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Egyptian Regional Human Rights Authority
Report of Findings
09-110-9054
Chester Mental Health Center
April 27, 2010

The Egyptian Regional Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission has completed its investigation concerning Chester Mental Health Center, a state-operated mental health facility located in Chester. The facility, which is the most restrictive mental health center in the state, provides services for approximately 250 male residents. The specific allegation is as follows:

A recipient at Chester Mental Health Center has not been provided with adequate care and services.

#### Statutes

If substantiated, the allegation would be a violation of the Mental Health and Developmental Disabilities Code (Code) (405 ILCS 5/2-102, 405 ILCS 5/2-107, and 405 ILCS 5/2-107.1).

Section 5/2-102 states, "A recipient of services shall be provided with adequate and humane care and services in the least restrictive environment, pursuant to an individual services plan."

Section 5/2-107 (a) states, "An adult recipient of services or the recipient's guardian, if the recipient is under guardianship, and the recipient's substitute decision maker, if any, must be informed of the recipient's right to refuse medication or electroconvulsive therapy. The recipient and the recipient's guardian or substitute decision maker shall be given the opportunity to refuse generally accepted mental health or developmental disability services, including but not limited to medication or electroconvulsive therapy. If such services are refused, they shall not be given unless such services are necessary to prevent the recipient from causing serious and imminent physical harm to the recipient or others and no less restrictive alternative is available. The facility director shall inform a recipient, guardian, or substitute decision maker, if any, who refuses such services of alternate services available and the risks of such alternate services, as well as the possible consequences to the recipient of refusal of such services".

Section 5/2-107.1 (4) states, "Psychotropic medication and electroconvulsive therapy may be administered to the recipient if and only if it has been determined by clear and convincing evidence that all of the following factors are present. In determining whether a

person meets the criteria specified in the following paragraphs, (A) through (G), the court may consider evidence of the person's history of serious violence, repeated past pattern of specific behavior, actions related to the person's illness or past outcomes of various treatment options. (A) That the recipient has a serious mental illness or developmental disability. (B) That because of said mental illness or developmental disability, the recipient currently exhibits any one of the following: (i) deterioration of his or her ability to function, as compared to the recipient's ability to function prior to the current onset of symptoms of the mental illness or disability for which treatment is presently sought, (ii) suffering, or (iii) threatening behaviors. (C) That the illness or disability has existed for a period marked by the continuing presence of the symptoms set forth in item (B) of this subdivision (4) or the repeated episodic occurrence of these symptoms. (D) That the benefits of the treatment outweigh the harm. (E) That the recipient lacks the capacity to make a reasoned decision about the treatment. (F) That other less restrictive services have been explored and found inappropriate. (G) If the petition seeks authorization for testing and other procedures, that such testing and procedures are essential for the safe and effective administration of the treatment."

## Complaint Information

According to the complaint, a recipient at Chester Mental Health Center has not been provided adequate care for "severe tremors". Allegedly, facility medical staff members have not adequately treated the recipient's problem that was created by the administration of psychotropic medication.

## **Investigation Information**

Allegation: A recipient at Chester Mental Health Center has not been provided with adequate care and services. To investigate the allegation, the HRA Investigation Team (Team), consisting of three members and the HRA Coordinator (Coordinator), conducted a site visit at the facility. During the visit, the Team spoke with a Representative (Representative) of the facility's Human Rights Committee and the recipient whose rights were alleged to have been violated. The recipient's clinical chart was reviewed with his written authorization. Information from the emedicine.medscape.com and MedicinePlus.com websites were also reviewed.

## I...Interviews:

## A...Recipient:

When the Team spoke with the recipient, he stated that he experiences some "shaking", which is the result of years of taking psychotropic medication. He stated that a facility psychiatrist had examined him and reported that the condition was irreversible. When asked if he had been provided with adequate care, he stated that he would like to have new glasses and dentures. He informed the Team that he spoke with a staff member regarding his need for glasses and dentures, the staff member stated that the "State is broke". The recipient stated that he would appreciate the Team members' assistance in resolving the matter by speaking to facility staff about his concerns.

## B...Representative:

When the Team spoke with the Representative regarding the recipient's issues of concern, she stated that she would make certain that referrals were made for the dental and visual evaluations. However, she was not aware whether any previous evaluations had been completed without reviewing the recipient's clinical chart.

