obvious is in providing direct services that help individuals maintain a home- or community-based living arrangement. These services often include case management to help coordinate clinical, medical, vocational, housing, educational, and social support, services that are often accessed through several separate entities (Zendell, 2007). The Bazelon Center (2009) also notes other clinical services that have proven effective in enabling people with disabilities to adjust to and maintain a home-or community-based living arrangement, including individual Cognitive Behavioral Therapy, functional family therapy, and family psychoeducation.

Beyond the clinical role, Zendell (2007) notes that social workers can and should use their knowledge of clients' strengths and needs, and service usage and delivery to help policy-makers shape *Olmstead*-related policies and plans. Additionally, social workers should become familiar with the language of *Olmstead* and

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their state's obligations and options for funding *Olmstead*-related programs in order to advocate for community integration. Social workers' advocacy should not end at the policy level, but should also reach into the community. Community integration efforts are often met with resistance from local communities who may hold stereotypes and fears about people with disabilities, particularly those with mental illnesses, and may result in a "not in my backyard" response. Social workers can collaborate with advocacy organizations such as the National Alliance on Mental Illness (<http://nami.org/>) and ADAPT (<http://www.adapt.org/>) to develop community outreach and education programs about the importance of community integration and the benefits that integration holds, not just for individuals with disabilities, but for the community itself (Zendell, 2007).

### Conclusion

Numerous barriers around funding, housing, employment, and government bureaucracy have made progress toward *Olmstead's* aim of community integration for people with disabilities slow and arduous (Bazelon Center, 2009). Nevertheless, social work's values compel us to continue working toward this goal. Social workers should use their skills as clinicians and advocates to promote current efforts to set long-term care for people with disabilities back on the course toward community integration. The life of Lois Curtis, the "L.C." of *Olmstead v. L.C.*, is a shining example of the contributions people with disabilities can make when they are given the opportunity to live independently and pursue their passions and interests. (Learn more about Ms. Curtis' life and art here: <http://loiscurtisart.com/index.html>).

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### References

- Bazelon Center for Mental Health Law (2009). *Still waiting – The unfulfilled promise of Olmstead*. Washington, DC. Retrieved November 17, 2010, from <http://www.wvdhhr.org/oig/Olmstead/What%20is%20the%20Olmstead%20decision/Still%20Waiting%20the%20Unfulfilled%20Promise%20of%20Olmstead.pdf>
- Bazelon Center for Mental Health Law (2010). *Implementing the integration mandate*. Retrieved January 26, 2011, from <http://www.bazelon.org/Where-We-Stand/Community-Integration/Olmstead-/Implementing-the-Integration-Mandate.aspx>
- Cottrell, R. P. F. (2005). The issue is—The *Olmstead* decision: Landmark opportunity or platform for rhetoric? Our collective responsibility for full community participation. *American Journal of Occupational Therapy*, 59, 561–568. doi: 10.5014/ajot.59.5.561.
- Depoy, E., & Gilson, S. (2008). Social work practice with disability: Moving from the perpetuation of a client category to human rights and social justice. *Journal of Social Work Values and Ethics*, 5(3).
- Desonia, R. (2003). *Is community care a civil right? The unfolding saga of the Olmstead decision*. Washington, DC: National Health Policy Forum. Retrieved November 17, 2010, from [http://www.ncsl.org/Portals/1/documents/health/BP\\_Olmstead\\_3-03.pdf](http://www.ncsl.org/Portals/1/documents/health/BP_Olmstead_3-03.pdf)
- Elaine Wilson, plaintiff in *Olmstead* case, dies at 53. (2004, December 14). *The Atlanta Journal-Constitution*. Retrieved January 28, 2011, from <http://www.ccfi.us/news/general/elainewilson1.13.05.html>
- Illinois Housing Taskforce Supportive Housing Working Group (2008). *Final report*. Springfield, IL. Retrieved March 30, 2011, from <http://www2.illinois.gov/nursinghomesafety/Documents/Final%20Report%20-%20IL%20Housing%20Task%20Force%20Supportive%20Housing%20Working%20Group.pdf>
- Koyanagi, C. (2007). *Learning from history: Deinstitutionalization of people with mental illness as precursor to long-term care reform*. Kaiser Commission on Medicaid and the Uninsured: Menlo Park, CA. Retrieved December 1, 2010, from <http://www.kff.org/medicaid/upload/7684.pdf>
- Mackelprang, R. W. (1993, March). *Social work education and persons with disabilities: Are we meeting the challenges?* Paper presented at the Annual Program Meeting of the Council of Social Work Education, New York.
- Mackelprang, R. W., & Salsgiver, R. O. (1996). People with disabilities and social work: historical and contemporary issues. *Social Work*, 41(1), p.7–14. Retrieve from <http://www.heart-intl.net/HEART/Stigma/Comp/Peoplewithdisabilities&socialwork.htm>.
- Mann, C. (2010). *Testimony: The ADA and Olmstead enforcement: Ensuring community opportunities for individuals with disabilities*. Retrieved November 21, 2010, from <http://www.hhs.gov/asl/testify/2010/06/t20100622a.html>
- National Association of Social Workers (2010). *Code of ethics*. Retrieved November 21, 2010, from <http://www.naswdc.org/pubs/code/code.asp>

## The Olmstead Decision and the Winding Road toward Community-Based Care

- Olmstead v. L.C., (98-536) 527 U.S. 581 (1999). Retrieved November 17, 2010, from <http://www.law.cornell.edu/supct/html/98-536.ZS.html>
- Rosenbaum, S. (2001). *Olmstead v. L.C. federal implementation guidelines, and analysis of recent cases regarding Medicaid coverage of long term care services for persons with disabilities*. The George Washington University School of Public Health and Health Services, Washington, DC. Retrieved November 17, 2010, from [http://www.treatment.org/Topics/pdf/Olmstead article2.PDF](http://www.treatment.org/Topics/pdf/Olmstead%20article2.PDF)
- Rosenbaum, S., Stewart, A., & Teitelbaum, J. (2002). *Defining "reasonable pace" in the post-Olmstead environment*. Center for Healthcare Strategies, Inc., Hamilton, NJ. Retrieved on November 18, 2010, from <http://www.gwumc.edu/sphhs/departments/healthpolicy/chpr/downloads/reasonablepace.pdf>
- Service Employees International Union (2007, October 3). *SEIU Launches Multi-State Grassroots Campaign Calling on the Carlyle Group To Put Care Above Profits in Buyout of Nation's Largest Nursing Home Chain* [Press Release]. Retrieved January 26, 2011, from [http://webcache.googleusercontent.com/search?q=cache:qP\\_tmqK6VMQJ:www.seiu.org/2007/10/seiu-launches-multi-state-grassroots-campaign-calling-on-the-carlyle-group-to-put-care-above-profits-in-buyout-of-nations-largest-nursing-home-chain.php+what+are+the+annual+revenues+of+private+nursing+homes&cd=48&hl=en&ct=clnk&gl=us](http://webcache.googleusercontent.com/search?q=cache:qP_tmqK6VMQJ:www.seiu.org/2007/10/seiu-launches-multi-state-grassroots-campaign-calling-on-the-carlyle-group-to-put-care-above-profits-in-buyout-of-nations-largest-nursing-home-chain.php+what+are+the+annual+revenues+of+private+nursing+homes&cd=48&hl=en&ct=clnk&gl=us)
- Shapiro, J. (2010, December 9). A new nursing home population: The young. *National Public Radio*. Retrieved January 26, 2011, from <http://www.npr.org/2010/12/09/131912529/a-new-nursing-home-population-the-young>
- Williams v. Blagojevich, (1:05-cv-04673) IL (2005). Retrieved March 30, 2011, from [http://www.equipforequality.org/resourcecenter/WilliamsNoticePlan\\_05-27-2010.pdf](http://www.equipforequality.org/resourcecenter/WilliamsNoticePlan_05-27-2010.pdf)
- Yong, F. (2007). The *Olmstead* decision and the journey toward integration. *Journal of Gerontological Social Work*, 49(1), 115-126. doi: 10.1300/J083v49n01\_07
- Zendell, A. (2007). Impact of the Olmstead decision five years later. *Journal of Gerontological Social Work*, 49(1), 97-113. doi: 10.1300/J083v49n01\_06



## Policy Changes for Processing PTSD Disability Claims at the Department of Veteran's Affairs

By: W. Edward Brown & Rebecca Thompson

### Abstract

*On July 13, 2010, the Department of Veterans' Affairs (VA) released new policy guidelines making it easier for veterans diagnosed with post-traumatic stress disorder (PTSD) to get disability benefits (and mental health services). This change will impact thousands of veterans from World War II, Korea, and Vietnam as well as those returning from the Iraq and Afghan wars, who may not have met the VA PTSD standard under the old policy. It is important for social workers to be aware of this change as they may be in the position to inform eligible veterans who are their clients or recipients of services at employing social service agencies. This paper examines the reasons for the policy change and offers an assessment of whether the policy will succeed in meeting its goals.*

### Introduction

Military historians believe that the syndrome known as Post-Traumatic Stress Disorder (PTSD) has been around for as long as man has gone to war (Dreazen, 2008). PTSD is currently defined as a mental health disorder whose symptoms include heightened sensitivity, intense fear, helplessness, horror, avoiding stimuli associated with the trauma, and the numbing of general responsiveness. People who have PTSD often have suicidal ideation and feelings of guilt associated with surviving the event. PTSD and its associated symptoms can cause impairment in social, occupational, or other important areas of functioning (American Psychiatric Association [DSM-IV-TR], 2000).

The term "shell shock" was used during World War I, and "combat fatigue" was used in World War II to describe veterans who exhibited stress and anxiety resulting from combat trauma (Parrish, 2008). When the first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM) was published in 1952, the VA adopted the DSM-I approach to diagnosing mental

health disorders. The DSM-I did not contain a diagnosis of PTSD. The first official designation of PTSD occurred in 1980 with the publication of the third edition of the DSM (American Psychiatric Association [DSM-III], 1980). The VA added, by regulatory amendment, PTSD as a diagnostic entity in its schedule for rating mental disorders on April 11, 1980 (Department of Veteran Affairs, 1997). PTSD was quickly used to describe the suffering of veterans traumatized by what they had seen and done in Vietnam (Dreazen, 2008).

### Problem Description

Today, PTSD is involved in a high percentage of VA disability claims and requires an increasingly large portion of the VA's mental health resources. PTSD is "emerging as one of the signature maladies of the long wars in Iraq and Afghanistan which lack clear front lines and pit U.S. forces against enemies who operate out of densely packed civilian areas" (Dreazen, 2008, p. 11). Consequently, a large number of veterans returning from these wars will suffer from PTSD. According to a Stanford study, the rate of PTSD in veterans deployed to Iraq and Afghanistan may be as high as 35 percent (Editor, 2009). With two million troops deployed to Iraq and Afghanistan, the United States can expect that at least 700,000 veterans will suffer from PTSD (Editor, 2009).

PTSD will impact these veterans' mental health in other ways as well. Researchers working with Iraq and Afghan war veterans with PTSD found that as many as 45 percent had experienced suicidal thoughts and behaviors in the month prior to seeking care. Of those veterans, three percent reported an actual suicide attempt within four months prior to seeking care (Science Daily, 2009). Because PTSD puts these returning veterans at risk for suicide, it is important that they receive timely treatment.

Many veterans and active members of the

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military remain concerned about the significant barriers to military personnel getting the PTSD treatment they need (Kingsbury, 2008). One such barrier has been the dual standard for the evidence required to establish that an "in-service stressor," which is the event or part of the event that caused PTSD, occurred during combat or non-combat service. Another barrier is that the VA's disability claims process has been plagued by backlogs (Cogan, 2010). By some estimates, there are currently almost 1.1 million backlogged disability claims at the VA (Cogan, 2010). The difficulty of establishing the evidence for non-combat veterans, coupled with delays from extended review processes and growing case backlogs means many veterans either are dissuaded from seeking help or those who do seek help face significant delays before assistance is available (Kingsbury, 2008).

### History of PTSD Claims in the VA System

Under the previous VA policy, veterans seeking disability based on PTSD had to establish a current PTSD diagnosis, provide credible (independent) evidence that an in-service stressor occurred, and show evidence supporting a conclusion that the incident was linked to the current PTSD diagnosis (Philpot, 2009). In PTSD disability cases, the former VA policy provided that if the evidence established that the veteran "engaged in combat with the enemy," the veteran's testimony alone was sufficient to establish that the stressor event occurred as long as the stressor is consistent with the "conditions" or "circumstances of their service" (Philpot, 2009, p. 1). However, the former policy required veterans who were *not* in actual combat to develop independent evidence and submit considerable documentation to show that fear of injury or death caused their chronic PTSD (Philpot, 2009). The VA then reviewed Department of Defense (DoD) records to verify the fearful event or stressful period of service (Philpot, 2009). This review process could add an average of six to eight months to the claims process, making an already lengthy process even longer (Philpot, 2009).

This dual evidentiary standard made it difficult for "non-combat" veterans to gain timely access to the mental health services they required, largely due to the overly burdensome requirement to produce documentation and independent evidence that would almost by necessity have to come from the time when

they were in service in a hostile environment and under extreme stress. Even if such documentation was produced, the non-combat veterans then had to wait for the lengthy VA review process to conclude before they gained access to mental health services, assuming their claim was approved. Many Iraq and Afghan veterans are considered to have served in non-combat roles because these conflicts do not have the traditional front lines associated with early wars. Thus, the old policy's evidentiary requirements for non-combat PTSD claims discriminated against veterans from the wars in Iraq and Afghan, where many did not serve in combat roles but still endured traumatic experiences (Daly, 2010).

Bringing about the recent policy change took some time and involved many different players putting pressure on many different fronts. Congressman John Hall (D-N.Y.), Chairman of the House VA Subcommittee on Disability Affairs and Memorial Assistance, was instrumental in defining the problems with the former VA PTSD disability policy. Rep. Hall stated that he pressed the VA for two years to relax its requirements for showing service-connection in PTSD cases (Hall, 2010). On February 10, 2009, Rep. Hall introduced the Combat PTSD Act (*Bill Summary & Status*, 2010), a bill that would be aggressive in easing evidentiary rules for PTSD by creating a presumption of service-connected disability for veterans diagnosed with PTSD. Rep. Hall states on his website that he discussed the issue with President Obama in 2009, which led to a meeting with Secretary of the VA, Eric K. Shinseki (Hall, 2010). On August 24, 2009, the VA published a proposed regulatory rule to modify the evidentiary standards for PTSD cases. Hall's bill did not pass since the VA amended its regulations, relaxing its PTSD standards. Senator John Kerry (D-Mass.) and Senator Charles E. Schumer (D-N.Y.) introduced similar bills in the Senate in July 2009, which, like Hall's bill, were not passed (*Bill Summary & Status*, 2010).

One of the other factors that precipitated the recent policy change was that Veterans' groups filed lawsuits against the Bush administration over delays in PTSD claims and other service-related claims, which brought the problems of the old policy out in the open (Ruggeri, 2008). President Bush's administration had resisted congressional efforts to increase the VA budget enough to cover treatment for the dramatic increase in traumatic brain injury and PTSD cases (The Public Record Staff, 2009). Before the Iraq invasion in 2003, the VA had expected a maximum of 8,000 PTSD cases. A RAND Institute study released in 2008 stated that

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more than 320,000 veterans of the Iraq and Afghan wars suffered from depression, PTSD and/or traumatic brain injury (Public Record Staff, 2009). The DoD and the VA were not prepared for such an influx in PTSD disability claims. The Bush administration did not offer any extra support or move to ease the guidelines for PTSD claims, perhaps out of fear that too many people would try to commit fraud.

Another factor that created a favorable environment for the policy change was that President Obama made it clear he did not support the old policy with its burdensome and impractical evidentiary requirements (Obama, 2010). Tammy Duckworth, VA Assistant Secretary for Public and Intergovernmental Affairs, stated that the old policy was "neither fair, nor sustainable. This is especially true in the current wars in Iraq and Afghanistan where there are no static front lines and the combat zone is everywhere" (2010, p 1). Duckworth urged the VA to give veterans the benefit of doubt stating, "This means that if a Veteran was in a certain place at a certain time- and they present us with diagnosable symptoms, then we'll presume those symptoms were caused by their experience in combat" (2010, p 1). Finally, the VA stated in the summary of the new policy that by liberalizing the PTSD evidentiary standard it takes into consideration the current scientific research relating PTSD exposure to hostile military and terrorist actions (Department of Veterans' Affairs, 2010).

