Assessment of Therapeutic Practices at The Judge Rotenberg Educational Center, Inc.

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On July 9th, 2015, I accepted an invitation to assess and tour the Judge Rotenberg Educational Center (JREC), Inc. JREC is a residential treatment center located in Canton, MA which specializes in treatment of children, adolescents and adults with severe developmental, psychiatric or other behavior disorders that have been resistant to other environments. Their highly controversial use of aversive therapies, particularly electric shock meant to cause pain, has caused the school to be heavily scrutinized by numerous politicians, psychologists, psychiatrists and human rights advocates. The United Nations Rappoture on Torture has also publicly come out against the Judge Rotenberg Educational Center. Much of the current international outcry against JREC came after a lawsuit was brought by the mother of a former student who had Autism, which resulted in the release of video of one particular incident that caused clinically significant neurological damage and was horrifying to much of the general public when seen.

When I arrived that morning, I was greeted by Ms. Glenda Crookes, the current executive director of the school. Myself and a colleague spoke with her about the Judge Rotenberg Center, its current practices, treatment outcomes, student population, diagnosis and recruitment. Through this and the subsequent tour, I was able to both learn about and observe the JREC in practice.

In addition to the school buildings, JREC operates forty group homes in the Boston area that house their student population of 246 (as of July 2015). Student placement in each group home is based upon age and gender. Group homes are not gender inclusive, but do vary slightly in average age. Staff/student ratio is claimed to be considerably low and rarely exceeds a ratio of 1:4. According to the executive director, the oldest current student is sixty-two years of age at the time of this report. The fact that a student has been there for such a long time (all students are

admitted prior to their eighteenth birthday) alone raises questions about the efficacy of JREC's program.

In classrooms, students are classified primarily by JREC reward system level and secondarily by physical age. Cognitive level appears to be secondary in classroom placement, as well. According to JREC, students do approximately fifty percent of their work independently on computers, while the rest of the work is spread out over reading and typical lectures. However, students in lower level classrooms do more of their work independently, at their desks in front of a computer, while those students in higher level classrooms have more interactive and lecture-type teaching.

JREC claims to have move toward an approach more consistent with PBIS and away from aversive therapies. I observed one such aspect of their reward system grounded in PBIS in a classroom of 10th grade students. Students were given monetary rewards based on meeting their respective behavioral goals. These goals were highly individualized for each student, as was goal difficulty. The amount of money each student in the class had earned could be seen by the students in a shared folder among their computer accounts. JREC claims that the students enjoy this; but because of the variability in goal difficulty and the severe behavioral issues in the population of students JREC accepts and works with, it is likely that a clinically significant reaction of envy and/or anxiety by at least some students who are not doing as well or have more difficult goals to earn the same amount in rewards as another are likely expressed inside or outside of the classroom (Mohr, et al, 2009).

However, because JREC focuses solely on behaviors, connections between other aspects of psychological well being (such as emotion, the self, metacognition, neuropsychiatric processes

and analytic and PBIS-related interventions) are dangerously neglected. This is counter to the nature-nurture approach that heavily integrates genetics, neurological processes, upbringing and experiences (Kandel, 1998). Many psychotherapists have found that an integrative approach that focuses on the needs of and alliance with each patient or group are more effective (Curtis, 2011). More recently, JREC claims to have slightly broadened its services, provide cognitive-behavioral therapy on a regular basis as a right, rather than a reward (a strict definition of "regular basis" from JREC could not be determined, despite repeated inquiries). As a self-proclaimed student-centered program, this is disappointing, as other approaches, such as dialectical behavior therapy, psychodynamic psychotherapy and psychoanalysis may be more effective for certain students.

Such alternatives to behaviorist-related approaches to psychotherapy (excluding PBIS and behavior analysis) are inconsistent with JREC's practices and are not known to be utilized. Such a rigid approach can deprive students who don't respond well to any behaviorism-derived therapy in the long term from approaches that would be significantly more effective. This is especially true for the large proportion of students with Autism Spectrum Disorders at JREC, who can be significantly more responsive to alternative or more intense therapies, such as psychodynamic psychotherapy or psychoanalysis (Shapiro, 2008 & Emanuel, 2014).