# II...Clinical Chart Review:

#### A...Treatment Plan Reviews (TPRs):

According to a 03/17/09 TPR, the 54-year-old recipient was admitted to Chester Mental Health Center on 07/22/03 from a county jail with a Not Guilty by Reason of Insanity (NGRI) legal status. Documentation indicated that the recipient had 34 previous admissions to state operated mental health facilities since 1985. The record indicated that the recipient responds to treatment in a structured setting with minimal incidents of aggression and partial insight into his mental illness. However, when he is not medicated, he suffers from paranoid/grandiose delusions, overall disorientation, and dangerousness to self and others.

Documentation indicated that the recipient attended and actively participated in the TPR. During the review, he reported that the medication was not working because he continued to shake. According to the record, when the Treatment Team discussed and demonstrated through example that the medication, Olanzapine 30 mg, had reduced his aggression and agitation, the recipient acknowledged the benefit of the medication. Documentation indicated that the recipient was compliant with taking medication. Additional recordings revealed that a facility psychiatrist indicated that medication changes were not warranted, and documented that there was no effective treatment for Tardive Dyskinesia.

The recipient's diagnoses were listed as follows: AXIS I: Schizoaffective Disorder, Bipolar Type, History of Alcohol Dependence, History of Cocaine Dependence; AXIS II: Antisocial Personality Disorder; AXIS III: History of right knee surgery; Tardive Dyskinesia AIMS score=3, Chronic constipation; and AXIS IV: Since 1973 hospitalized 35 times; History of Medication Noncompliance; NGRI for Attempted Murder in 2001; Theim date is in the year 2031.

The recipient's medications were listed as follows: Olanzapine 30 mg to control psychosis; Valproic Acid 1000 mg twice daily to stabilize mood, and Lorazepam 2 mg tablet twice daily to control anxiety and agitation.

TPR Problem areas were listed as psychotic symptoms, aggression toward others, and bowel elimination. A goal to reduce the psychotic symptoms, which included hallucinations and delusions, by taking medications as prescribed was incorporated into the TPR. Documentation indicated that the recipient was taking court enforced medication that was crushed. An RN reported that the recipient had not refused to take medication during the reporting period. The RN stated that the recipient remained delusional; however, his maladaptive behaviors were

controlled; he had been generally pleasant; and he had interacted with staff and peers appropriately. Documentation indicated that the recipient was involved in education/vocational classes to improve reality orientation, attention and concentration, and frustration tolerance. Additionally, the recipient is seen by his therapist at least weekly and when needed to review maintenance of his stable mental status and aggression-free behaviors and to increase his knowledge of alternative methods of managing aggression and reducing his paranoid ideation.

The TPR contained a goal for the recipient to be free of displaying aggressive behaviors toward others. Taking his medication as prescribed, demonstrating understanding of his medications, having no instances of physical aggression and property destruction, and reinforcement of appropriate social behavior via the facility's level system were listed as objectives in meeting the goal. Documentation indicated that nursing staff provided education to the recipient concerning his medication, including medication dosage, potential side effects and expected effects. The record indicated that the recipient's last restraint episode was 11/30/08, and since he had being taking court enforced medication he had ceased arguing and approaching others in a threatening manner. According to the documentation, the recipient had attained green level, the highest level of participation in the facility's Level System.

To address the bowel elimination problem, nursing staff members were assigned to monitor and record the recipient's bowel movements twice daily; give medication as ordered; and notify the facility Medical Doctor if necessary. Additionally, staff members should encourage him to have adequate fluid and nutritional intake and to participate in activity therapy.