### The New VA PTSD Policy

On July 13, 2010, the VA published its final rule for "Stressor Determinations for PTSD" (Department of Veterans' Affairs, 2010). The amendment was proposed on August 24, 2009 as 74 Fed. Reg. at 42618 and finalized on July 12, 2010 as 75 Fed. Reg. 39843. Changes were reflected most clearly in a new paragraph designated 38 CFR 3.304(f)(3), which reads:

If a stressor claimed by a veteran is related to the veteran's fear of hostile military or terrorist activity and a VA psychiatrist or psychologist, or a psychiatrist or psychologist with whom VA has contracted, confirms that the claimed stressor is adequate to support a diagnosis of posttraumatic stress disorder and that the veteran's symptoms are related to the claimed stressor, in the absence of clear and convincing

evidence to the contrary, and provided the claimed stressor is consistent with the places, types, and circumstances of the veteran's service, the veteran's lay testimony alone may establish the occurrence of the claimed in-service stressor. For purposes of this paragraph, "fear of hostile military or terrorist activity" means that a veteran experienced, witnessed, or was confronted with an event or circumstance that involved actual or threatened death or serious injury, or a threat to the physical integrity of the veteran or others, such as from an actual or potential improvised explosive device; vehicle-imbedded explosive device; incoming artillery, rocket, or mortar fire; grenade; small arms fire, including suspected sniper fire; or attack upon friendly military aircraft, and the veteran's response to the event or circumstance involved a psychological or psycho-physiological state of fear, helplessness, or horror. (Department of Veterans' Affairs, 2010).

As such, the rule change was done internally through the VA and not through the Office of the President or through Congressional legislations. The new rule abolishes the old, draconian policy where the soldier had to prove an in-service stressor led to the PTSD. The new policy acknowledges medical and scientific findings that demonstrate simply being in a war-zone is liable to give a person trauma that becomes PTSD. The new rule, however, is not limited to veterans of current conflicts. Thousands of veterans from World War II, Korea, and Vietnam, in addition to veterans returning from Iraq and Afghan, may now be eligible for benefits and healthcare, even if their claim was previously denied (Hall, 2010).

The new policy provides that the stressor leading to a PTSD diagnosis must relate to a "fear of hostile military or terrorist activity . . . and be consistent with the places, types, and circumstances of the veteran's service" (Department of Veterans' Affairs, 2010, p 39852). This wording reflects today's wars where terrorism and guerilla tactics are common and a clear front line of combat is rarely identifiable (Daly, 2010). Thus, the new rules expand eligibility for VA disability benefits to include, for the first time, veterans suffering from PTSD who did not directly engage in combat (Daly, 2010).

This change no longer requires strict documentation of the stressor, just that the stressor is

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“consistent with the places, types, and circumstances of the veteran’s service” (Department of Veterans' Affairs, 2010, p. 39852). Just being in a war-zone seems to be enough to meet this requirement, especially when the rule continues to say stressors may be “experienced, witnessed, or... confronted with an event or circumstance that involved actual or *threatened* death or serious injury” (Department of Veterans' Affairs, 2010, p 39852, emphasis added). The claimant is assumed to be telling the truth, and the burden of proof is put on the agency to prove contrary with “clear and convincing evidence” (Department of Veterans' Affairs, 2010, p 39852). It is important to point out that being around traumatic events is not a guarantee that one will get PTSD. To establish a claim for PTSD, a VA psychiatrist or psychologist must agree that the stressors are related to experience one had in service, and a VA adjudicator must approve his or her assessment.

In addition, the new policy shuts out all non-departmental services. Only a VA or a VA contracted psychiatrist or psychologist, not social workers or physicians, have the ability to rule if the stressors would be consistent with the place of service (Department of Veterans' Affairs, 2010). A veteran cannot use a private doctor. Furthermore, claims and appeals will still be processed within the VA in much the same way as before with only two noticeable changes. The first change is that the adjudicator approves the diagnosis of the mental health providers, making the mental health care professionals’ opinion evidentiary. The second is that the burden of proof is no longer on the veteran to prove the event happened, but on the VA to prove that it did not happen (Department of Veterans' Affairs, 2010).

Statewide VA office personnel that hear the claims, and to a large extent the regional offices that hear the appeals, will be responsible for implementing these policy changes. To date, there has not been any discussion on administrative oversight. One may assume the standard chain-of-command within the VA and the occasional Congressional oversight hearing will be used to determine if the changes are being implemented properly and whether the policy is effective. Ultimately, the political responsibility for implementing the policy falls on the shoulders of the Secretary of Veteran’s Affairs.

As with all government policies, the price tag of this policy is hotly debated. It would appear to the authors that the money spent printing the new rule, doing trainings, and completing public relations would be minimal. Much of the debate seems to center around

the money used to rehear appeals and the money given out in benefits to the claimants. Disability benefits include free physical and mental health care plus monthly checks that vary but can be more than \$2000 (Dao, 2010). According to James Dao of *The New York Times* (2010), the implementation of these new rules is expected to cost \$5 billion in the next several years and around \$42 billion over the next decade. The official document issued by the VA projects that the cost of this rule change would not exceed \$100 million in any one year (Department of Veterans' Affairs, 2010). At any rate, the money for the increase of benefits will come out of the VA’s annual budget, although President Obama promised to increase funding to the VA (Obama, 2010).

### Goals

The VA’s willingness to change its policy to be consistent with current scientific research relating to PTSD in military cases is significant recognition of PTSD as a debilitating and often long-term disorder that requires long-term treatment (American Psychiatric Association [DSM-IV-TR] 2000). As such, the authors believe that there should be no doubt that the goals of this policy change are just. It is only decent for the country to take care of the people who fought it’s battles. In changing the policy to eliminate some bureaucracy, the VA is seeking to correct a long-standing injustice to this country’s service men and women.

The new PTSD policy raises a major issue for social welfare. It is time to recognize and deal with the stigma in the military that prevents troops and veterans from getting help for PTSD and other mental health issues. Shame remains a significant barrier to military personnel and their families who need assistance (Kingsbury, 2008). In addition, there is still a lot stigma surrounding mental health treatment within the military culture (Kingsbury, 2008). In his July 10, 2010 announcement, President Obama noted that one of the reasons veterans do not seek help for PTSD is that troops and their families often felt stigmatized or embarrassed when it came to seeking help (Obama, 2010). Along with the policy change, President Obama highlighted the efforts his administration, as well as senior Pentagon personnel, have made to encourage people that need mental health services to seek the help, without fear of punishment, and to normalize that need (Obama, 2010). The new policy gives veterans the

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benefit of the doubt and goes a long way toward removing blame from the individual, which may in turn reduce the stigma attached to the diagnosis.

The new policy seeks to reverse decades of governmental behaviors that often created a hostile and adversarial process for veterans seeking help for PTSD relating to their military service. This is a much-needed step in the right direction. The new policy highlights one of the many failures of the broken VA claims system (Walck, 2010). It must be noted that the policy change occurred July 13, 2010, less than a year ago at the time of writing this article. As such, it is impossible to evaluate how successful it has been in improving claimants' lives. No studies have been published on this matter, but initial accounts at local VA centers spoke of a large influx of new applications and reviews for PTSD disability services two weeks after the change (WBUR Newsroom, 2010). There is no guarantee that these claims will be approved, and even if they are it may still be possible for the VA to down play their disability rating (Plattner, 2008). A disability rating is the VA's assessment of how much the disability impacts a claimant (e.g. a disability rating of 50% means one is 50% disabled, a rating of 20% means one is 20% disabled). Thus, the rule change will do little good if the service members get approved for disability but get a disability rating of ten or twenty percent.

### Political Feasibility

There does not appear to be any hidden agendas with the VA's new policy liberalizing the evidentiary standards in PTSD claims. Rather, it seems to be a long overdue and much needed approach. As a commentator wrote the day before Veteran's Day, "For decades, the VA operated as if too many of its bureaucrats saw their role as workers in a Department of Veterans Adversaries" (Schram, 2010, p 1). The VA policy change was led by Rep. Hall behind the scenes. Staying out of the media spotlight, he sought to convince the VA to stop demanding that a veteran prove the specific stressor that caused his or her PTSD (Schram, 2010).

The 111<sup>th</sup> Congress may be the end of a historically productive era of House leadership by staunch veterans' advocates, led by House VA Committee leader Chairman Bob Filner, (D-Calif.), Rep. Hall, and veterans subcommittee chair Stephanie Sandlin (D-S.D.). Representatives Hall and Sandlin

were defeated in the recent election. With these key supporters of veterans not returning to the House, it remains to be seen how much support Congress will give veterans in the 112<sup>th</sup> Congress. Many worry that the trend in Congress to cut spending will negatively affect the VA's budget and thus their ability to provide support to veterans suffering from PTSD (Schram, 2010).

President Obama has helped create a favorable environment for changes to VA benefits but it remains to be seen if Congress will continue to honor his requests to increase the VA budget. Also, President Obama chose retired U.S. Army General and Vietnam veteran Eric Shinseki, who has been sympathetic to the veterans' needs, to head the VA. At his Senate confirmation hearing, Shinseki said he wanted to streamline the disability claims system and increase the quality, timeliness and consistency of claims processing (Shinseki, 2009).

Although veterans and their families are concerned about the new VA policy, there is no evidence of concern by a large portion of the public. In theory, the public supports the new policy, but in the current political and economic climate that concern could quickly change if politicians start suggesting fraud in VA claims or that billions of dollars will be needed to fund the policy.

### Economic Feasibility

As discussed previously, there is much debate about how much the program is going to cost. The VA officially projects the cost will not exceed \$100 million in any one year (Department of Veterans' Affairs, 2010). The money to pay for the new services will come out of the VA's budget. Once the disability claims are approved, they become a liability for the VA - similar to Social Security disability claims - and those claims will have to be paid as long as the new policy remains in place. President Obama's proposed VA budget for 2011 requests \$125 billion, a 10 percent jump from what Congress enacted in 2010, which was 16 percent more than 2009 (Rowland, 2010). His budget directs \$5.2 billion in specialized funds for PTSD and traumatic brain injury treatment (Rowland, 2010). It remains to be seen what the incoming Congress will do, but there is certainly no guarantee that they will continue to increase the VA's budget. If the VA budget gets cut, the whole VA claims system will remain backlogged, including

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these new PTSD claims. Since the new policy will definitely increase the number of PTSD disability claims and grant the claimants access to free health and mental health care at the VA, the cost could be substantial.

### **Administrative Feasibility**

Whether the policy accomplishes its goal or not depends largely upon the local bureaucrats overseeing the claims and the administration in Washington, DC. The Bush administration gave directives to limit the number and amount of claims given for PTSD. The low number of approved claims reflected this charge (The Public Record Staff, 2009). In contrast, the Obama administration, requested a change in policy and has promised to give more money to the VA (Rowland, 2010). Future administrations could tighten the amount of money sent to the VA, which would in turn have to tighten the amount of money it distributes to veterans. Along with the administrative factor from Washington, DC, there is the concern with whether the local VA offices will follow the new policy. If they do, and more claims are approved, there is also the issue of the disability rating which - if figured unjustly - could undermine the effectiveness of the new policy.

### **Policy Critique**

Many believe that this policy will alleviate the problem of veterans with PTSD not receiving adequate mental health care. The supporters believe that, over time, the policy change will save money by reducing costs in local communities (less emergency room visits, fewer PTSD related suicides and homicides, etc.). Detractors are concerned about the cost estimates. Some claim it will cost much more than the VA estimates. Others are concerned that by making it easier to establish a PTSD disability, there will be a rise in fraud. Still others claim that giving benefits to people, especially the younger veterans, for PTSD will create a culture of dependency and inhibit their ability to get back to work (Dao, 2010). It is notable that these detractors have not come up with an alternative method other than retaining the old policy. It is the opinion of the authors that money spent on veterans to get the mental health care they need is a wise investment. While there will invariably be cases of fraud and dependency, these will comprise a minor percentage of

the population receiving benefits, as historically has been the case with other social services (Zilka & Frye, 2010).

There remain important unresolved social welfare issues when looking at how the VA determines benefits for returning service members. For years, the American public has closed its eyes to the VA's treatment of returning veterans and forced those returning from war to fight the very system that was supposed to support them (Hallman, 2010). How does America address the VA's overall failure to meet the needs of returning veterans and fix the system on a long-term basis? Can average Americans be persuaded that veterans should receive as much from us when they return from war as we expected them to sacrifice in going to war? Will Congress have the political will to fund veterans' benefits at levels that support a re-structured VA system? Many other questions must be answered and will likely be debated heavily during any attempt to overhaul the VA.

### **Implications for Social Workers**

On the surface, the new VA PTSD policy ushers in no change for social workers. As mentioned previously, social workers are not allowed to give diagnoses – those can only come from psychiatrists or psychologist on the VA payroll. VA Social workers are, however, allowed to keep helping veterans through the process and are often in roles which support and advocate for them, so it is important to know about these policy changes. The most significant change for social workers is that with an increase in returning veterans, and the potential for an increase in the approval of PTSD claims, the VA will continue to need more social workers to run groups, manage cases, and do psychotherapy, among other tasks.

For social workers outside of the VA, it is important to be aware of these changes in order to provide accurate information to any veteran or veterans' families that you may see in your practice. For older veterans from World War II or Vietnam, who have been frustrated by their inability to get their PTSD claims approved, there may now be new opportunity to give accurate information and make a positive referral. This may be very affirming for some of the older veterans. Some may feel vindicated in their fight to get their claims recognized. Others may feel less stigmatized about their trauma and be willing to take the first steps

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to filing claims. Many may be angry that it has taken so long. All of these possible reactions are worth exploring among veterans and their family members.

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### References

- American Psychiatric Association. (1980). *Diagnostic and statistical manual of mental disorders* (3rd ed.). Washington, DC: Author.
- American Psychiatric Association. (1994). *Diagnostic and statistical manual of mental disorders* (4th ed.). Washington, DC: Author.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4th ed., text rev.). Washington, DC: Author.
- Bill summary & status: 111th Congress H.R.952.* (2010). Retrieved December/1, 2010, from <http://www.thomas.gov/cgi-bin/bdquery/z?d111:HR00952:/home/LegislativeData.php>
- Cogan, M. (2010, February 23) Veterans battle disability-claim backlog. Message posted to <http://www.politico.com/news/stories/0210/33307.html>
- Daly, R. (2010). New regulations make it easier for vets to prove they have PTSD. *Psychiatric News*, 45(15) pp1 Retrieved from <http://pn.psychiatryonline.org/content/45/15/1.2.full>
- Dao, J. (2010, July 7). V.A. is easing rules to cover stress disorder. *The New York Times*, pp. A1. Retrieved from [http://www.nytimes.com/2010/07/08/us/08vets.html?\\_r=3](http://www.nytimes.com/2010/07/08/us/08vets.html?_r=3)
- Department of Veterans' Affairs. Summary of precedent opinions of the general counsel. *62 Federal Register*, pp. 63603 - 63605 (December 1, 1997). Retrieved from <http://www.federalregister.gov/articles/1997/12/01/97-31329/summary-of-precedent-opinions-of-the-general-counsel>

## Policy Changes for Processing PTSD Disability Claims at the Department of Veteran's Affairs

- Department of Veterans' Affairs. Stressor determinations for posttraumatic stress disorder. *75 Federal Register*, 75(133) pp. 39843-39852 (July 13, 2010). Retrieved from <http://www.gpo.gov/fdsys/pkg/FR-2010-07-13/pdf/2010-16885.pdf>
- Dreazen, Y. J. (2008, May 13). What are the wounds of war? *The Wall Street Journal*, pp. A11. Retrieved from <http://online.wsj.com/article/SB121063207588086509.html>
- Duckworth, T. (2010, July 12). PTSD claims: Making the process easier for our veterans. Message posted to <http://www.whitehouse.gov/blog/2010/07/12/pt-sd-claims-making-process-easier-our-veterans>
- Editor. (2009, September 19). Stanford study finds staggering rates of PTSD among Iraq and Afghanistan veterans. *Lake County News*, Retrieved from [http://lakeconews.com/index2.php?option=com\\_content&do\\_pdf=1&id=10392](http://lakeconews.com/index2.php?option=com_content&do_pdf=1&id=10392)
- Hall, J. (2010). *Veterans issues*. Retrieved December/1, 2010, from [http://johnhall.house.gov/index.php?option=com\\_content&view=article&id=1035&Itemid=86](http://johnhall.house.gov/index.php?option=com_content&view=article&id=1035&Itemid=86)
- Hallman, T. (2010, April 19). VA still battling errors, claims backlog. *Gannett*, Washington Bureau, Retrieved July 11, 2011, from: <http://www.federaltimes.com/article/20100619/DEPARTMENTS04/6190301/1021/DEPARTMENTS04>
- Kingsbury, K. (2008, May 1). Stigma keeps troops from PTSD help. *TIME Magazine*, 171(19) Retrieved from <http://www.time.com/time/health/article/0,8599,1736618,00.html>
- Obama, B. (2010, July 10). *President Obama announces changes to help veterans with PTSD receive the benefits they need*. Washington, DC: The White House, Office of the Press Secretary. Retrieved from <http://www.whitehouse.gov/the-press-office/weekly-address-president-obama-announces-changes-help-veterans-with-ptsd-receive-be>
- Parrish, I. S. (2008). *Military veterans PTSD reference manual* (Revised ed.). Bryn Mawr, PA: Infinity Publishing.
- Philpott, T. (2010). *Rule aims to ease PTSD claims*. Retrieved November/30, 2010, from <http://www.legion.org/veteransupdate/3104/rule-aims-ease-ptsd-claims>
- Plattner, P. B. (2008). *Getting a fair, thorough and accurate VA disability evaluation*. Retrieved November/23, 2010, from <http://www.ptsdhelp.net/id21.html>
- Public Record Staff, The. (2009). White House spins Bush's neglect of veterans. Retrieved November/30, 2010, from <http://pubrecord.org/nation/433/white-house-spins-bushs-neglect-of-veterans/>
- Rowland, K. (2010, April 29). Vets salute Obama on funding. *The Washington Times*, Retrieved from <http://www.washingtontimes.com/news/2010/apr/29/vets-salute-obama-on-funding/>
- Ruggeri, A. (2008, November 10). Veterans groups sue Bush administration over delayed benefits claims. *US News*, Retrieved from <http://politics.usnews.com/news/national/articles/2008/11/10/veterans-groups-sue-bush-administration-over-delayed-benefits-claims.html>
- Schram, M. (2010, November 10). Honoring vets, aiding their battles. *The Times Herald*, Retrieved from <http://www.timesherald.com/articles/2010/11/10/opinion/doc4cdb66eb3a9dc069313720.txt?vieemode=fullstory>