JREC staff are also trained in restraint practices, but they are not trained in the most evidence-based, widely used and successful model, developed at Cornell University known as Therapeutic Crisis Intervention (TCI). Their training in restraint is not known to require retraining at any regular interval, nor is the efficacy of its implementation- a problem at many programs throughout the United States (Mohr, et al, 2009). They are also neither trained in, nor utilize the Sanctuary Model, a comprehensive method utilized worldwide to address severe psychological trauma. In fact, JREC focuses solely on behaviors. Diagnostic, biochemical (Fuchs, 2004),

personality, environmental factors and unconscious processes related to such disorders- including those directly resulting from child abuse (Bloom, 1993) are rarely addressed directly. Ms. Crookes, JREC's executive director, told me that JREC "does not focus on diagnoses; only behaviors."

Students are provided with a full lunch each day (JREC claims no form of food deprivation is currently utilized and hasn't been for the past four years, but I was not able to confirm, nor deny this claim). If a student does not like a certain lunch, JREC has said that they will make something else for that student. However, that generalized claim, considering the hypersensitivity to touch, taste, or sight or hearing associated with Autism (Ross, et al, 2006) and the high incidence of Autism in JREC's student population, it is unlikely that this system works as described; maintaining such a system would be a significant burden (both financially and in practice) upon kitchen staff, as well as the maintenance of a kitchen prepared for any variety of culinary preferences across all forty group homes and the school. Although the amount of requests for alternatives each day is not known and therefore, any assertion regarding burden of such a system cannot be conclusive, there is reason to believe that such an issue exists.

While interacting with lower-functioning students there (with staff present for the entire duration of said interactions), I was concerned that these interactions were not organic. Each student had looked toward a staff prior to any interaction or response; indicating that the content of each interaction between myself and any student may have been coached and/or censored.

Numerous aversive and physical equipment designed to prevent negative behaviors are still in use and its incidence is statistically significant. Helmets that do not cover the face and are similar in size, shape and material of the helmets utilized while sparring in martial arts are still a

common intervention, but are significantly less dangerous and sensory-depriving than previous white noise helmets. I was told by staff that these helmets had to be removed for at least ten minutes per hour and some students do not have to wear them to bed at all. However, it was not stated whether or not the helmet was removed every sixty minutes or if they could take it off at varying times within each hour on the clock (e.g. 2:00PM-3:00PM). Without such intervals, it is possible for a helmet to stay on for more or less time than stated.

The most controversial aversive device, known as the General Electronic Decelerator (GED), utilizes skin shocks in order to eradicate self-defeating behaviors. JREC claims that the GED is only utilized on 20% of the student population, but this was inconsistent with my observations of students. However, because a number of students were home on vacation, this observation may be skewed. Regardless, the number of students seen on the GED was significant. There are two iterations of the GED still in use: the GED-3A; and the GED-4. Each device in numerical order is claimed to be an improvement on the previous device, but I could not test this and therefore, can neither support, nor refute that claim.

A common misconception in regards to the GED is its use on new students. Several years ago, a rumor surfaced stating that the GED could no longer be utilized on new students, while students already on the GED could be grandfathered in, despite the new law. This rumor, however, is not the case, according to JREC and a closed settlement allowing its use to continue on new students with higher scrutiny by the Massachusetts judicial system. This monitoring by the courts, while more frequent in regards to continued use on a given child, is far from adequate, and the courts do not observe the device in practice, nor in a naturalistic manner.

Because the GED electrodes are placed on the torso and upper and lower limbs, there is a potential danger of damage to the peripheral nervous system. According to JREC, these electrodes are not placed by qualified physicians (e.g. a neurologist, neuropsychiatrist, clinical neurophysiologist or epileptologist) and therefore, may be a significant danger to students (especially if any psychiatric symptoms or behaviors are the result of an underlying physiology). There is also speculation that such shock can damage cellular DNA and result in cancerous tumors, but because JREC is the only institution to utilize the GED device or electric shock as a whole and has elected to refrain from performing such longitudinal studies (or any studies on the subject at all), the aforementioned speculation has not been tested.

Also a concern and observed at JREC is the size and weight of the GED devices. In addition to the electrodes placed on the torso and upper and lower limbs, the device itself is stored in a backpack or fanny pack attached to the wearer. The size and weight of them, depending on a child's height, weight and age, are concerning, as said weight and positioning of the GED device may cause permanent musculoskeletal damage. Girls in puberty who are starting to develop breast tissue or have fully developed breasts may be especially at risk for chronic pain in the back, shoulders or hips. One former student that I spoke to suffers from such pain attributed to the GED and this has been confirmed by her physician (Personal Communication).

