Department of Mental Retardation Office of Quality Management, Quality Enhancement Division Survey and Certification

Report Date: January 9, 2009

Agency: The Judge Rotenberg Educational Center

Review Dates: September 29, 2008 to October 10, 2008

Licensure: November 6, 2008 to November 6, 2009

Licensure Level: Conditional One-Year License

Follow-Up Required: Yes, "People are valued."

"People's rights are affirmed."
"People's rights are protected."
"People maintain good health."
"People's funds are safeguarded."

"The organization has systems in place to safeguard individuals."

Certification Performed By: Department of Mental Retardation for Residential & Employment Supports

Certification Outcome: Certified with 1 out 6 Quality of Life Areas "Achieved"

Survey Team: Stephen Abreu (Team Leader), Jennifer Petersen & Edward Sutka

Citizen Volunteers: None

Number of Individual Reviews Completed: [18]

[12] Residential Reviews

[6] Work/Community Reviews

[0] Respite Reviews (Not Rated)

[2] Safeguard System Reviews

(Not Rated)

EXECUTIVE SUMMARY

The Judge Rotenberg Educational Center (JRC) is a private non-profit organization providing both day and residential supports to children and adults. The agency specializes in supporting individuals with a history of severe behavior disorders. Many of the individuals JRC supports (over 70%) come from states other than Massachusetts and often with many previous unsuccessful attempts in treatment supports from other service providers. The agency has had a decrease in enrollment since the last survey and now supports just over 180 individuals. As many of the individuals supported (111) are under the age of eighteen, the agency is also licensed by another state entity, Department of Early Education and Care (EEC). This other entity is responsible for the licensure of the residences in which one or more individuals is age eighteen or younger. This full Licensure and Certification Review by DMR focused on a sample of individuals from the Adult Services Program which consists of residential and vocational services for a total of seventy-three adults. Of these seventy-three adults, thirty-one are Massachusetts residents receiving funding through the Department of Mental Retardation (DMR.)

The survey sample for the current Licensure and Certification Review was comprised of a random sample of twelve individuals who received twenty-four hours of residential supports and six individuals who received employment supports. Safeguard System Reviews, which were not focused upon a specific person, were also conducted at two of the agency's remaining four homes that provide twenty-four hour supports.

Since the previous survey the agency had moved forward on the renovations of both buildings that make up its campus. One building now had a fully functional cafeteria that prepared and served all meals. This location also prepared the meals that were sent to each home for dinner Friday through Sunday. Other physical changes included a gymnasium with basketball court and exercise equipment. The day support location for adults was moved from its previous location and occupied several "classrooms" at its new location. The agency had completed its process of separating adult's residential supports from its children residential supports. Additional changes occurred in its systems of information integration as individual files were expanded to contain information that had been maintained in separate locations in the past such as medical, legal, and financial information. The system for access and storage of individual daily data had also been improved to allow for a more systematic review of the implementation of treatment plans.

DMR recognizes that the agency serves some of the most behaviorally challenged individuals in the Commonwealth. As a result, its treatment modality is inherently restrictive with regard to individual freedoms. The agency's highly structured programming and settings are emphasized over other treatment strategies, such as psychotropic medication.

Indeed, controlling the environment continues to be a primary component of treatment at JRC and viewed as a contributing factor in successfully managing maladaptive behaviors. While acknowledging this component of its programs, the survey team nevertheless found the agency's policies to be overly restrictive with regard to individuals' protected rights and freedoms.

Moreover, some of the agency's practices are markedly restrictive. For example, adults (and children) at the agency spend an excessive amount of time at the agency's campus location rather than their home. This practice of keeping adult clients in their work (day support) environment through dinner and into the evening period Monday through Thursday impacts on the individuals' rights in a number of ways described below.

The practice of people going home at 4 p.m. on Friday's and spending the entire weekend at home was implemented in August 2008. Prior to this date, individuals were transported to the day support location seven days a week, and remained there until after dinner on Monday through Thursday. Although the current practice provides a greater opportunity for people to be at home, the agency should continue to provide opportunities for individuals to spend more time in their home and expand the choice making options available to individuals while at home.