## Policy Changes for Processing PTSD Disability Claims at the Department of Veteran's Affairs

- Shinseki, E. (2009) Confirmation hearing statement: Committee on Veterans' Affairs, Senate,. Retrieved from [http://www.cfr.org/publication/18281/eric\\_shinsekis\\_confirmation\\_hearing\\_statement.html](http://www.cfr.org/publication/18281/eric_shinsekis_confirmation_hearing_statement.html)
- Wiley - Blackwell (2009, August 26). Post-Traumatic Stress Disorder Primary Suicide Risk Factor For Veterans. *ScienceDaily*. Retrieved July 11, 2011, from <http://www.sciencedaily.com/releases/2009/08/090825151341.htm>
- Walck, P. (2010, March 28). Veterans waiting years for benefits say Veterans Benefits Administration needs improvements, reforms. *Savannah Morning News*. Retrieved July 11, 2011, from <http://savannahnow.com/news/2010-03-28/veterans-vas-benefits-system-broken#.Thz91-YZFbI>
- Zilka, J., & Frye, J. (2010). *Using data collaboration and analytics to detect fraud in social service programs* (PowerPoint. Los Angeles: National Association for Welfare Research and Statistics. Retrieved from <http://www.nawrs.org/LA2010/Papers/t2c2.pdf>
- WBUR Newsroom (2010, July 26). *Mass. vets claim more PTSD benefits under new rule*. Retrieved November/22, 2010, from <http://www.wbur.org/2010/07/26/ptsd-benefits>

## Sex Work in the Transgender Community: Implementing ENDA

By: Nic Riek

### Abstract

*This article attempts to expose the consequences of lacking federal anti-discrimination laws for transgender individuals. As a group that is often over-looked and stereotyped, transgender individuals are often assumed to participate in detrimental practices such as sex work by choice. In reality, transgender individuals are often forced into illegal work due to the discrimination they experience in legal working environments. The Employment Non-Discrimination Act (ENDA) has been proposed in Congress for the last seventeen years and has yet to be passed, therefore denying transgender individuals protection against discrimination in the workplace. Although passing ENDA does not inherently insure the protection of transgender individuals against discrimination, it does provide an outlet to pursue legal action in the event that discrimination exists. Transgender individuals require the alliance and advocacy of social workers to improve the quality of their lives and work towards their equality. This article provides suggestions for approaching social work practice with the transgendered population.*

### Introduction

Susan Stryker's, *Transgender History* (2009) tells the often-overlooked history of a trans identity starting as early as 1850. At this time historical records began documenting men as well as women who were "cross-dressing" and in some cases living full lives as the opposite sex of which they were born. These individuals were often rejected from mainstream society and were required to live in isolated environments such as asylums or research institutions. Within the context of these two living situations, transgender individuals were not required to participate in traditional labor, making them somewhat capable of structuring their identities outside of the social scrutiny, but also leaving them exposed and vulnerable to the label of mentally ill. Interest from both the medical and psychological fields provided one avenue of support, but the agrarian

lifestyle and investment in familial relationships provided the most essential support for sustaining livelihood for the gender non-conforming. With the advancement of the capitalistic economic structure, men, women, and transgender individuals were all influenced to participate in the labor force (D'Emilio, 1992). Because these people were becoming more noticeable, laws in the United States especially began to place strict limitations on public appearance; men and women were by law required to wear clothing that was deemed appropriate for their sex and faced arrest and punishment usually in the form of jail time or fines if they defied the rules (Stryker, 2009). Increased public exposure elevated the opportunities for discrimination against gender non-conforming individuals in the workforce. Note: The label "transgender" is often used as an umbrella term, which encompasses the experiences or labels of gender non-conformity, transsexuality, cross-dressing, genderqueer, drag queens & kings, in addition to a wide range of other gender labels or descriptions. Transgenderism is also commonly used to describe the opposition between gender identity and birth sex, such that an individual's gendered presentation or identity is incongruent with their biologically labeled sex (Feinberg, 1998).

In response to increasingly visible discrimination, the Equality Act of 1974 was first introduced in Congress with the expectation of eradicating discrimination against lesbian, gay and gender non-conforming individuals. The initial failure of the Act, as well as the emerging AIDS epidemic, complicated and stifled the progress of equality legislation, denying the protection of marginalized workers. In the early 1990's, protection legislation reemerged as the Employment Non-Discrimination Act (ENDA), which specifically proposed to address workplace discrimination against LGBT individuals. Although this legislation has been put forward for consideration numerous times, ENDA has yet to be enacted into law, therefore leaving lesbian, gay, bisexual, and transgender individuals unprotected against workplace discrimination at a federal level. While the lack of protection possible through the

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eradication of ENDA had affected numerous individuals, this article analyzes current anti-discrimination legislation specifically to male-to-female (MTF) transgender individuals in the workforce.

### Employment Non-Discrimination Act

A proposed addition to the current Equal Employment Opportunity (EEO) laws is the Employment Non-Discrimination Act (ENDA). This law would secure the protection which is currently provided based on race, sex, national origin, disability and age, but would also be extended to sexual orientation and gender identity. Under the current legislation of the EEO, particular securities are allotted to particular protected workers, which guarantee their rights as employees to equality within the context of their working environment. The EEO ensures that protected employees have equal protection in employment practices, which would include hiring and firing, but also decisions concerning promotion or compensation. Under the EEO, employment decisions that are based on stereotypes or assumptions concerning the abilities, traits or performance potential of protected individuals are not permitted, such that protected parties are able to sue companies that practice any discriminatory policies against them. Even denying employment opportunities to a qualified individual due to their association with or marriage to anyone of a protected group under the EEO is also strictly enforced with the legislation. Not only is protection against discrimination extended to all companies with fifteen or more employees, but both Congress and the federal government, as well as state and local governmental employees are protected under the EEO. While these laws serve an essential role in the protection of the rights of certain workers, they are not applicable to everyone, which influenced the proposition of the ENDA.

According to the Gay and Lesbian Taskforce website, ENDA was first introduced in Congress in 1974 as the Equality Act and has yet to become a law. Anti-discrimination policies are clearly outlined within the government-sponsored website hosted by the Equal Employment Opportunity Commission (EEOC), which explains the rights and protections of individual workers. Under the proposed legislation of ENDA, both public and private employers, as well as employment agencies and labor unions would be prohibited from

using an individual's sexual orientation or gender identity as the basis for employment decisions. The proposed legislation of ENDA is similar to the established legislation of Title VII, as well as the Americans with Disabilities Act, however some distinctions can be drawn which identify some of the limitations of the ENDA. Essentially, the additional protection of employees based on their sexual orientation or gender expression would be represented through the pre-established avenue of the EEO laws and would not require unique policy adjustment, but rather would mandate additional marginalized identities be acknowledged.

### Anti-Discrimination Laws in Progress

According to the Equal Employer Opportunity Commission, the EEO laws were enacted in response to the growing necessity for minority protection within the context of the American workforce, such that individuals falling into specific identity categories were safe from discrimination in work environments. One of the first anti-discriminatory laws concerning workforce environments was Title VII of the Civil Rights Act of 1964, which was established to ensure the protection of workers against discrimination on the basis of race, religion, sex or national origin. Under complimentary legislation of the Equal Pay Act of 1963, men and women performing substantially equal work in the same establishment were guaranteed protection against sex-based discrimination. The Age Discrimination in Employment Act of 1967 was an important amendment which secured the protection of individuals of forty years or older.

Over two decades later, Title I and Title V of the Americans with Disabilities Act of 1990 were established to prohibit employment discrimination against qualified individuals with disabilities within the context of the private sector and in state and local governments as well. Federal governmental protection for qualified individuals with disabilities was also established with the enactment of Section 501 and 505 of the Rehabilitation Act of 1973. Title II of the Genetic Information Nondiscrimination Act of 2008 was also established to protect working individuals against workforce discrimination on the basis of genetic information about an applicant, employee or former employee. The Civil Rights Act of 1991 was also an

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essential amendment to legislation, which among other things, provided monetary compensation in the event that working individuals were victims of intentional employment discrimination. Throughout the course of the adjustments and amendments to employee protection legislation, an increasingly expansive population of workers was protected and worked to ensure that both the rights and identities of some individuals were validated.

While legislation to protect individual workers against workplace gender discrimination does not exist, some individuals have attempted to employ contemporary laws in an effort to protect themselves against discrimination. Although many minority groups gradually gained legal protection against workplace discrimination, transgender individuals did not receive immediate protection. Claiming minority status, some transgender individuals attempted to sue companies under Title VII, which protected against discrimination on the basis of sex, race, color, religion and national origin. One of the first reported cases invoking this legislation took place in 1975, *Voyles v. Ralph K. Davies Medical Center*, which occurred when a transsexual woman revealed her intent for sexual reassignment surgery and was promptly terminated from her position. The outcome of the suit however did not yield favorable results for the plaintiff:

The [U.S. Supreme] court dismissed her case, holding that Congress had enacted Title VII to protect women, not transsexuals, and that nothing in the legislative history of Title VII indicated any congressional intent “to embrace ‘transsexual’ discrimination”, or any permutation or combination thereof (Broudas, 2006, p. 95).

Results from the case were upheld in similar discrimination suits for roughly the next decade, in which courts sustained that “the ‘plain’ or ‘traditional’ meaning of the term *sex* refers only to a person’s biological identity as male or female, not to change of sex” (Broudas, 2006, p. 95). Unfortunately for transgender individuals, employers were legally protected from discrimination allegations based on Title VII such that employees were eligible for termination based on sex transitions.

An important milestone in redefining the legislative interpretation of both “sex” and “gender” emerged during the 1989 *Price Waterhouse v. Hopkins* case. The plaintiff, Hopkins, filed suit against the law firm she was employed with, citing discrimination based

on her “masculine” appearance. On multiple occasions, Hopkins had been advised by the partners of the firm that if she presented with a more traditionally feminine appearance, she was likely to achieve greater success. Judges ruled in favor of the plaintiff, supporting the notion that discrimination based on gendered appearance was unconstitutional. In the context of this ruling, the judicial system expanded on the capacity for Title VII protection, such that individuals were protected against discrimination that was rooted in perceptions of their gender non-conformity. The U.S. Supreme Court determined that under Title VII, discrimination based on sex “also includes stereotypical assumptions and preconceptions about how men and women are supposed to behave, dress, and appear” (Broudas, 2006, p. 95). A dramatic and progressive improvement on previous legislation, the outcome of the *Price Waterhouse v. Hopkins* case protected individuals from discrimination based on their gender expression. Although the results from this case did not inherently challenge or allow for the inclusion of transgender individuals, it did expand the definition of sex discrimination to include gender non-conformity.

Only recently were transgender individuals able to access protection under Title VII with results from state-level court systems. Broadus explains that in the dawn of the 21<sup>st</sup> century, states such as Connecticut, Massachusetts, and New York have cited the U.S. Supreme Court decision in *Price Waterhouse v. Hopkins* as the precedent for acknowledging transsexuals as a protected group under the Title VII legislation (2006). Transgender status is protected within a few states and under the anti-discrimination policies of some companies according to the Human Rights Campaign and the Gay and Lesbian Task Force, however individuals residing outside of protected states or employed with companies that have no gender based anti-discrimination guidelines remain unprotected.

### Effects of Marginalization

Lack of protection against discrimination continues to have negative consequences for transgender individuals; “Among a community sample of transgender individuals, nearly 50% of the respondents had experienced sex-based employment discrimination or harassment” (O’Neil et al., 2008, p. 291). When specifically considering transgender youth of color, however, difficult experiences with

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employment have been shown to be as high as 61% in a given sample (Garofalo, 2006). Within the transgender community, female transsexuals are particularly vulnerable targets for occupational discrimination, such that they are often driven to participation in illegal sex work, which can be difficult to escape (Garofalo, 2006). Within the framework of a heteronormative work force, transgender individuals are often at a great disadvantage concerning their integration into mainstream employment atmospheres. Without the necessary legal and policy enforcements to encourage and sustain their protection, transgender individuals are not capable of attaining equal opportunities in legal employment, which contributes to marginalization in numerous facets of their lives.

Common perceptions of transgender women participating in sex work often assume that these individuals willingly and actively pursue their occupation, however the experiences in sex work environments are considerably less than favorable. One of the most pervasive and negative results from engaging in sex work is the contraction of sexually transmitted infections, specifically HIV. Transgender women are at the greatest risk for contracting HIV when participating in sex work. Research conducted by Operario et al. (2008) revealed that the overall prevalence of HIV among transgender women engaged in sex work was 27.3%, biological male sex workers 15.1%, and biological female sex workers 4.5%. Garofalo et al. (2006) found that for transgender sex workers “inconvenience and fear of anger or rejection from sexual partners were raised by youth as rationale for inconsistent condom use”, which would have ultimately contributed to the potential to contract and transmit HIV to other individuals (p. 235). In addition to contracting STI’s and HIV, transgender individuals engaging in sex work also experience extremely high rates of physical assault (65%) and rape (67%), which was often described as an ever-present risk and expected in numerous circumstances (Sausa et al., 2007). Research has identified substance abuse as another characteristic of participation in sex work among transgender populations, primarily used to cope with the stressful circumstances of their occupation (Garofalo et al., 2006, Wilson et al., 2009).

Transgender individuals experience extremely hazardous circumstances as a result of their discrimination in mainstream employment situations. Rather than maintaining legal employment, transgender women are often forced into sex work, where they are

subjected to increased exposure of HIV, sexual violence, substance abuse, and even incarceration. Results from Garofalo et al. (2006) indicated that, “of participants engaged in commercial sex, over 90% reported a history of incarceration or arrest” (p. 235). While participation in sex work may be preferable for some transgender individuals, providing a sense of independence and the ability to avoid discriminatory practices within a mainstream work environment, it is clear that there are severe and potentially fatal consequences from their social and occupational discrimination. It is a social responsibility to advocate for and protect this marginalized and severely underrepresented population.

### Goals of ENDA

Ultimately, the established and maintained goal of the ENDA is to prevent the discrimination of individuals based on their sexual orientation and gender identity within the context of a working environment in all federal, state and local institutions employing more than fifteen people (Human Rights Campaign, 2010). This objective aims to create the equal opportunity for employment and evaluation of individuals based on their skills and capabilities, which directly relate to the working position, as opposed to characteristics which are not applicable to a working environment. Within the context of the contemporary capitalist society, it is the expectation and often a necessity that every capable individual participate in the workforce. Therefore, the enforcement of laws and policies that ensure all people are provided protection against discrimination within the working environment is necessary. Although contemporary opportunities for transgender individuals have expanded through increased social acceptance and some legal interventions, day-to-day experiences in the workforce still remain uncomfortable and unstable. Within the confines of legal work, transgender individuals often face significant discrimination from potential and current employers. One transgender woman explained:

It’s been tough finding work as a female, because I think employers are able to read me as transgender, and that’s a big disqualifier. Even though it’s illegal in [city] to discriminate... there are other more qualified candidates or something like that employers argue. But I fly-in with stellar credentials, in many cases excellent resume, etc., because I

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was getting interviews, but I wasn't getting offers (Budge et al., 2010, p. 387).

Although transgender individuals possess qualifications required for certain positions, they frequently report disproportionate offers from interviews and even disqualification from positions. One transgender woman recalled being fired from a job during her gender transition process; however, when she temporarily interrupted the process and reverted back to a masculine appearance, she was able to obtain employment (Sausa et al., 2007). Experiences such as these indicate that while some legal protection has been implemented to secure equal employment opportunities for transgender individuals, companies and employers still stigmatize and regard transgender workers as unfavorable.