Because JREC admits students who have violent psychiatric histories, severe cognitive deficits and/or treatment resistance to neuroleptic medications, it is likely that this populations of students will have a significantly higher incidence of underlying organic conditions- especially inborn errors of metabolism (Walterfang, et al, 2012). However, any possibility of misdiagnoses of any JREC students is vehemently denied JREC and claim that all students are seen by a multitude of specialists. However, these are extremely difficult to diagnose and many physicians

are not aware of them (Walterfang, et al, 2012). It is also not known if the claim that all students are seen by a multitude of specialists is accurate.

Since there are so few diagnosed cases of organic conditions in this population at JREC, it is likely, based on numerous epidemiological studies, that a clinically significant number of students remain misdiagnosed (Lauterbach, et al, 2008).. These conditions, typically rare and genetic, often include psychiatric and developmental symptoms such as Autism, intellectual disability or phenocopies of numerous psychiatric disorders (Autism or phenocopies of psychiatric disorders may be the sole presenting symptom and remain isolated for years) and are typically highly resistant to neuroleptic medications (Van Karnebeek, C. D., & Stockler, S. (2012). Such conditions that may present with two or more of those three symptoms and are extremely difficult to diagnose include, but are not limited to: Inborn errors of metabolism such as Acute Intermittent Porphyria, Niemann-Pick Disease Type C, Wilson's Disease, Late Onset Tay-Sachs/Sandhoff Disease and Brunner's Syndrome (Brunner, et al, 1993); autoimmune diseases such as Systemic Lupus Erythematosus, Narcolepsy, Behcet's Disease, Neurosarcoidosis and Multiple Sclerosis; and chromosomal disorders such as William's Syndrome; 1p36 Deletion Syndrome and 22q11.2 Deletion Syndrome (Lauterbach, et al, 2008).

In recent years, the number of positive behavioral interventions at JREC have increased, according to staff and JREC's own materials. As the executive director of JREC, Ms. Crookes allocates multiple hours each day in which students can walk into her office and interact with her. In order to examine the depth in which emotion and unconscious processes are deduced from behavior and context at JREC, I asked several staff deducing emotion and unconscious processes from behaviors and context. None were able to make any connections beyond behavior when presented with the following hypothetical scenario:

"A fourteen year old female student has been admitted to JREC due to high promiscuity and a diagnosis of conduct disorder which had failed to be successfully addressed in other day and residential programs. She is particularly violent toward men. Why would she behave this way?"

The following answer is the most commonly given:

"The student in the above scenario had been physically and sexually abused by a multitude of men who came to the house and to have sex with the mother and yelling had a tendency to come from the bedroom during these times. The student eventually learned that women communicate with men solely be sex and violence. Since this issue was never addressed with the student, she continues to express these behaviors, as she had never learned any other form of communication with men."

Although JREC has made some improvements to their program (such as psychotherapy being made a right, rather than a privilege) since its founder and former executive director, Dr. Matthew Israel, left the school, many practices at the school (such as the use of aversive skin shocks and varying degrees of isolation) remain highly questionable at best and torturous at worst). The rewards and broader inclusion of PBIS are positive, but the expectations required to achieve such rewards can be extraordinarily high and aversive interventions are remain a prominent fixture. In my experience in the mental health filed in both direct care and research, JREC remains an institution that leaves much to be desired, as integrative interventions, an absence of aversive intervention and the avoidance of punishment and negative reinforcement as much as possible have a higher efficacy- even in some of the most difficult students. Focusing solely on behavior only masks the problem- understanding what the underlying issue is and

resolving it is key to growth and change; with recurrence of difficult behavior more likely to result without said understanding.

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About the Author

Mr. Rosenthal currently works with children and adolescents with severe developmental and psychiatric disorders at a residential and day school in Yonkers, NY and is a member of the board of directors of a nonprofit organization dedicated to serving and advocating for children with rare or undiagnosed diseases and their families. An active human rights advocate for over five years, Mr. Rosenthal has worked with the Community Alliance for the Ethical Treatment of Youth (CAFETY), as well as done independent work on the investigation of practices throughout the troubled teen industry. He holds a bachelor's degree in psychology from the Derner Institute of Advanced Psychological Studies at Adelphi University, where he focused on applications of psychoanalytic theory and interventions; and organic causes of psychopathology. Mr. Rosenthal has also been publicly acknowledged for his clinical work with patients with Late-Onset Tay-Sachs Disease, as well as public speaking engagements. His current research focuses on psychopathology in lysosomal storage diseases and other inborn errors of metabolism, which are treatment resistant to most psychiatric medications, notoriously difficult to diagnose and fatal if not diagnosed and properly treated early. He is also a member of the American Psychological Association, the Society for the Study of Inborn Errors of Metabolism and the International Neuropsychoanalysis Society.