The agency utilized a variety of practices that did not promote individuals as valued adults. For example, individuals throughout the survey were referred to by staff at all levels of the organization, as "low-functioning" or "high-functioning," and this terminology was also noted in two documents utilized as staff training

Individuals were also required to stand in line in large groups and walk from room to room waiting for individuals from their line to be dropped-off at the appropriate room.

A number of agency practices did not promote individuals' rights. These can best be categorized as practices that were generalized amongst all individuals supported within both residential and day supports. Examples of generalized practices that violated individuals' rights as set forth in DMR regulations included: mandatory bed times and bed checks, restricting talking, and not allowing any deviation from the food menu. These were implemented universally, across sampled individuals. Since these restrictions and other practices were not individually based and not specified within treatment plans, their application affected all the individuals

sampled and thus resulted in an overall rating of "Partially Achieved" in the Quality of Life Areas pertaining to rights affirmation and protection.

All of the individuals who participated in the survey were supported with interventions with restrictive components, such as Level I plans with a restriction of possessions and funds or Level III behavior plans with the use of physical and mechanical limitation of movement, and/or the administration of behavior-modifying medication, and/or the use of health-related protection devices. Concerns were seen for all people who participated in the survey in one or more aspects of the implementation of these restrictive practices. These included compliance with the procedural safeguards such as ensuring that interventions were the least intrusive and based on the individual's needs; that all of the interventions being implemented are included in the written plan; that consent was obtained; that review and the necessary approval for the type of intervention being used such as HRC for the restriction of possession and funds, is sought; and that interventions are safely and consistently implemented.

The agency identified a system to support optimum healthcare that primarily relied on coordination amongst internal nursing, contracted physicians, and community based practitioners. However, supporters at other levels of the organization were also involved in the coordination and oversight of individuals' healthcare. For example, individuals were typically brought to healthcare appointments within the community by their case manager or another designated staff. Additionally, although a system to communicate with external medical professionals was developed, this was not consistently implemented nor was a comprehensive consult form complete for the physician to review. Thus, physicians would have to rely on the staff person attending the appointment. It was unclear however, whether staff had been trained to fully understand the individuals' medical needs or brought sufficient written information with them to effectively communicate their healthcare needs, to observe and record symptoms, or to summarize pertinent data. For instance, two case managers who regularly attended and/or communicated with external physicians reported that knowledge and understanding of a person's medical diagnosis was a function of the nursing department and not their responsibility. Additionally, in some cases medical diagnoses and recommendations available within the confidential records were not fully acknowledged by agency personnel. This resulted in failure to seek specialized services or reasonable accommodations, and issues regarding the diagnoses were not tracked and presented to an appropriate specialist for some of the individuals that participated in the survey. The agency needs to strengthen the coordination of medical services to ensure that all personnel involved in the coordination of care are knowledgeable of people's healthcare needs and their role in promoting a continuum of care.

Further compromising this area was the practice of staff administering medication without the required Medication Administration Program (MAP) certification and maintaining (storing) medication at homes that had not been registered through the Department of Public Health as required by regulation. (See 115 CMR 5.15.) For example, although most were not administered daily, medications stored and administered at individual's homes by non-licensed or non-certified staff were comprised of both over-the-counter medications and those prescribed on an as needed basis.

The agency structured its residential homes in a hierarchy of restrictiveness. Individuals were moved within this hierarchy for a variety of reasons relating to behavioral reward or consequence, between settings which tied to an individual's assigned level of functioning. This impacted individual rights, choice, privacy, and control for all of the agency's adult clients. Additionally, individuals were transferred from one residential location to another based not necessarily upon their own behavior, but upon other individuals' behavior.

Although individuals spent their day at a location within a business district, and homes were located within residential neighborhoods in close proximity to community based resources, individuals were not supported to regularly use local resources or to become integrated into their neighborhoods. For instance, the staff ensured

that individuals did not socialize with others who are not associated with the JRC while on a "field trip." In addition, for all of the sampled individuals, the use of community resources was typically done in groups and was not necessarily based on individuals' unique interests or preferences.