Without necessary changes to support gender status (legal name and consistent documents) as well as workplace sensitive issues (e.g., use of female restrooms), transgender women especially experience fear and anxiety about maintaining legal employment (Sausa et al., 2007). In extreme cases, individuals experience tremendous distress concerning their employment circumstances, such that "some participants felt so emotionally overwhelmed with hiding their transgender identity at work that they attempted suicide" (Budge et al., 2010, p. 381). Rather than enduring incredibly stressful and unstable employment situations, some transgender individuals perceive participation in sex work as a preferable alternative. While sex work is not a particularly lucrative or fulfilling occupation, some structural components of the occupation are preferable in comparison to mainstream employment, which does not support or advocate for transgender workers.

Establishing and enforcing the requirements advocated by the ENDA would ultimately provide transgender individuals with the opportunity to safely and comfortably participate in legal working environments. The addition of ENDA to the EEO laws would not only provide access to similar job opportunities as many other people are provided, but it would also serve to ensure transgender individuals protection against harassment within the working environment. One of the primary safety concerns facing transgender women is the access to safe and secure restroom facilities, which is not always provided in legal working environments. Adding ENDA to the EEO would enforce the need for secure facilities for all individuals and would require that all employees had access to equal amenities. In addition to the

establishment of protected facilities for transgender women, the adoption of the ENDA might also serve to improve the social perceptions of transgender individuals and their integration and acceptance within mainstream society.

The EEOC's annual report (2009) indicated that 96% of agencies provided their EEO compliant staff with the required training, which reinforced their fundamental policies. With nearly all EEO compliant facilities exposing employees to the maintained non-discriminatory policies and guidelines, the concept of equality is reinforced through exposure to information and education. Adding ENDA to the policy maintained by the EEO would contribute to the advocacy concerning equality within sexual orientations and gender identities, which would be a fundamental stepping-stone towards promoting equality and acceptance of all individuals.

### Implementation Challenges

#### *Catholic Response to ENDA*

A religious—specifically Catholic opposition exists concerning the passage of ENDA. Although the Catholic Church does not inherently condone the discrimination of any group or community, it does not advocate for the legal protection of transgender individuals. Statements and sentiments produced from the Catholic Church have suggested that, "homosexual persons, as human persons, have the same rights as all persons including that of not being treated in a manner which offends their personal dignity. Among other rights, all persons have the right to work, to housing, etc" (Ratzinger & Bovone, 1986). The overall sentiments of the Catholic Social teachings affirm that, "work is a good thing for man—a good thing for his humanity—because through work man *not only transforms nature*, adapting it to his own needs, but he also *achieves fulfillment* as a human being and indeed, in a sense, becomes more a human being" (Pope John Paul II, 1981). As human beings, everyone is then allotted equal freedoms and liberties through the perspectives maintained by the Catholic Church, which should be equally applicable to transgender individuals. The official position of the Catholic Church asserts that considering "homosexual orientation" or transgender identity as legally protected identities, might easily lead to regarding them as acceptable life styles, which is not the agenda of the religious institution.

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Contrary to this concept however, one of the beliefs of the Catholic Social teachings identifies the possibility and reality that in various ways the labor process works against humankind, through the means of exploitation and oppression. In effect, the ultimate goal should be the creation of regulations within the workforce, which would eliminate discrimination and exploitation of workers, as well as secure their right to dignity and respect as human beings (*Laborem Exercens*). While the Catholic Church would not inherently support an amendment to judicial policies concerning the protection of transgender individuals against workplace discrimination, it is evident that the position of the Church does advocate for the right to equal access for all individuals regardless of their sexual orientation or gender identity.

Citing Catholic tenets as justification, religious individuals often reference church values as reasoning for discrimination against transgender people, however investigation into the Catholic Social teachings would likely produce a different result. Exploration of the Catholic Social teachings would reveal a distinction between the policy concerning employment opportunities, discrimination, and the overall position concerning homosexuality and transgenderism. While the Catholic Church as a whole may not fully support homosexual and transgender individuals, the social teachings advocate for equal treatment of all individuals within the work force, such that anti-discriminatory behavior should be accepted as standard procedure. Although adopting this policy may be perceived as threatening to some organized groups, many companies have adopted policies protecting individuals based on the goals of ENDA. According to the Human Rights Campaign, forty-one percent of fortune 500 companies, as well as twelve states across the nation have already adapted policies which protect workers against gender identity discrimination. On one hand there is a strong religious objection to the inclusion of gender identity to the EEO, while on the other there is a progressive movement of local institutions embracing gender identity without federal legislature. The persistence of this perspective has stifled the passage of ENDA even though the passage of the bill would not inherently affect religious organizations. Specifically, an important clause outlined in ENDA stipulates that religious institutions are not required to adhere to the guidelines.

### *State Feasibility*

In addition to the stifling Christian response to ENDA, the perception of financial feasibility has also compromised its success. While our current economic climate poses an obstacle for many policy reform initiatives, the Congressional Budget Office has reported that the passage of ENDA would not deplete necessary and limited government resources. Although the EEO laws have yet to embrace the proposed legislation of ENDA, projections concerning monetary requirements are available which examine the financial necessities. During the initial discussions surrounding the implementation of the ENDA of 2003, the Congressional Budget Office (CBO) estimated that the execution of the proposed legislation would roughly cost \$22 million over the course of the 2003-2007 period (less than one percent of the total budget) within the EEOC—money which would primarily be allocated to the additional discrimination cases emerging from increased protection. In addition to the projections of the CBO, the EEOC estimated that the enactment of ENDA would increase the overall caseload of the Commission by roughly five to seven percent and require sixty to ninety additional staff members.

Based on these projections, the CBO reports that the adaptation of the ENDA would not create a significant strain on the annual monetary investment that is currently allocated to the EEO laws. Funding is not currently allocated to specifically service the individuals that would be protected by ENDA (a request for additional funds is optional), current funds could be reallocated to ensure the protection of more individuals. The estimate of the CBO concerning the monetary requirements of ENDA suggests that the financial impact is manageable. Additionally, rather than the creation of an entirely new organization, the EEOC would require only additional staff members, and not the establishment of entirely new facilities to accommodate the additional cases brought in from the ENDA (Congressional Budget Office, 2002).

Over the course of a year, the CBO has estimated that the cost of employing an additional seventy-five EEOC employees would total roughly \$5 million, and likely increase some of the workload for similar agencies such as the Merit System Protection Board, as well as the Department of Justice's Civil Rights Division. While these departments may experience some additional cases, they would likely

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only experience a minor increase in caseloads, primarily because the adoption of ENDA would only raise the total number of caseloads by a small percent (Congressional Budget Office, 2002).

### Conclusion

Adoption of the ENDA would protect all individuals on the basis of their gender identity and sexual orientation and would not be solely applicable to homosexual and transgender individuals. Heterosexual and gender-conforming individuals are also protected against discrimination on the basis of their sexuality or gender expression within the context of a work environment as well. In this sense, ENDA does not exclusively service marginalized groups, but rather is applicable to the working population at large. Ideally, anti-discrimination policies serve to protect marginalized individuals, such that they are protected against workplace discrimination.

ENDA ultimately aims to protect gender non-conforming and sexually marginalized individuals and secure their rights as workers and protect them against prejudice. While obtaining jobs is exceedingly difficult, once transgender individuals are able to secure employment they are still subject to discrimination and have a particularly unstable employment status. Transgender women often explained,

Typically, the job loss was explained by employers as being attributed to other factors, such as budget cuts or improper conduct at work. The participants who experienced this kind of job loss indicated that the employer's reasoning did not make sense, such as having seniority over others when there were budget cuts, and not understanding where the improper conduct occurred (Budge et al., 2010, p. 387).

Protecting transgender individuals against discrimination within the workforce is essential to securing their ability to be self sufficient and productive members of society. Adoption of ENDA would improve the policies protecting individuals against judgment based on person characteristics as opposed to qualifications for a specific position. Enacting policy to secure the rights of transgender individuals would also benefit financial investments and related social problems. Within the transgender female community, sex work is prominent theme, which has extremely negative health results including high rates of HIV/AIDS prevalence. According to the Henry J.

Kaiser Foundation (2010), an estimated \$15.8 billion was invested in research and education concerning AIDS in 2008. Reducing the prevalence of sex work within the transgender community would lead to reduced contraction of HIV and STIs, likely lessening the overall necessity for research surrounding HIV/AIDS. Not only is the overall EEO budget minimally affected by ENDA, but the allocated funds required over the course of four years is only a fraction of the resources allotted for HIV/AIDS prevention and treatment.

### Limitations

Within the construct of the American capitalist ideal, all capable and qualified individuals would participate in the workforce, which ENDA allows. Individuals could not be disqualified from a position based on their physical appearance or personal preferences, but rather would be solely evaluated based on their capabilities related to a specific work scenario. Although the goals of ENDA would ensure these rights and the equal treatment of all employees and candidates, it does not guarantee that both organizations as well as workers are abiding by the principles and policies they are subject to. Ultimately, the goals of ENDA are limited, such that transgender individuals that participate in sex work may not be able to access legal employment even with the enactment of policies, which are intended to protect them against discrimination. Evaluations and projections concerning the effectiveness of ENDA's policies may not be an accurate representation of the realistic experiences and responses from society. While no guarantee can be provided to secure that transgender individuals, particularly women, cannot be discriminated against within the context of a work environment, ENDA would ensure that these individuals would be able to take legal action against organizations that blatantly discriminated against them.

### Implications for Social Workers

Not only would the addition of the ENDA be congruent with the policies supported by the EEO laws, but it would also be complimentary to the position of the values advocated by the social work profession. A current publication indicated that, "NASW [National Association of Social Workers] recognizes that there is



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considerable diversity in gender expression and identity among our population and believes that people of diverse gender — including those sometimes called “transgender” — should be afforded the same respect and rights as any other person” (NASW, 2011). Acknowledging the legitimacy of gender variance and transgender identities suggests that the social work position and the goals of the ENDA are complimentary and conducive to the improvement of the quality of life for gender non-conforming individuals. With support from the social work community, and the addition onto the existing policies of the EEO laws, it is feasible that the ENDA could be adopted and enforced similarly to the established laws.

As an extremely marginalized group, transgender individuals require the advocacy and

support of social programs and institutions to promote their equality. For social workers, the primary mission is to, “seek to enhance the effective functioning and well-being of individuals, families, and communities through its work and through its advocacy” (NASW, 2011).

By promoting this specific agenda, it is clear that harnessing the skills and goals of social workers can significantly improve the lives of transgender individuals. While a transgender movement exists and is building momentum, it is essential to partner with allies possessing useful tools for advocacy, and complimentary goals. Enacting ENDA does not conflict or compete with social workers mission, rather helps to further serve the populations that require protection and support.

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### References

- Broadus, Kylar W. (2006). “The Evolution of Employment Discrimination Protections for Transgender People”. In Paisley Currah et al. *Transgender Rights*. Minneapolis, MN: University of Minnesota Press.
- Budge, S. L. et al. (2010). “The Work Experiences of Transgender Individuals: Negotiating the Transition and Career Decision-Making Processes” *Journal of Counseling Psychology*. 57(4) 377-393.
- Congressional Budget Office. (2002). *S. 1284 Employment Non-Discrimination Act of 2002*. Retrieved from <http://www.cbo.gov/doc>.
- Equal Employment Opportunity Commission. “Federal Equal Employment Opportunity (EEO) Laws”. Retrieved from <http://www.eeoc.gov/facts/qanda.html>.
- Feinberg, L. (1998). *Transgender warriors: Making history from Joan of Arc to RuPaul*. Boston, MA: Beacon Press.
- Garofalo, Robert et al. (2006) “Overlooked, misunderstood and at-risk: Exploring the lives and HIV risk of ethnic minority male-to-female transgender youth”. *Journal of Adolescent Health*. 38, 230-236.
- Gay and Lesbian Task Force. “Issues: Narrative: The Task Force’s commitment to ending discrimination against lesbian, gay, bisexual and transgender Americans has a long history”. Retrieved from <http://www/taskforce.org/issues>

## Sex Work in the Transgender Community: Implementing ENDA

- Henry J. Kaiser Foundation. (2010). "Financing the Response to AIDS in Low- and Middle-Income Countries: International Assistance from the G8, European Commission and other Donor Governments in 2008". Retrieved from <http://www.kff.org/hiv/aids/7347.cfm>.
- Human Rights Campaign. (2010). "Employment Non-Discrimination Act". Retrieved from [hrc.org](http://www.hrc.org).
- National Association of Social Workers. (2011). "Mission Statement". Retrieved from <http://www.socialworkers.org/nasw/annualReport2003/mission.asp>.
- National Association of Social Workers. (2011). "Gender Identity Disorder and the DSM". Retrieved from <http://www.socialworkers.org/diversity/new/lgbtq/51810.asp>
- Operario, Don et al. (2008). "Sex Work and HIV Status Among Transgender Women". *Journal of Acquired Immune Deficiency Syndrome*. 48(1).
- O'Neil, Maya Elin et al. (2008). "Transgender Identities and Gender Variance in Vocational Psychology". *Journal of Career Development*. 34(3), 286-308.
- Pope John Paul II. (1981). "Laborem Exercens". Retrieved from [http://www.newadvent.org/library/docs\\_jp02le.htm](http://www.newadvent.org/library/docs_jp02le.htm).
- Ratzinger, J., & Bovone, A. (1986) "Letter to the Bishops of the Catholic Church on the Pastoral Care of Homosexual Person". Retrieved from [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19861001\\_homosexual-persons\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19861001_homosexual-persons_en.html)
- Sausa, L. et al. (2007). "Perceived Risks and Benefits of Sex Work among Transgender Women of Color in San Francisco" *Arch Sex Behav* (2007) 36:768–777
- Styker, Susan. (2008). *Transgender History*. California: Seal Press.
- Wilson, Erin C. et al. (2009). "Transgender Female Youth and Sex Work: HIV Risk and a Comparison of Life Factors Related to Engagement in Sex Work". *AIDS Behavior*. 13: 902-913.

## Reducing the Stigma of Mental Illness in College Students

# Reducing the Stigma of Mental Illness in College Students Through Early Implementation of Educational Programs on Mental Health in Elementary and Middle Schools Nationwide

By: Lindsey Dawn Pasko

### Abstract

*Stigma associated with mental illness plays a significant role in why people do not seek treatment for their mental health problems (Balderas, 2006; Mechanic, 2008; New Freedom Commission on Mental Health, 2003; Surgeon General Report, 2000). The importance of reducing the effects of stigma for college students lies in that “approximately three quarters of lifetime mental disorders have first onset by age 24” (Eisenberg, Downs, Golberstein & Zivin, 2009, p. 523). The early detection and appropriate treatment of mental disorders is important and may contribute to improved academic, occupational, health, and social outcomes (Eisenberg et al., 2009). The Surgeon General’s Report on Mental Health (2000) prescribes the alleviation of stigma towards individuals with mental illness through the dispelling of myths and provision of accurate information about mental illness to the public. Currently, education on mental illness at all grade levels is not mandated in most states (Strauss, 2009). This policy brief makes its recommendation that an effective way to decrease stigma of mental illness in college students is by incorporating educational programming about mental health and mental illness, such as “Breaking the Silence” created by the National Alliance on Mental Illness, into elementary and middle schools nationwide (National Alliance on Mental Illness, 2011).*

### Introduction

Stigma associated with mental illness in our society today plays a significant role in preventing people from seeking treatment for their mental health problems (Balderas, 2006; Mechanic, 2008; New Freedom Commission on Mental Health, 2003; Surgeon General Report, 2000). The word *stigma* has its origins in ancient Greece and denotes “a physical brand or mark

applied to social outcasts...to indicate socially devalued status” (Goffman as cited in Hinshaw & Stier, 2008, p. 368). All age groups are susceptible to this stigma, and stigmatized views can be adopted as early as middle childhood (Hinshaw & Stier, 2008). College students, therefore, are not exempt from the effects of stigma.

What is the significance of the effects of stigma on college students in particular? This past fall (2010), 19.1 million students were expected to attend one of the country’s two-year or four-year colleges or universities, an increase of approximately 3.8 million from ten years ago (National Center for Education Statistics, n.d.). At the same time, “approximately three quarters of lifetime mental disorders have first onset by age 24” (Eisenberg et al., 2009, p. 523). This puts college students at a unique vulnerability for experiencing mental illness for the first time while they are away at school; the added stressors of being away from home and academic rigor of courses may only exacerbate their problems. “Mental health problems early in life are associated with adverse academic, occupational, health, and social outcomes” (Eisenberg et al., 2009, p. 523). Thus, early detection and treatment of mental disorders experienced during college is vital. Of equal importance is overcoming the stigma which might prevent college students from seeking treatment for their mental health problems.

Two current problems unique to college campuses which may be closely intertwined with mental illness are campus violence and college binge drinking/substance abuse.

Perpetrators of mass shootings at colleges and universities are often graduate students – older individuals who turn to violence in response to what they perceive to be unbearable pressure to succeed or the unacceptable reality of failure” (Fox & Savage, 2009, p. 1475).

College students are especially at risk for binge drinking and substance abuse (Bennett, Miller & Woodall, 1999; Goldstein & Flett, 2009). The co-occurrence of mental

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illness and substance abuse is common and often is a result of individuals' attempts to self-medicate (Buckley & Brown, 2006). If college students felt compelled to seek treatment for their mental health concerns, the prevalence of these specific campus problems may be reduced.

### Pre-Existing Policies

Reducing barriers to treatment by reducing stigma is not a new idea for policy makers. Over ten years ago, the Surgeon General's Report on Mental Health (2000) stated, "stigma must no longer be tolerated," and recommended its alleviation through the dispelling of myths and provision of accurate information about mental illness to the public (p. 454). Hinshaw and Stier (2008) warn, "unless strategies for change include altered laws and social policies *and* meaningful efforts to change fundamental attitudes in members of society, the likelihood is that reform will be piecemeal and even counterproductive" (p. 382). Unfortunately, today reform remains just that -- piecemeal. It is difficult to find tangible ways in which the dissemination of information concerning mental illness is being accomplished on a large, uniform scale to confront public perception about mental illness. These piecemeal reform efforts very much reflect an entire mental health system that is piecemeal and fragmented itself (Mechanic, 2008).

The National Alliance on Mental Illness (NAMI), the largest grassroots mental health advocacy organization in the country, focuses on "educating America about mental illness, offering resources to those in need, and insisting that mental illness become a high national priority" (National Alliance on Mental Illness, 2011). The Americans with Disabilities Act prohibits discrimination against individuals with physical or mental disabilities, both in the workplace and in public settings (Hinshaw & Stier, 2008). There continues to be a push for parity legislation for mental health insurance coverage to obtain equality with physical health coverage. Finally, the Individuals with Disabilities Education Act requires that students with disabilities receive their appropriate education in the least restrictive environment (U.S. Department of Education, n.d.).

Teaching about mental illness in schools is not mandated by most states (Strauss, 2009). At best, most high schools offer an elective introduction to

psychology course. By the time students have begun college, they have probably received introductory information about drug and alcohol abuse from the D.A.R.E program and health class, and very little, if any, information concerning mental health and specific mental illnesses. Unfortunately, whether through cognitive development processes or from socialization experiences, "the stigmatization of mental disorder begins early in development" (Hinshaw & Stier, 2008, p. 382). Therefore, it becomes clear that by the time students are first introduced to educational material about mental illness, either in high school or college, negative attitudes about mental illness have most likely already been formed. There is a lack of education about mental illness for students leading up to the time they enter college.

### Identification and Critique of Policy Options

Most efforts at reducing stigma attached to mental illness in our society are aimed at adults. One option policy makers have is to continue down this route, persisting in the fight for parity and continuing to offer educational information and resources through agencies like NAMI to adults and young adults *who show interest*. The hope would be that eventually as attitudes and behaviors of adults begin to change regarding stigma against individuals with mental illness, there would be a trickle-down effect; children would adopt the new attitudes and behaviors learned from their parents, families, and other significant adults in their lives. Unfortunately, the fight to reverse stigma towards people with mental illness in our society has been slow-going. "The stigma that the public associates with mental illness has remained persistent, with no apparent improvements over the past ten years" (Golberstein, Eisenberg & Gollust, 2009, p. 1254).

Or policy makers can choose an alternative route: they can begin to target the younger generations with the hope that by providing the appropriate education about mental health, entire generations will begin to be raised on the information needed to halt stigmatizing attitudes before they become substantial. In 1999, the National Alliance on Mental Illness Queens/Nassau Education Committee created "Breaking the Silence: Teaching the Next Generation About Mental Illness," an educational program designed to teach upper elementary, middle, and high school

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students about mental illness (National Alliance on Mental Illness, 2011). The lessons use stories to put a human face on mental illness and teach that it is biology, not a character flaw that causes mental illness. Students also learn the warning signs of mental illness, that psychiatric disorders are treatable, and how to fight the stigma that surrounds mental illness (Susin, 2004). The program educates through use of “lesson plans, games, stories, poems, and posters on serious mental illnesses” (Wahl, Susin, Kaplan, Lax & Zatina, 2011, p. 45).

### Policy Recommendations

This policy brief makes its recommendation that an effective way to decrease stigma in college students is by incorporating educational programming about mental health and mental illness such as NAMI’s “Breaking the Silence” program into elementary and middle schools nationwide. It has been proven that children in our society are vulnerable to the stigma of mental illness, and providing this type of education will work to combat that stigma (Hinshaw & Stier, 2008).

The “Breaking the Silence” curriculum has already proven to be successful, and teachers using the educational materials “consistently rate them very effective or effective in dispelling myths and stereotypes about mental illness” (National Alliance on Mental Illness, 2011). Empirical evidence supporting the effectiveness of “Breaking the Silence” at the middle school level is provided by Wahl et al. (2011). Research findings from this study reveal that “following ‘Breaking the Silence’ instruction, students showed more accurate understanding of the symptoms and treatments of mental illnesses, more accepting attitudes about mental illnesses, and greater willingness to interact with a person with a mental illness” (Wahl et al., 2011, p. 50).

The program has received support from the American Psychiatric Foundation, the National Institute for Mental Health, and commendation from the Easter Seal Foundation (Susin, 2004; National Alliance on Mental Illness, 2011; Breaking the Silence, n.d.). Implementing “Breaking the Silence” into elementary and middle schools nationwide is a cost-effective choice for policy makers because it is a program already up-and-running and already proven to be effective, thus

saving the costs of formulating and piloting alternative mental health educational programs.

Whether efforts are put forth towards implementing “Breaking the Silence” or alternative programs for educating elementary and middle school students about mental health, it is time that educating students about mental health and mental illness be given the same attention as AIDS, sex education, alcohol and drug abuse, and physical illnesses like heart disease, cancer, and diabetes in elementary and middle schools (Susin, 2004). The more factual information these children are given concerning mental health and mental illness in elementary and middle school, the greater the chances are that stigma will not prevent these same students from seeking help for mental health problems when they become college students.

### Implications for Social Work Practice

The successful implementation of educational programming about mental health in elementary and middle schools depends on educating the public, policymakers, and school administrators about the need for such programming. Social workers are in a unique position to advocate for putting this programming into practice because of their presence in the schools, communities, and in policy-making arenas. School social workers are able to play an essential role in the proper implementation of the programming, as well as in helping elementary and middle school students to process the information contained within the programming.

In order to encourage college students to seek help for their mental health problems, attention must be given towards educating these students as well. Social workers may run university-sponsored, psycho-educational sessions on-campus discussing topics such as stress management, self care, depression, eating disorders, substance abuse, and mental illness. For those students seeking help for mental health problems, proper screening must be done to rule out symptoms of depression, anxiety, psychosis, and suicidal/homicidal ideation. Social workers may also lead on-campus therapy groups for students with mental illnesses in order to promote student support and prevent students with mental illnesses from feeling isolated and alienated from others.

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### References

- Balderas, J. B. (Moderator). (2006, June 1). *Kaiser Family Foundation Broadcast Studio* [Audio podcast]. Retrieved from [http://www.kaisernetwork.org/health\\_cast/hcast\\_index.cfm?display=detail&hc=1727](http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=1727).
- Bennett, M. E., Miller, J. H., & Woodall, W. G. (1999). Drinking, binge drinking, and other drug use among southwestern undergraduates: Three-year trends. *The American Journal of Drug and Alcohol Abuse*, 25(2), 331-350.
- Breaking the Silence. (n.d.). *Media*. Retrieved from [www.btslessonplans.org/articles.htm](http://www.btslessonplans.org/articles.htm)
- Buckley, P. F., & Brown, E. S. (2006). Prevalence and consequences of dual diagnosis. *The Journal of Clinical Psychiatry*, 67(7).
- Eisenberg, D., Downs, M. F., Golberstein, E., & Zivin, K. (2009). Stigma and help seeking for mental health among college students. *Medical Care Research and Review*, 66(5), 522-541.
- Fox, J. A., & Savage, J. (2009). Mass murder goes to college: An examination of changes on college campuses following Virginia Tech. *American Behavioral Scientist*, 52(10), 1465- 1485.
- Golberstein, E., Eisenberg, D., & Gollust, S. E. (2009). Perceived stigma and help-seeking behavior: Longitudinal evidence from the healthy minds study. *Psychiatric Services*, 60(9), 1254-1256.
- Goldstein, A. L., & Flett, G. L. (2009). Personality, alcohol use, and drinking motives: A comparison of independent and combined internal drinking motives groups. *Behavior Modification*, 33(2), 182-198.
- Hinshaw, S., & Stier, A. (2008). Stigma as related to mental disorders. *Annual Review of Clinical Psychology*, 4, 367-393.
- Mechanic, D. (2008). *Mental Health & Social Policy: Beyond Managed Care* (5th ed.). Boston: Pearson Education, Inc.
- National Alliance on Mental Illness. (2011). *State and Local Programs, Breaking the Silence: Teaching School Kids About Mental Illness*. Retrieved from [http:// www.nami.org](http://www.nami.org)
- National Center for Education Statistics. (n.d.). *Fast Facts*. Retrieved from <http://nces.ed.gov/fastfacts/display.asp?id=372>
- New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.
- Strauss, V. (2009, October 27). Why most schools don't teach about mental illness. *The Washington Post*. Retrieved from <http://voices.washingtonpost.com>

## Reducing the Stigma of Mental Illness in College Students

- Susin, J. (2004). Promoting mental illness education in schools. *The Bulletin, New York State Psychiatric Association*, 47(1).
- U.S. Department of Education (n.d.). *Building the Legacy: IDEA 2004*. Retrieved from <http://idea.ed.gov/explore/home>
- United States; Public Health Service; Office of the Surgeon General; Center for Mental Health Services (U.S.), and National Institute of Mental Health (U.S.). (2000). *Mental Health: A Report of the Surgeon General*. Last modified: [2000-02-22] ed. Washington, DC: Dept. of Health and Human Services. <http://www.surgeongeneral.gov/library/mentalhealth/home.html>
- Wahl, O. F., Susin, J., Kaplan, L., Lax, A., & Zatina, D. (2011). Changing knowledge and attitudes with a middle school mental health education curriculum. *Stigma Research and Action*, 1(1), 44-53.

## Educated Eaters

**By: Marina Barcelo, Teresa Duffey, Stephanie Duncan, Stephanie Goldfarb,  
& Ashley Huerta**

### Abstract

*In the U.S. and other parts of the world, changes in diet and lifestyle have led to dramatic increases in obesity and other poor health conditions in individuals and families. Current research indicates disturbingly high rates of children and adolescents who struggle to maintain healthy body weights and face serious physical and mental health challenges as a result. This article examines the physical and emotional impacts of obesity and malnutrition in young people and outlines a psycho-educational group aimed at both preventing childhood obesity and helping kids lead happier, healthier lives. The authors examine current efforts to intervene at both national and local levels, highlighting programs such as Michelle Obama's "Let's Move: America's Move to Raise a Healthier Generation of Kids" campaign as well as local initiatives, all of which help to inform our own intervention program and from which similar groups might draw resources and support. Ultimately, the authors propose a psycho-educational group wherein children are given a safe space to talk, learn, engage in activities, and feel empowered to make changes in their eating and exercise habits. It is our hope that social workers in other parts of the country might use this template to create and conduct similar groups in their own communities.*

### Introduction

As current research indicates, incidence rates of children who struggle to maintain healthy weights are disturbingly high, and children who are overweight or obese face serious physical and mental health challenges. It is for these reasons that the authors propose a psycho-educational/support group called "Educated Eaters" that addresses these issues and provides children a safe space to talk, learn, engage in activities, and feel empowered to make changes in their eating and exercise habits. It is our hope that this type of

intervention will produce positive effects at the individual level and will ultimately engender positive change in families and communities as well.

The Centers for Disease Control and Prevention classify a child as being overweight if he or she has a body mass index (BMI) at or above the 85<sup>th</sup> percentile and lower than the 95<sup>th</sup> percentile, relative to children of the same age or sex. Obesity in children is defined as a BMI at or above the 95<sup>th</sup> percentile for children of the same age or sex (CDC, 2010). In establishing the need for the proposed group, the authors will heretofore refer to obesity and overweight status in children according to these definitions. While children who fall into these two groups are at heightened risk of developing physical and psychological problems, the authors also recognize that being overweight is not necessarily the only indicator of poor nutrition, relationship to food and exercise, or body image. This group aims to reach a wide range of children and to improve the knowledge and habits of all participants, regardless of weight.

### Prevalence and Effects of Childhood Obesity and Malnutrition

Presently, one in three American children are overweight or obese (The Economist, 2010). Strategies to tackle this problem are being devised on the local, state, and national levels. No longer is childhood obesity simply a danger to personal health and well-being; it has become a matter of national security. A recent report issued by an organization called "Mission: Readiness" estimates that 27% of Americans of military recruitment age are "too fat to fight" (The Economist, 2010). The physical and emotional consequences of childhood obesity can be devastating. Not only are children with weight issues more likely to experience that struggle throughout their adult lives, but also they are more vulnerable to experiencing a myriad of physical and mental health problems (Wang & Veugleres, 2008).



## Educated Eaters

Must and Strauss (1999) identify a number of immediate, intermediate, and long-term negative effects of childhood obesity. Their research indicates that children who struggle with obesity and malnutrition are primed for a lifetime of physical problems affecting their orthopedic, neural, pulmonary, gastrointestinal, and endocrine systems. Beginning in childhood and through adulthood, children struggling with obesity are more likely to develop hypertension, heart problems, sleep disorders, and Type II diabetes, to name only a few (Melnyk & Moldenhauer, 2006).

Of additional concern is the mental and emotional well-being of children who struggle to maintain healthy weights. McCullough, Muldoon, and Dempster (2009) note that negative self-perception is high among overweight children, along with decreased social acceptance. A sedentary lifestyle, poor diet, and excess body weight are all risk factors for low self-esteem and accompanying psychological problems in a child. Furthermore, a strong correlation exists between excess body weight and poor school performance (Wang & Veugelers, 2008). Overweight children are also reported to have greater body dissatisfaction and higher rates of depression with greater severity of symptoms than children of average weight (Goldfield et al., 2010). These children are also more likely than others to develop unhealthy habits to try to lose the weight, including dietary restraint or related eating disorders (Goldfield et al., 2010). It is clear that the psychological consequences of obesity can be as grave as the physical.

### National Efforts to Address Childhood Obesity and Malnutrition

Committed to wiping out childhood obesity within one generation, President Obama supports the Senate Agriculture, Nutrition, and Forestry Committee's Healthy, Hunger-Free Kids Act of 2010 (The Economist, 2010). This bill allocates \$4.5 billion for children's nutrition, specifically to invest a larger sum into healthier school lunches over the next ten years. The Healthy, Hunger-Free Kids Act allows more children to enroll in the National School Lunch Program, which provides free or reduced-cost lunches to 30 million American children each day. This is considered the largest investment in federal child

nutrition in our nation's history. Overall, the bill aims to do the following:

help schools improve the nutritional quality of school meals, establish national nutrition standards for all foods sold in schools, promote nutrition and wellness in child care settings, connect more children to healthy local produce through Farm-to School Programs, strengthen local school wellness policies, support breastfeeding in the WIC Program, and improve school food financing (United States Senate Committee on Agriculture, Nutrition, and Forestry, Highlights of S.3307: Promoting Health and Reducing Childhood Obesity, 2010).

The Healthy, Hunger-Free Kids Act is a particularly innovative piece of legislation. Although it will only increase each school meal by six cents, the bill will introduce more fresh fruit and vegetables in school cafeterias nationwide (The Economist, 2010). In addition, this legislation will help promote Michelle Obama's "Let's Move" campaign against obesity. "Let's Move" is the most recent White House initiative to fight childhood obesity, promoting better federal nutrition standards, more funding for healthy school meals, increased physical activity amongst youth, and affordable food access throughout our country (Let's Move: America's Move to Raise a Healthier Generation of Kids, 2010). "Let's Move" not only targets children, but parents as well, encouraging women to watch their weight during pregnancy and to breastfeed.

The fight against childhood obesity is undoubtedly an uphill battle, but national initiatives like The Healthy, Hunger-Free Kids Act and the "Let's Move" campaign are steps in the right direction and address the seriousness of the problem: "more than 23 million Americans, including 6.5 million children, live in low-income urban and rural neighborhoods that are more than a mile from a supermarket" (Let's Move: America's Move to Raise a Healthier Generation of Kids, 2010). Under the leadership of President Obama and first lady Michelle Obama, federal decision-makers ambitiously hope to eliminate food deserts within the next seven years.

In order to address obesity and malnutrition in America, it is important to understand how food insecurity relates to health and nutrition. Food insecurity is defined as a lack of nutritious, culturally appropriate food for all members of the community (Wang, 2008). Families who live in food deserts must maximize caloric

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intake for each dollar spent which can lead to over consumption and a less healthful diet:

Compared with food-secure youths, food-insecure youths were more likely to perceive that eating healthfully was inconvenient and that healthy food did not taste good. Additionally, food-insecure youths reported eating more fast food but fewer family meals and breakfasts per week than did youths who were food secure. Food-insecure and food-secure youths perceived similar benefits from eating healthfully. Compared with those who were food secure, food-insecure youths had higher fat intakes. Food-insecure youths were more likely to have a body mass index above the 95<sup>th</sup> percentile (Widome, Neumark-Sztainer, Hannan, Haines, and Story, 2009).