The use of restrictive interventions was prevalent in all the supports identified; however, organizational systems to address essential safeguards, protection of human rights, and management of risk were not consistently implemented or monitored. Issues included the failure of the provider to support its Human Rights Committee to fulfill its role of ensuring supports are the least intrusive and most appropriate, the safeguarding of individuals' funds, and the administration of medication and healthcare coordination. In terms of managing risks, the agency needs to more effectively monitor GED trouble reports for trends. Additionally, as it was indicated that the device, including the electrodes used, were last assessed in 1994 by John M.R. Bruner, M.D. The agency needs to have the more periodic regular reviews of the devices used to ensure that these operate safely and do not pose a safety threat to individuals.

The agency's philosophy of education and treatment was based on one of the basic principles of behavioral psychology, "that all behaviors are powerfully influenced by the consequences that they produce." As many restrictions were generalized to the general population that JRC serves, there restrictions went beyond what was intended to be more individualized treatment. It is recommended that the agency continue to explore ways in which it can assure an individualized approach to treatment interventions at the same time that it both protects the health, safety, and rights of all served.

Based on the findings of the survey, the agency is certified with one out of six Quality of Life Areas "Achieved." As the agency received a rating of "Partially Achieved" in the Quality of Life Areas of "Rights and Dignity" and "Personal Well-Being," and an overall rating of "Not Achieved" in the Outcomes for the Organization, it will receive a Conditional One Year License. This status necessitates a Follow-up Review within sixty days.

Provider Certification Scoring Summary

Quality of Life Area Residential	Day	Overall Provider Rating
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Organizational Outcome: The organization has systems in place to safeguard people.

Quality of Life Area	Residential	Day	Overall Provider Rating
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Organizational Outcome:	Staff have the skills and knowledge to support the quality of life of people.
Organizational Outcome:	The organization supports growth and change to continually improve its quality of supports.

Organizational Combined Rating:

(Based on both the licensure organizational outcome and the two certification quality of life outcomes.)

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QUALITY OF LIFE AREA #1: RIGHTS AND DIGNITY

Rating: Partially Achieved

QUALITY OF LIFE SCORING SUMMARY

People are valued.	Residential			Day			Respite			% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People's rights are affirmed.	Residential			Day			Respite			% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People's rights are protected.	Residential			Day			Respite			% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People are safe at home and work.	Re	Residential			Day		Respite			% of Indicators		
Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People are protected from harm.	Residential				Day		F	Respite	е	% of Indicators		
Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People maintain good health.	Residential			Day			F	Respite	•	% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA
	7	5	0	4	2	0				61%	39%	N/A
	11	1	0	5	1	0				89%	11%	N/A

People's funds are safeguarded.	Residential				Day		F	Respite	e	% of Indicators		
Not Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

The organization has systems in place to safeguard people. Not Achieved	Finding
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People are understood.	Residential		Day			Respite			% of Indicators			
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People make choices in their everyday lives.	Residential			Day			Respite			% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People are the primary decision-makers in their lives.	Residential			Day			Respite			% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People are integrated into their community	Residential			Day			F	Respit	е	% of Indicators			
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA	

People are connected with their community.	Residential			Day			Respite			% of Indicators			
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA	

People have relationships.	Residential			Day			Respite			% of Indicators		
Partially Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People accomplish their goals.	Residential			Day			Respite			% of Indicators		
Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People have autonomy.	Residential			Day			Respite			% of Indicators		
Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

People grow through their life experiences.	Residential			Day			Respite			% of Indicators		
Achieved	Yes	No	NA	Yes	No	NA	Yes	No	NA	Yes	No	NA

PART II: OUTCOMES FOR THE ORGANIZATION

Staff have the skills and knowledge to support the quality of life of people. Partially Achieved	Finding
The organization supports growth and change to continually improve its quality of supports. Not Achieved	Finding