The Healthy Hunger-Free Kids Act is a step in the right direction. However, the Act has showed recognizable negative results. Ironically, the Healthy Hunger-Free Kids Act cuts 2.2 billion from food stamps (SNAP) leaving less food for families to put on the table. The Act took an additional \$1.2 billion from SNAP-Education, a nutrition education program (Center for American Progress, 2010). The goal is for families to purchase healthy, high quality food. Despite claims from the United States Department of Agriculture that the food stamp program serves as a first line of defense against hunger, food as a major profit industry often leaves large communities of people dependent on convenient stores and gas stations for food. Cutting funds from SNAP will only make this problem worse.

The question remains: how do lower income families stretch their food dollars? Lower income families may shop in discount food stores, purchase less food, and purchase lower quality food. The authors contend that if youth from low-income families are encouraged to understand the importance of eating more healthfully, they may have an influence on the quality of food that is purchased in their homes.

### Community-Level Interventions

While the success of national endeavors to address obesity and malnutrition in American children remains to be seen, the authors contend that community-level interventions may be more immediately effective. Surprisingly, a review of the literature of such community-level interventions yielded minimal results. A doctor of osteopathy in Royal Oak, Michigan, Paul Ehrmann, has proposed one such community-level

program with objectives, lessons, and activities aimed at addressing childhood obesity and malnutrition. Ehrmann's proposal is for a grassroots, community-based healthy living program, which he outlines in his book, *Generation XL: The Childhood Obesity Pandemic: A Community-Based Approach*. This approach, entitled the Children's Health Initiative Program (CHIP), is designed to be implemented in the public schools, but can also be modified for use in private and home school settings.

Ehrmann collaborated with professionals in the health, education, business, government, and philanthropic fields to develop a multi-disciplinary, community-sponsored program aimed at promoting healthy lifestyles for children and families. The program is designed to be replicated in additional schools and communities, to involve children of various ages and backgrounds, and to be operated at no cost by volunteers and community partners (Ehrmann, 2008). CHIP consists of five 90-minute, sequential sessions that are intended to build upon one another. Both children and parents are present during the group meetings, and families are given homework assignments to complete together in order to complement and put into practice the concepts presented in each session. On a volunteer basis, different professionals from within the community (doctors, nutritionists, dieticians, nurse practitioners, psychologists, social workers, and physical therapists, for example) present information about nutrition, exercise, and wellness. The sessions are didactic, interactive, and encourage active participation of all group members. The fifth session culminates in a review of concepts and new habits learned and in a graduation ceremony in which participants are presented with a certificate of program completion.

Developed only as recently as 2008, CHIP has yet to yield a wealth of measurable results. However, positive outcome data was generated by both its pilot project and a subsequent project, including participant improvements in eating breakfast and in daily exercise practices. CHIP also makes use of evidence-based practices, including a circuit training and obstacle course exercise program that has been proven to be accessible and beneficial to a wide array of body types and physical fitness levels (Ehrmann, 2008). The CHIP program is facilitated by community partners to address the childhood obesity pandemic. Like Ehrmann, the authors acknowledge the mental and physical health effects of poor nutrition and exercise habits in children and seek to empower kids, families, and communities to

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make healthier choices and live healthier lives. The proposed group, Educated Eaters, has the potential to promote such changes.

### Group Design

Built in 1959, The Robert R. McCormick Boys and Girls Club serves hundreds of families each year and is an integral institution to many residents of the Uptown neighborhood in Chicago. Aside from providing a comprehensive array of athletic, educational, recreational, social, artistic, and leadership opportunities to Uptown youth, the Club helps to prevent children from participating in or becoming victims of crime and violence (Gardner & Brooks-Gunn, 2009) and from the effects of childhood obesity that are particularly significant for low income, urban children (Molnar, B., Gortmaker, S., Bull, F., & Buka, S., 2004).

The authors chose to pilot the Educated Eaters program at the Uptown Boys and Girls club for several reasons. As evidenced by Wang and Veugleres (2008), a low income directly corresponds to increased risk of obesity and health complications related to malnutrition. The authors anticipate that many participants will come from low-income homes as evidenced by the recent Chicago Uptown Commission report that there are 15,330 persons and 2,455 families living below the poverty line in Uptown (Uptown Chicago Commission, 2001) and as such, are susceptible to such health risks. Next, the Robert R. McCormick Boys and Girls club has a very high attendance rate due to the wealth of programming available to members as well as its easily accessible location near bus and train lines. The high rate of Club membership will allow Educated Eaters administrators to recruit and maintain membership during the pilot year of programming. Furthermore, while the authors originally contemplated running the Educated Eaters pilot program within the confines of a middle school, a public school setting would not afford the type of flexibility necessary to most effectively run the program. The Club's mission statement is to "enable all young people, especially those who need us most, to reach their full potential as productive, caring, responsible citizens" (Boys and Girls Club of Chicago, 2010). The philosophy of the Boys and Girls Club innately lends itself to the dynamic and unique purpose of the group. Lastly, the Boys and Girls Club of Uptown is physically structured to accommodate the many different activities necessary to effectively administer

the program. The facility contains such areas as a swimming pool, dozens of classroom and common areas, a gymnasium, and a communal garden.

Educated Eaters will be advertised to Boys and Girls Club members as a psychoeducational opportunity to engage and learn about nutrition, food accessibility, and health. Furthermore, the group will provide members with the environment to address feelings of anxiety and/or depression related to poor body image, inaccessibility to nutritious food, and other food-related stressors and topics. Program staff will advertise Educated Eaters to Club members as an opportunity to engage in: leadership opportunities; programming that will not only empower them to make healthy life decisions, but to advocate for greater accessibility to nutritious food; exciting weekend programming and field trips outside the confines of the Club; and opportunities to express personal struggles with body image.

Both a social worker and a registered dietician will work together to provide nutrition and mental health services to group members. Further, program staff will administer programs, maintain the membership and facilitate a safe, supportive environment for members. Specific recruitment efforts will include: posters detailing the mission of the group, English and Spanish brochures and other materials sent to the parents of Boys and Girls Club members, promotion of the group by Club staff members, staff identification of likely candidates to encourage parents to facilitate participation, advertisements on the Club website, and open, preliminary informational/drop-in meetings held during peak hours of Club operation. The most significant recruitment effort will be a quarterly "open house" event for the families of potential participants to learn more about the purpose of the group. During these meetings, program staff will address the preparatory procedures as specified by Yalom (2005), such as clarifying misconceptions, unrealistic fears, and expectations, as well as generating realistic and positive expectations about the group's purpose and capacity.

There are four specific criteria for member inclusion. The first is that members agree to participate in at least 80 percent of group meetings and weekend field trips. Due to the very nature of members' academic commitments and family dynamics, the authors anticipate some inability of members to fully participate in all programming and wish to build in some flexibility to accommodate the greatest number of participants.

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Second, members must abide by the norms that are developed in the early stages of the group (behavioral, social, support, etc...). Members must also participate in the creation and signing of a contract detailing the expectations of group members to remain confidential about shared personal information revealed by fellow group members. Lastly, members must be respectful of fellow group members. Group member violation of any of the above stated criteria will result in termination and/or exclusion.

Educated Eaters will operate in a partially closed group system of between 12-15 middle school-aged, mixed gender group participants. The group will run for 12 months on a conventional quarterly basis (four, three month-long quarters). In recognition of the relatively short attention span of many pre-adolescents/adolescents, the group will meet once per week for 50 minutes per session. During each three-month long quarter, the group will stay closed so as to encourage strong group cohesion. At the end of each quarter, the group will open to include new members and to dismiss those who no longer wish to participate. The reason for this structure is two-fold. First, due to the nature of academic commitments and family dynamics of members, the authors recognize that it is unrealistic to maintain a consistent closed youth member base for 12 months. Further, the authors recognize the power of the “snowball effect” by which current members can recruit their peers to the program. It is vital to the life of the group that as many youth who wish to participate are afforded the opportunity to do so.

In order to accommodate new members into the group after each quarter, some repetition of the information learned in the previous quarter must occur. In an effort to maintain interest among recurring members and to provide leadership opportunities, those members who wish to continue in the group will be encouraged to do so as “peer leaders.” Specifically, this entails aiding group facilitators in the dissemination of materials already acquired in the previous quarter(s); helping new members to adjust to the format, expectations, and norms of the group; and contributing to the actual programming of group weekend activities and field trips. It is hoped that by empowering group members to act as leaders, the information and experiences acquired while in the group will become personalized. This will encourage peer leaders to share their newly gained knowledge with their peers, family members, and greater community. In an effort to make the leadership requirements more compelling to group

members, leadership positions will be acknowledged by badges similar to those found in groups such as the Boy / Girl Scouts of America. By advertising their leadership accomplishments, peer leaders will not only enjoy a boost to their self-esteem but will help to generate interest to non-group Club members about joining the group.

## Stages of Group Design

Educated Eaters was designed specifically to be a co-educational group, so that both boys and girls could learn together about commonalities and differences they have about food and body image. However, the authors acknowledge that some group meetings might inspire extremely sensitive reactions among group members, and some might feel more comfortable sharing their experiences in same-sex meetings. If this is the case, the authors acknowledge the importance of offering such same-sex discussion opportunities for members.

The authors designed the group based upon Garland, Jones, and Kolodny’s five-stage model of group development. By conceptualizing the life of the group in this way, program staff will not only be more thoughtful about programming but will also anticipate the natural ebbs and flows of the life of the group. During the first few sessions of the program, staff will secure informed consent and discuss the parameters of confidentiality with the group members. The purpose of the group will be established and solidified, pre-tests will be administered, and the program staff will answer questions about the group’s structure. In addition, the first sessions will include dissemination of basic nutrition education, activities (such as the creation of a group garden) geared toward building group cohesion, discussion about the connection between mind and body (how one’s nutrition and access to healthy food can affect not only the body, but also the mind), and the creation of group contract and establishment of behavioral norms and consequences.

As members establish their roles within the group and test the limits of the program staff, activities will be geared toward solidifying group cohesion, the advancement of nutrition education and opening discussion about the politics and policies surrounding access to food. As the group begins to take on a family dynamic, activities will begin to focus on the mental health (body image, self esteem, etc) of participants. Cooking classes will also begin in this stage and will be

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designed to emphasize not only the nutritional benefits of cooking but also the communal and interpersonal dynamics of cooking food and eating in a community. This will also be an excellent opportunity for participants to apply the nutrition knowledge acquired earlier in the group. Lastly, increased attention will be paid to issues of body image and self esteem as well as weight-related bullying.

There are several examples of activities designed for use in the beginning stages of the group. One such example is “Food Memory Icebreaker,” where participants share a significant food memory with the group. The purpose is to help participants grow comfortable talking openly about food and the feelings associated with it. Further, this will afford the opportunity for program staff to gauge the food culture of the group. Another example is “Food Jeopardy,” where participants work together in pairs to provide the answers to nutrition-related questions in order to score points and compete against other teams. The goal of this activity is to foster trust and collaboration between group members as well as to open up communication and have fun.

Once group members have done a fair amount of bonding and relationship building and reached a level of intimacy, group facilitators will conduct sessions that highlight foods from around the world. Each group member will be asked to share about the foods that represent his or her culture, whether they are recent immigrants from Iraq, of mixed descent from Mexico and the Philippines, or from an African American family that has been living in Chicago for many generations. In doing so, we hope to acknowledge the variety of relationships to food across cultures, the ways in which food plays an important role in daily family life and in cultural celebrations, and to increase the cultural competency and respect and appreciation for diversity of all group members. Activities may include taking turns sharing about a special family meal and what types of foods it includes, sharing a family recipe, and learning about how to make healthy, balanced choices within specific cultural diets.

There are a variety of activities selected for the middle-stage of the group. One such example is “When I Eat This I Feel... When I Feel ( ) I Eat This....” during which participants work in pairs to draw an outline of their own bodies on a large sheet of butcher paper. The group leader will prompt the participants to answer questions such as “When I feel anxious, I like to eat...” or “When I feel happy, I like to eat...” The

participants will then draw pictures of those answers somewhere on the outline of their body. The goal of this activity is to help participants to connect their emotions to their food choices. In another activity, “Building a Balanced Meal,” the group leader will cut out pictures of many different types of ingredients that can be used to make a meal. Some of the ingredients will be high calorie, some will be low calorie, some will have a high vitamin and mineral count, others will be “empty” of nutritional content, and so on. The participants will work in small groups to build a healthy breakfast, lunch, dinner, and snack utilizing the ingredients at their disposal.

An example of an activity in the end stages of this group is “Create a Recipe Book”, during which participants will work together to collaborate on a recipe book highlighting their unique family traditions and cultural heritages. The purpose of this activity is to strengthen understanding of the idea that food is not just a source of energy and sustenance, but it can also be a deeply intimate and complex part of our lives that can be celebrated and shared.

When group cohesion is at its highest, participants will be encouraged to engage non-group Boys and Girls Club members with an educational outreach effort. Activities will be aimed at empowering participants to seek knowledge outside of the group about national and local food access and nutrition policies, news, and politics. Upon termination, the program staff will recapitulate the whole group experience and process the challenges for individuals and within the group as a whole. The 12-week group will terminate when the participants cook a meal together to share with their family members during a celebration at the Boys and Girls Club. This activity will offer participants the opportunity to share what they learned, and to commemorate the termination of the group process.

In addition to weekly meetings, weekend field trip activities will occur once per month. Field trip activities include:

- Visiting a local farmers market
- Taking a tour of Uncommon Ground’s Rooftop garden in Uptown.
- Exercise classes facilitated by local YMCA’s or other fitness gyms.
- Starting an Educated Eaters garden at the Boys and Girls Club.

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- Attending cooking classes at local restaurants with health conscious chefs to promote healthy cooking skills.
- Shopping trips to grocery stores

### Financial Arrangements

As most of the programs will run under the roof of the Boys and Girls Club and the program staff will be unpaid volunteers, the authors do not anticipate great financial need associated with the administration of Educated Eaters. However, some financial resources will be necessary to cover the cost of transportation, participation fees, and food costs for weekend field trips. Program staff will work to build relationships with potential guest speakers to provide their services on a pro-bono basis and will also seek donations from local business to support the activities of the group. For example, staff will contact local grocery stores to donate healthy snacks and fresh ingredients for cooking activities. Working under the umbrella of the Boys and Girls Club will allow program staff to utilize the organization's 501(c)(3) public charity status to compete for grants and other funding for costs not covered by the pro-bono contributions listed above. Further, the Boys and Girls Club will contribute resources such as buses, vans, food coolers, office supplies, cooking supplies, audio-visual equipment, computer labs, and other tools needed to administer Educated Eaters programming.

### Group Evaluation

As the mission of the Educated Eaters group is psychoeducational in nature, group evaluation will be partially based upon measurements of the participants' acquisition of nutrition and health-related knowledge during participation. Specifically, nutrition and health-related pre-tests will be administered to all participants upon entrance into the group in order for program staff to establish a baseline of the incoming knowledge level of each participant. Upon the completion of each program quarter, post-tests identical to the pre-tests will be administered. The results of the post-tests will be compared with the pre-tests in order to measure how much knowledge each participant retained throughout the course of the group.

Additionally, program staff will conduct interviews with each participant upon entrance into the group and upon termination in order to evaluate the mental health mission of the group. Such interviews will consist of open-ended questions aimed at assessing the psychological needs of participants in relation to anxiety and/or depression related to poor body image, inaccessibility to nutritious food, and other food-related stressors and topics. Program staff will know that the purpose of the group has been met when participants score higher on the post-tests than they did on the pre-tests and when participants appear more confident and empowered upon each quarterly termination of the group than they did at the beginning.

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## References

- Boys & Girls Club of Chicago. (2010). Mission Statement. Retrieved from <http://www.bgca.org/whoweare/Pages/Mission.aspx>
- Center for American Progress (2010) *Don't Cut One Hunger Program to Pay for Another*. Retrieved from [http://www.americanprogress.org/issues/2010/09/child\\_nutrition\\_bill.html](http://www.americanprogress.org/issues/2010/09/child_nutrition_bill.html)
- Centers for Disease Control and Prevention. (2010). *Defining overweight and obesity*. Retrieved from <http://www.cdc.gov/obesity/defining.html>
- Ehrmann, P.R. (2008). *Generation XL: The childhood obesity pandemic: A community-based solution*. Michigan: ML Publishing.
- Gardner, Margo & Brooks-Gunn, Jeanne. (2009). Adolescents' exposure to community violence: Are neighborhood youth organizations protective? *Journal of Community Psychology*, 37(4), 505-525. DOI: 10.1002/jcop.20310
- Goldfield, G., Moore, C., Henderson, K., Buchholz, A., Obeid, N., Flament, M. (2010). Body dissatisfaction, dietary restraint, depression, and weight status in adolescents. *Journal of School Health*, 80(4), 186-192.
- Let's Move: America's Move to Raise a Healthier Generation of Kids (2010). Retrieved <http://www.letsmove.gov/>
- McCullough, N., Muldoon, O., & Dempster, M. (2009). Self-perception in overweight and obese children: A cross-sectional study. *Child: Care, Health, and Development*, 35(3), 357-364.
- Melnyk B. M. & Moldenhauer, Z. (2006). *The KySS (Keep your children/yourself Safe and Secure) guide to child and adolescent mental health screening, early intervention, and health promotion*. Cherry Hill, NJ: National Association of Pediatric Nurse Practitioners.
- Molnar, B., Gortmaker, S., Bull, F., & Buka, S. (2004). Unsafe to Play? Neighborhood Disorder and Lack of Safety Predict Reduced Physical Activity Among Urban Children and Adolescents. *American Journal of Health Promotion*, 18(5), 378-386.
- Must, A. & Strauss, R.S. (1999). Risks and consequences of childhood and adolescent obesity. *International Journal of Obesity*, 23(2), 2-11.
- Nutrition in Schools: Fighting the Flab (2010, June 5). *The Economist*.
- United States Senate Committee on Agriculture, Nutrition, and Forestry (2010). Current Legislation. Retrieved from <http://ag.senate.gov/site/legislation.html>
- United States Senate Committee on Agriculture, Nutrition, and Forestry (2010). Highlights of S.3307: Promoting Health and Reducing Childhood Obesity.

## Educated Eaters

- Uptown Chicago Commission (2001). Census Information: Community Area 3 Uptown. Retrieved from <http://www.uptownchicagocommission.org/census.htm>
- Uptown Chicago Commission. (2001). Resource links. Retrieved from <http://www.uptownchicagocommission.org/links.htm>
- Uptown Update. (2010). Spring weather: Shots fired. Retrieved from <http://www.uptownupdate.com/2010/03/spring-weather-shots-fired.html>
- U.S. Census Bureau Chicago Communities (2000). Chicago: 77 Communities Demographics. Retrieved from [http://www.public-record.com/content/municipalities/cook/chicago\\_and\\_77communitiescensus\\_demographics.asp](http://www.public-record.com/content/municipalities/cook/chicago_and_77communitiescensus_demographics.asp)
- Wang, F. & Veugelers, P.J. (2008). Self-esteem and cognitive development in the era of the childhood obesity epidemic. *International Associate for the Study of Obesity*, 9, 615-623.
- Widome, Rachel; Neumark-Sztainer, Dianne; Peter, Hannan; Haines, Jess; Story, Mary. Eating When There is Not Enough to Eat: Eating Behaviors and Perceptions of Food Among Food-Insecure Youths *American Journal of Public Health* 99 (5) 822-828.
- Yalom, Irvin D. & Leszcz, Molyn. (2005) *The Theory and Practice of Group Psychotherapy* New York, NY: Basic Books.



## **A Multifaceted Integrative Model for Working with Pakistani-American Muslim Youth**

### **A Multifaceted Integrative Model for Working with Pakistani-American Muslim Youth**

**By: Cassandra Roos, Jim Welch & Maria Perez**

#### **Abstract**

*Muslim populations in the United States have seen their place in society change dramatically since 9/11. The impact of discrimination and geopolitical events cannot go unnoticed in the field of social work. Pakistani-American youth are one group of Muslims who struggle with identity crisis. Even more recently, the killing of Osama Bin Laden in Pakistan by U.S. security forces in May 2011 has further placed Pakistanis in the media and political limelight. In order for social workers to assist Pakistani-American immigrant youth effectively, clinicians should approach therapy from a multifaceted perspective that acknowledges the personal and social effects of international events. When working with the Pakistani population it is best to use an integrative model that focuses on the political, cultural, religious, and theoretical aspects of the life of a Pakistani-American. This article proposes an integrative model developed to specifically address the needs of Pakistani and particularly Pakistani-American youth.*

#### **Introduction**

As current research indicates, incidence rates of Social work with immigrant populations in the United States can be practiced best through adaptive, nuanced, and creative approaches to clinical theory. This paper will provide an overview of how to work with a specific population in the United States today - Pakistani-American Muslim youth and their families. The goal of this paper is to help social workers develop theories and work more effectively with Pakistani-American youth by understanding the legal, social, cultural and political realities that Muslims and South-Asian immigrants today face in the post 9/11 era. The death of Osama Bin Laden in May 2011 in Pakistan by American forces has solidified Pakistan's importance in US strategic foreign policy and prevalence in the media. While Western media is quick to jump on the flaws in

Pakistani intelligence and society, it is important to remember that many Pakistanis and Pakistani-Americans endure personal and struggles beyond the media's selective lens. The media scrutiny as to why Pakistani forces did not find bin Laden sooner is a story that will surely contribute to the general American public's apprehension towards Pakistani people. These recent events make it even more important for social workers to remain aware of the complexities related to work with Pakistani-American families.

Social workers will be able to provide better care for Pakistani-American youth if they can also understand the basics of the culture, religion, traditions, customs, individual family systems and migration history of their clients. This paper will introduce an integrative culturally competent model for working with Pakistani youth in the United States by approaching treatment simultaneously from political, cultural, religious, and theoretical perspectives.

#### **Political Perspective**

Since the terrorist attacks on the World Trade Center in New York City on 9/11, Pakistani Muslims and other ethnic minorities in the United States saw their lives forever changed (Tummala-Narra, 2005). A study by Ghaffar-Kucher (2009) shows how that the post-9/11 environment of hostility, suspicion, surveillance and fear towards Muslims has directly impacted the lives of Pakistani-American youth.<sup>i</sup>

Youth are sensitive to changes in social attitudes and the growing aversion and discomfort among some Americans of Arab, Muslim, and South Asian populations. Ongoing United States drone attacks in Pakistan and Afghanistan continue to fuel anti-American sentiment and fear among citizens in Pakistan. Due to the transnational nature of newer immigrant populations, the political and social environment in the host country is indeed of relevance to Pakistani youth and their families in the United States

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today. These events can play a role in shaping Pakistani-American youth's sense of identity, belonging, acculturation, and duty. The nature of transnational identities of immigrants today speaks directly to the Pakistani-American struggle (Drachman & Paulino, 2004). Transnationalism means that Pakistani American youth today may have relatives abroad; another reason why the tumultuous relationship between the US and Pakistan matters in social work.<sup>ii</sup>

An estimated 193,893 Pakistani-Americans live in the United States with 62 percent in the labor force and 29 percent speaking English "very well" (Purkayastha & Ray, 2010).<sup>iii</sup> Pakistani-Americans are active in the fields of medicine, engineering, finance, and technology. The US Census Bureau reports that around 54.6% of Pakistani-Americans are educated at the college level or beyond, and the median household income is \$57,502. Despite these relatively positive statistics on Pakistani population in the US, children of Pakistani families are particularly at risk for discrimination in schools by teachers and peers and in after school activities (Ghaffar-Kucher, 2009).

News media focuses only on sensational "war on terror" related stories of Pakistani-Americans and rarely on the efforts of Pakistanis who are active contributors to American civil society and progress (Ghaffar-Kucher, 2008). Lack of balanced coverage in the mainstream media of Muslims and Pakistani-Americans and legislation in the United States have contributed to increased discrimination of Pakistani-Americans and other Muslim groups since 9/11. In 2002, the United States Department of Homeland Security implemented National Entry-Exit Registration System (NSEERS) requiring non-citizen males over the age of 25 from "at-risk" countries to register formally with the government. Pakistani-Americans were the largest immigrant group on this list (Kim et al, 2007). Of the 13,000 deported under the NSEERS program in 2002-2003, 35 percent were of Pakistani descent. In fact, the "disproportionate impact of the program meant that entire communities were eliminated, such as Pakistanis in Brooklyn" (Yang, Junck, & Ling, 2010, p. 498).<sup>iv</sup>

Hate crimes against Muslims have risen 1,500 percent since 9/11. Discrimination has been so rampant in the workplace that the Equal Employment Opportunity Commission created a new category to track discrimination specifically against Middle Eastern,

Muslim and South Asian workers (Yang, Junck, and Ling, 2010). Around 33 percent of the detainees rounded up for suspicion of terrorism by the US government after 9/11 were of Pakistani descent, and often the FBI terrorism detained people without sufficient evidence (Iyer 2010). Social workers should recognize the hidden impact of political conflict, Guru (2010) notes:

Mental health problems caused by Islamophobia and the 'war on terror' may not simply be resolved by producing better talking therapies. A more fundamental critique of the domestic and foreign policies, alongside initiatives for social work to engage with human rights organizations and others to campaign and agitate against the root causes of the problems may be needed (p. 285)

Conwill and Jooma (2008) present an analysis of Muslim female youth at the University of Tennessee who used community-based activism to educate the public about Islam. Conwill and Jooma (2008) lay out the groundwork for theoretical approaches to working with Pakistani-American Muslim youth by focusing on successful community action, empowerment, and strengths-based counseling. A number of studies have shown how Muslim immigrant youth struggle to find a balance between multiple identities - Pakistani, Muslim, American, individual, family member, etc. (Ghaffar-Kucher, 2009; Guru 2010; Sundar, 2008; Schmidt, 2004).

A recent Pew Survey on public attitudes towards Muslims shows that more Americans view Islam as a religion that encourages violence than did in 2002 (see below).

### Public Remains Split Over Whether Islam Is More Likely to Encourage Violence

	Mar 2002	July 2003	Aug 2007	Aug 2009	Aug 2010	Mar 2011
<i>Islamic religion ...</i>	%	%	%	%	%	%
Is more likely than others to encourage violence	25	44	45	38	35	40
Doesn't encourage violence more than others	51	41	39	45	42	42
Other/Don't know	24	15	16	16	24	18
	100	100	100	100	100	100

PEW RESEARCH CENTER Feb. 22-Mar. 1, 2011. Figures may not add to 100% because of rounding.

## A Multifaceted Integrative Model for Working with Pakistani-American Muslim Youth

In March of 2002, only 25 percent of Americans viewed Islam as more likely to encourage violence than other religions, compared with 40 percent viewing Islam as more violent in March 2011 (Pew Research Center 2011a).

Although the majority of the public does not agree that Islam encourages violence, people in the US are clearly divided in their views on Islam and violence. These attitudes can affect the school and social environment for Pakistani and Muslim youth. These factors are not necessarily present in all work with Pakistani-American youth, but social workers must remember that they can play a role.

### Cultural and Religious Perspective

In addition to the social and political influences on Pakistani youth, social workers can benefit from understanding the cultural traditions of this population in order to conduct relevant therapy. During the events of 9/11, Muslim-American youth found themselves in strenuous situations struggling to remain faithful to their cultural and religious beliefs while, at the same time, trying to avoid being targets of discriminatory acts (Fine & Sirin, 2007). When working with Pakistan-American Muslim youth and families it is vital to have an understanding of how such roles can become crucial. Social workers should closely analyze how religion and culture can affect the overall well-being of an individual and his or her family structure.

Fine and Sirin (2007) find the events of 9/11 have caused Muslim-American youth to re-negotiate their cultural and religious identities. Fine and Sirin (2007) interviewed 70 Muslim-American adolescents, 32 girls and 38 boys, on the challenges they faced as a Muslim adolescent growing up in the US after the 9/11 events, and how they were able to deal with such challenges. Out of the 70 adolescents interviewed in the study, 59 reported discrimination.<sup>v</sup>

Social workers should also be cognizant of the gender roles within Pakistani culture and how those may affect practice with youth. Muslim boys and girls may differ when it comes to reactions from discrimination, acculturation, and identity negotiation. Fine and Sirin (2007) found that Muslim girls saw “Muslim” and “American” as two facets of their identities that complemented each other, both characteristics bringing opportunity and challenge. The boys in the study Fine

and Sirin (2007) found themselves struggling to integrate both worlds and cultures, even though they tended to experience less discrimination by doing so. When working with Muslim-American youth, it is important to have an understanding of their cultural and religious beliefs to help them explore multiple identities. Culture religion can become powerful forces youth can use to overcome struggles and maintain a genuine sense of self. Ross-Sheriff & Husain (2004) recommend that social workers remember: “one of the key elements of working with clients and of this background is to explore their identity and their decision making system...[therefore] practitioners need to acquire sufficient information to work effectively with Muslim clients” (p. 179).

Appropriately distinguishing between culture and religion will help social workers to better understand the construction of a client’s identity. Culture is considered to be a set of traditions or customs that is specifically associated with a social group and is not associated with religious beliefs which are ordained by God. Religion, on the other hand, is a commitment to follow a set of doctrines that can be applied globally beyond one’s race and nationality. Religious practices may include praying five times a day, following the five pillars of Islam and fasting during the holy month of Ramadan.

While culture can vary from place to place, religion is considered pure and tends to remain consistent throughout different parts of the world (Jacobson, 2010). For example, although the *hijab* is often times considered both a religious and cultural ritual, it can also be a personal decision as one Muslim girl explains, “I feel like I want to be pure Muslim but I don’t have to wear a *hijab* to show that” (Fine & Sirin, 2007, p. 158).

It is important for the practitioner to understand the difference between culture and religion when working with Muslim-American youth in order to develop an effective and culturally sensitive treatment model that can be molded to fit individual clients. Analyzing how each client views culture and religion is important to understand the client’s beliefs and how they perceive and define themselves.

A clinician’s understanding of family structure and interpersonal interaction patterns of Pakistani families is another important factor that should be taken into consideration when working with the youth of this population. In South Asian Muslim culture, the family is

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highly valued and is considered to be the most important social unit, but each individual plays an important role in the family to keep the family unified and strong. The man is seen as the leader of the family and is expected to take care for the welfare of his entire family. Elderly are respected and are cared for by the son's family. Children are required to be respectful towards their elders including their parents, siblings and other family members (Ross-Sheriff & Husain, 2004).

Validating the family structure and its interpersonal interaction patterns is vital, and extremely important in establishing an effective youth therapy. Ignoring the family structure and its interpersonal interaction patterns can impede the practitioner from working with the family and thus, create a number of barriers to working with Pakistani youth. It is important for the practitioner to analyze the family structure and dynamics to prevent members from reserving feelings during conjoint family sessions. The interconnectedness of Pakistani families links youth directly to family dynamics.

Different rates of acculturation may lead to generational gaps in Pakistani families. Youth may acclimate to Western culture faster than older generations. Family structures may exacerbate these tensions. If Pakistani children undergo acculturation faster than their parents they are disrupting the natural power structure of the family where the father plays the lead role. Practitioners will benefit if they remain open to involving the family when working with youth in order to involve parents who may already feel alienated from the dominant culture.

There are aspects of the Pakistani family that a practitioner may want to remember when working with youth in order to gain a larger perspective. It is important that the practitioner becomes aware of the family structure and dynamics, which can be affected by cultural and ethnic traditions, to help break the barrier between the family and foster a "contextual understanding of the client...and appreciation of the presenting problem as being multidimensional in nature" (Ross-Sheriff & Husain, 2004, p. 179). For example, in a Pakistani family, the mother might not be able to express her thoughts and feelings towards her husband, being that the wife often has a subordinate position and is considered inappropriate to criticize her husband in front of her children and or others. The husband, on the other hand, may feel reluctant to share his feelings in front of his wife and children to maintain

his authoritative position in the family (Daneshpour, 1998).

Close analysis of the family's cultural and ethnic traditions can help the practitioner to gain the family's trust and break any barriers that may impede the practitioner from working effectively with the family and a young client. Social workers should admit they are not experts on a particular culture, but should instead offer welcoming understanding and genuine interest in learning about cultural practices (Ellenwood, Synders, Poignon & Roberts, 2006). Validating the family's cultural, ethnic, and social context can provide the practitioner with further insight on the family's background history and longtime struggles.

For decades, South Asian Muslims have been migrating for political, environmental, economical, professional and educational reasons. Newer Pakistani immigrants have migrated to the United States only to receive low-paying service jobs (Ahmad, 2006). Large numbers of South Asian Muslims have existed in the United States for almost forty years, but they continue to struggle for acceptance in society. Since 9/11, practitioners have seen the rates of discrimination against Muslims increase, and culturally competent social work calls for a better understanding of demographics, migration history, Islamic worldview, and specific challenges faced by Muslim communities (Ross-Sheriff & Husain, 2004).

Understanding the migration history of the family as well as the common struggles and problems Pakistani families endure is necessary in order to understand and provide for Pakistani youth. Furthermore, it is important for the practitioner to look beyond language, culture and religious barriers and explore the family's migration history and identity to fully understand the complex historical forces that may affect a young client. Cultural diagnostic interviews and culturally sensitive treatment models are extremely important to use when working with Pakistani youth and their families, even when acculturation rates seem high.

### Theoretical Perspective

Pakistani youth encounter a myriad of social and psychosocial struggles in the United States. Current literature alludes to direct social work practices with youth; however, a gap exists when working with multifaceted identities – such as Pakistani Muslim youth. The subsequent material provides an integrative

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approach to working with Pakistani youth that engages and empowers the multiple identities to which youth commonly identify.

Traditional Western ideals of social work practice do not perfectly align with the values and ideals of Pakistani families. Most Western theories of social work rely on individualized treatment. Pakistanis value a collectivistic group identity (Nimer, 2002; Liviatan, 2010), which creates a status of the extended self. The concept of the extended self closely correlates with strong group identity. Some collectivistic cultures strive to attain a group identity because the group possesses key attributes and personality characteristics for the individual to attain (Liviatan, 2010). By adopting a community-based group practice, clinicians may use the concept of the extended self as a motivational factor within social practice.

First and second generation Pakistani immigrants are forced to create multiple identities when acculturating to American norms. These identities develop from multiple variables in the lives of youth. These include generational, environmental, and educational factors (Leonard, 2005). Pakistani youth have multiple societal labels: Pakistani, American, South Asian, and Muslim. The labels tend to manifest in contextual identities that a youth evokes in different social situations as a defense mechanism (Ghaffer-Kucher, 2008). Learning to process and use the different identities as empowerment, Pakistani youth need to invest their ideals in a collectivistic environment. Finding a group with similar ideals greatly helps create an ethnic identity, which provides support in the acculturation process (Farver, Xu, Bhadha, Narang, & Lieber, 2007).

Developing a strong sense of ethnic identity greatly helps Pakistanis adjust to the cultural changes experienced in the United States. Pakistani families in America tend to have the least interaction with Muslim groups of any Muslim culture (Ghaffer-Kucher, 2008). Because of this, social workers should establish a community environment in clinical work. Community practice would incorporate multiple individuals into therapy. This would alleviate the pressures associated with individual therapy. Additionally, the group mentality would provide social capital to the youth. The goal of group therapy with Pakistani youth is to establish a sense of community amongst the group. When part of a community that shares an ethnic identity, Pakistani youth have social capital manifested

in significant relationships (Ghaffer-Kucher, 2008). By establishing a group identity through clinical practice, social workers possess the ability to engage clients through group involvement. With a group that possesses multiple identities, it is imperative that the social worker focuses exclusively on one identity at a time, while remaining mindful of the elaborate interconnectedness and influence the identities have on the individual as a whole.

### **Islamic Group Development**

Pakistani culture closely correlates identity with religion (Jacobson, 1998). With Islam as an entirely separate facet of a Muslim youth's identity, practice in social work must exclusively focus on the Islamic traditions of the multidimensional personality. Islamic traditions in America vary slightly from traditions in Pakistan, but American Muslims value religion on the same level as traditional Pakistanis (Leonard, 2005). Many theoretical models in social work ignore the importance of religion in clinical practice. This causes social workers to lack the fundamental knowledge of Islam. Developing a nominal understanding of the Qur'an and the five pillars of Islam (the testimony of faith, prayer, Zakat, fasting for Ramadan, and the pilgrimage to Mecca) will help social workers understand the basics of Muslim faith, culture, and traditions (Nimer, 2002). Two major subgroups of Islam exist in the United States: the Sunnis and the Shiites. Acknowledging the subgroups will help direct religious practices.

Islamic traditions influence the development of individual Pakistani children, and traditions also help foster further development of group identity. Practicing Muslims share a common experience through group prayer. Prayer and meditation foster a norm in which participants can mutually identify. Through group prayer, individuals help one another process acculturation struggles, identity conflicts, and many other problems that Pakistani youth encounter. Despite some of the social stigma towards Muslims resulting from 9/11, the faith of many Muslim youth strengthened (Khuwaja, Selwyn, Kapadia, Mccardy, & Khuwaja, 2007). Social workers may use this empowering strength to improve the condition of the group. Religious practice is critical in group therapy with Pakistani youth.

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## Theories in Practice

It has been established that Pakistani youth have multifaceted identities correlated with political, cultural, and religious dimensions. Because Pakistanis are a dynamic population, not one exclusive Westernized theory adequately responds to the complexity of the problems experienced by Pakistani youth. Similar to the manner in which youth must actuate certain identities in different social settings, social workers must too adapt theories to appeal to separate identities. Ghaffer-Kucher (2008) established that Pakistani youth do not hold one identity to a higher esteem than another – each identity is valued relevant to the *situation*. A situational integrative model is presented to account for the complexity of working with Pakistani youth. This model dichotomizes group therapy into the individual self and the extended (group) self. A social worker must focus on improving the health of the individuals in the group and improving the health and identity of the community as a whole.

The situational integrative model utilizes Western theories that enhance working with Pakistani youth. Utilizing the multiple theories will help sensitize a social worker to the complex needs of the client. Three perspectives based in theory will particularly help clinicians address the needs of this population: the ecological systems theory, the cultural competence perspective, and the strengths perspective.

The ecological systems theory describes development as a direct result of the environment. The multiple environments the Pakistani youth encounter greatly implicate the development of identity and character. A practitioner must observe how the different environments affect the client. This theory also provides insight to any social capital a youth may possess. If an individual does not have a social network, the practitioner should encourage involvement with group therapy and group prayer to develop this social support system.

Secondly, without a culturally competent perspective, a practitioner may misdiagnose a client. Proper methods of treatment must reflect cultural norms and beliefs. The situational integrative model greatly relies on cultural competence in order to establish culturally relevant group therapy. This relates to Islamic practices as a method of therapy. Developing a group identity through Muslim traditions helps youth work on common problems through shared experience.

Thirdly, the strengths perspective highlights the special abilities of the individual and the extended self. Discussing resiliency and courage helps empower youth to take pride in their identities. Ghaffer-Kucher (2008) discusses the lack of role models in the Pakistani community within the United States. Due to the rigid hierarchy of class and the discrepancies of acculturation from generation to generation, highlighting the skills of youth will provide positive encouragement.

These three systems, used interchangeably, allows a social worker to structure clinical practice around the needs of each client. In the situational integrative model, the ecological systems theory can help a clinician identify how environmental factors affect the individual and the group as a whole. Through identification of hostile environments (school, sports, and extracurricular activity) the group may identify appropriate methods to respond to the environments. The shared experience of expressing emotion and developing actions to improve public environments will create a sense of mutual accountability and group solidarity.

A culturally competent model should be used when working with Pakistani youth and their families. The youth and their parents possess varying degrees of acculturation. Recognizing this fact will help individualize the treatment – even if in a group setting. By looking at the ecological systems theory through the lens of the culturally competent model, a practitioner will focus on environments and their direct relation to the Pakistani culture. In practice, practitioners should highlight individual and group strengths. The strengths perspective empowers the group, and through this empowerment Pakistani youth may better respond to the “Muslim stigma” in American society. A key component of the situational integrative model is the fact that it does not rely too heavily on one Westernized theory. This allows a practitioner to use individualized treatment to address the multifaceted identities of Pakistani youth.

## Conclusion

The problems faced by those of Pakistani descent are complex and multidimensional. To account for this, practitioners working with Pakistani youth in the United States should develop a multidimensional approach to treatment. Pakistani youth and their families face complex political, cultural, and religious exclusion

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in the post 9/11 era. The various facets of the Pakistani lifestyle affect the identity of youth. To properly respond to this, a situational integrative model was developed. This model connects the ecological systems theory, the culturally competent perspective, and the strengths perspective to community based therapy with the Pakistani culture. Pakistani youth have multiple identities, and they use specific identities based on the situation. This model simultaneously addresses the political, cultural, and religious identities in the culture with heavy implications on the situational context. The

situational integrative model allows a clinician to specifically address the needs of a Pakistani youth. This paper has outlined the general guidelines for conducting culturally competent social work with Pakistani youth in the United States by approaching treatment simultaneously from political, cultural, religious, and theoretical perspectives.

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### References

- Conwill, W. L., & Jooma, K. (2008). Thwarting Ethnoviolence Against Muslim Women Performing Identity in Social Action. *Journal for Social Action in Counseling and Psychology, 1* (2), 30-47. Retrieved from: <http://www.psysr.org/jsacp/Conwill-V1N2-08.pdf>.
- Daneshpour, M. (1998). Muslim families and family therapy. *Journal of Marital & Family Therapy, 24*(3), 355-368. doi: 10.1111/j.1752-0606.1998.tb01090.x.
- Drachman, D., & Paulino, A. (2004). Introduction: Thinking beyond United States' borders. *Journal of Immigrant and Refugee Services, 2* (1/2), 1-9. doi: 10.1300/J191v02n01\_01.

## A Multifaceted Integrative Model for Working with Pakistani-American Muslim Youth

- Ellenwood, A. E., Snyders, R., Poignon, J., & Roberts, A. (2006). Expanding the traditional diagnostic interview: Gathering migration history via a cultural diagnostic interview. *Journal of Family Psychotherapy, 17*(2), 51-65. doi: 10.1300/J085v17n02\_04.
- Elliott, D. (1993). Social work and social development: towards an integrative model for social work practice. *International Social Work, 36* (1), 21-36. doi:10.1177/002087289303600103.
- Ghaffar-Kucher, A. (2009). The (mis)education of Pakistani immigrant youth. *Dissertation Abstract International, 69*(8), 352A. (UMI 3327036) Retrieved from [http://gateway.proquest.com/openurl%3furl\\_ver=Z39.88-2004%26res\\_dat=xri:pqdiss%26rft\\_val\\_fmt=info:ofi/fmt:kev:mtx:dissertation%26rft\\_dat=xri:pqdiss:3327036](http://gateway.proquest.com/openurl%3furl_ver=Z39.88-2004%26res_dat=xri:pqdiss%26rft_val_fmt=info:ofi/fmt:kev:mtx:dissertation%26rft_dat=xri:pqdiss:3327036).
- Guru, S. (2010). Social work and the 'war on terror.' *British Journal of Social Work, 40*, 272-289. doi: 10.1093/bjsw/bcn129.
- Iyer, D. (2010). South Asians in a Post-September 11<sup>th</sup> Environment. In Chen, E.W., & Yoo, G.J. (Eds.), *Encyclopedia of Asian American issues today* (Vol.1 pp.527-534). Santa Barbara: ABC-CLIO.
- Jacobson, J. (1997). Religion and ethnicity: dual and alternative sources of identity among young British Pakistanis. *Ethnic & Racial Studies, 20*(2), 238-256. doi: 10.1080/01419870.1997.9993960.
- Jacobson, J. (2006). *Islam in transition*. New York, NY: Taylor & Francis e-Library.
- Kim, J., Kouros, N., Huckerby, J., Leins, K., & Narula, S. (2007) Americans on hold: Profiling, citizenship, and the war on terror. *Center for Human Rights and Global Justice NYU School of Law*. Retrieved from: <http://www.chrgj.org/docs/AOH/AmericansonHoldReport.pdf>.
- Khuwaja, S. A., Selwyn, B. J., Kapadia, A. McCurdy, S., & Khuwaja, A. (2007). Pakistani Ismaili Muslim adolescent females living in the United States of America: Stresses associated with the process of adaptation to US culture. *Journal of Immigrant and Minority Health, 9*(1), 35-42. doi: 10.1007/s10903-006-9013-y.
- Ledgerwood, A., & Liviatan, I. (2010). The price of a shared vision: Group identity goals and the social creation of value. *Social Cognition, 28*(3), 401-421. doi: 10.1521/soco.2010.28.3.401.
- Leonard, K. I. (2005). Introduction: Young American Muslim identities. *The Muslim World, 95*(4), 473-477. doi: 10.1111/j.1478-1913.2005.00106.x.
- Nimer, M. (2002). *The North American Muslim resource guide: Muslim community life in the United States and Canada*. New York, NY: Routledge.
- Nuttman-Shwartz, O. (2008) 'Working with others in a context of political conflict: Is it possible to support clients whose views you disagree with?' In Ramon, S. (Ed.), *Social Work in the Context of Political Conflict*, Birmingham, Venture Press.
- Pew Research Center. (2011a). Continuing divide in views of Islam and violence, Pew Research Center for the People and the Press, 9 March 2011, Retrieved from <http://pewresearch.org/pubs/1921/poll-islam-violence-more-likely-other-religions-petering-congressional-hearings>.
- Pew Research Center. (2011b). Religion in the News: Islam was no.1 topic in 2010. Washington DC: Pew Forum on Religion and Public Life / Project for Excellence in Journalism. Retrieved from <http://pewforum.org/Politics-and-Elections/Religion-in-the-News--Islam-Was-No--1-Topic-in-2010.aspx>.



## A Multifaceted Integrative Model for Working with Pakistani-American Muslim Youth

- Purkayastha, B and Ray, R. (2010). South Asian Americans. In Chen, E.W., & Yoo, G.J. (Eds.), *Encyclopedia of Asian American issues today* (Vol.1 pp.51-64). Santa Barbara: ABC-CLIO.
- Powell, M. (2003, May 29). An Exodus Grows in Brooklyn: 9/11 Still Rippling Through Pakistani Neighborhood, *The Washington Post*, Page A01.
- Ross-Sheriff, F., & Husain, A. (2004). South Asian Muslim children and families. In Rowena, F. (Ed.) *Culturally competent practice with immigrant and refugee children*. (1<sup>st</sup> ed., pp. 163-182). New York: The Guilford Press.
- Schmidt, G. (2004). Islamic identity formation among young Muslims: The case of Denmark, Sweden and the United States. *Journal of Muslim Minority Affairs*, 24 (1), 31-45. doi: 10.1080/1360200042000212223.
- Sundar, P. (2008). To Brown it up or to 'Bring down the brown: Identity and strategy in second-generation, South Asian-Canadian youth, *Journal of Ethnic and Cultural Diversity in Social Work* 17 (3), 251-278. doi: 10.1080/15313200802258166.
- Shamai, M. & Boehm, A. (2001). Politically oriented social work intervention. *International Social Work*, 44 (3), 343-360. doi: 10.1177/002087280104400306.
- Sirin, S. R., & Fine, M. (2007). Hyphenated selves: Muslim American youth negotiating identities on the fault lines of global conflict. *Applied Developmental Science*, 11(3), 151-163. doi: 10.1080/10888690701454658.
- Tanzeela, A. (2006). The state of Muslim social service in America. *University of Tennessee Honors Thesis Projects*. Retrieved from [http://trace.tennessee.edu/utk\\_chanhonoproj/929](http://trace.tennessee.edu/utk_chanhonoproj/929).
- Tummala-Narra, Pratyusha. (2005). Addressing political and racial terror in the therapeutic relationship, *American Journal of Orthopsychiatry* 75 (1), 19-26. doi: 10.1037/0002-9432.75.1.19.
- Yang, B.H., Junck, A. & Ling, S.Y. (2010). Detention and deportation. In Chen, E.W., & Yoo, G.J. (Eds.), *Encyclopedia of Asian American issues today* (Vol.1 pp.491-502). Santa Barbara: ABC-CLIO.
- Yusuf, Huma. (2011). Dealing with Davis: Inconsistencies in the US-Pakistan relationship, *Asia Pacific Bulletin* 103, 1-3. Retrieved from [http://www.eastwestcenter.org/publications/search-for-publications/browse-alphabetic-list-of-titles/?class\\_call=view&pub\\_ID=3796&mode=view](http://www.eastwestcenter.org/publications/search-for-publications/browse-alphabetic-list-of-titles/?class_call=view&pub_ID=3796&mode=view).

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### ENDNOTES:

<sup>i</sup> Ghaffar-Kucher (2009) finds that “transnational geopolitics have created a hostile political climate in the United States for Muslim students... This phenomenon especially affects the everyday lived experiences of Pakistani-American and Pakistani immigrant youth as Pakistanis form the largest Muslim immigrant group in the United States.”

<sup>ii</sup> Take a recent example in the news that can affect Pakistani-Americans relatives abroad: Controversy continues over killing of two Pakistan’s by an American CIA officer, Raymond Davis. This international relations controversy has led the Pakistani intelligence service (ISI) to manipulate the press so that “news anchors and political talk show hosts have been encouraged to fuel anti-American sentiment by circulating extreme conspiracy theories (Yusuf 2011, 2).”

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<sup>iii</sup> The US Census Bureau asks a question on the American Community Survey “How well does this person speak English?” and the respondent can pick from very well, well, not well or not at all.  
<http://www.census.gov/hhes/socdemo/language/about/faqs.html>.

<sup>iv</sup> In Brooklyn, about 15,000 out of 120,000 Pakistani families have fled to Canada since 9/11 (Iyer 2010). For a look at the negative impacts of 9/11 on Brooklyn’s Pakistani population see article written by Michael Powell titled “An Exodus Grows in Brooklyn; 9/11 Still Rippling through Pakistani Neighborhood” printed in the Washington Post on May 29, 2003.

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<sup>v</sup> Fine & Sirin, 2007, 155) note: “ 84.3 percent of the survey participants... reported that they have experienced discrimination because of their religion or ethnicity during the past year, either at school, on the playground, while shopping, on the street, or in other public settings.