In the Extent to Which Benefitting From Treatment Section of the recipient's TPR, documentation indicated that the recipient had been on green level since 04/08 until he dropped to red level on 07/21/08. Red level is the lowest level of allowed activity participation in the facility's Level System. On 07/24/08, he required restraint. Following this restraint and his ongoing level of agitation, he was transferred from Unit C-1 to C-3 due to increased staff to monitor recipients. He returned to C-1 on 09/08/08. However on 10/24/08, he required restraints. When his psychotic delusions and aggressive, threatening behaviors increased, it became necessary for him to return to Unit C-3. As a result of a special TPR on 10/28/08, the treatment team recommended discontinuing the original plan to initiate Clozapine due to the recipient's ongoing refusal of the essential Echocardiogram. Instead, a facility psychiatrist began titrating Prolixin and Benztropine to discontinuation and initiated Olanzapine (15 mg) with the goal of titrating the Olanapine to 30 mg. When the recipient required restraint on 11/30/08 after he assaulted staff members who were involved in the containment of another recipient, Prolixin and Benztropine were discontinued and Olanzapine was increased to 20 mg. on 11/04/08. On 11/18/08, the recipient returned to court for a medication enforcement status review and Lorazapam 2 mg twice daily was initiated on 11/25/08. Olanzapine was increased to 30 mg on 12/22/08. The Brief Psychotic Rating Scales (BPRS) were conducted on 10/30/08, 11/12/08, 11/16/08, 11/19/08 and 12/15/08. Findings indicated an improvement of the positive symptoms of psychosis. When the NSRC Scale, an evaluation of negative symptoms, was conducted findings indicated that the negative symptoms also showed improvement. Additional documentation indicated that the recipient had not received any Behavior Data Reports (BDR) during the reporting period. A facility psychiatrist indicated that no medication changes were warranted since there was no treatment for Tardive Dyskinesia. The treatment team discussed

possible transfer to a less restrictive facility if the recipient remained aggression free for a period of three months.

Documentation in the Extent to Which Benefitting From Treatment Section of the recipient's 04/14/09 TPR indicated that the recipient had received no BDRs in the reporting period, and he had maintained green level since 01/29/09. Rehabilitation staff reported that he had been cooperative, stayed on task and took pride in his work. Activity staff reported that he had attended 33 off-unit activities, and nursing staff reported that he had been compliant with taking prescribed medication. The psychiatrist once more documented that there was no treatment for Tardive Dyskinesia.

Documentation in the response to medication section of the recipient's 05/12/09 TPR indicated the Tardive Dyskinesia movement score was decreased from 6 to 2. The record indicated monitoring for side effects of medication via blood testing, which were found to be within normal limits. According to the record, the treatment team indicated that they were closely monitoring the recipient in consideration of transfer to a less-secure facility. His medications were listed as Olanzapine 30 mg to control psychosis, Valporic Acid 1500 mg twice daily to stabilize mood and Lorazepam 2 mg three times daily to control anxiety and agitation.

# B: Dyskinesia Identification Condensed Users Scale (DISCUS):

Documentation indicated that a DISCUS was completed on 09/23/07 with a total score of 2, which indicated that the recipient had mild abnormal movements that occur infrequently. However, the movements are easy to detect. When the evaluation was conducted, his current antipsychotics/anticholinergics were listed as follows: Benztropine 2 mg daily, Risperidone 3 mg daily, Clonazepam 3 mg daily, Valporic Acid 2000 mg daily and Clozapine 600 mgs daily. Documentation indicated that the benefits of the medications outweighed the risks and the recipient understood the risks and has agreed to take the medication.

In a 08/21/08 DISCUS, the recipient was receiving Valproric Acid 2500 mg daily and the score was elevated to 8. A score of 8 indicated severe abnormal movements which occurred almost continuously.

When the DISCUS was completed on 09/10/08, the recipient was receiving Fluphenazine 30 mg daily, Valporic Acid 2500 mg daily, and Benztropine 6 mg daily. His score had decreased from 8 to 4; however, the score of 4 is in the lower range of severe. Documentation indicated that the benefits outweighed the risk and therapeutic maintenance was needed. Additional documentation indicated that Clozapine will be started on 09/15/08.

According to a 03/05/09 DISCUS, the score had decreased to 3, which was in the moderate range of abnormal movements. The record specified that the recipient was receiving Olanzapine 30 mg daily and Valporic Acid 2500 mg daily when the evaluation was conducted. Documentation indicated that the benefits versus the risks were explained to the recipient, and he accepted the risks.

#### C. Progress Notes:

Documentation throughout the progress notes indicated that the recipient was monitored for constipation issues, and prune juice and Milk of Magnesia were provided when needed. Additional recordings indicated that the recipient was provided with weekly educational sessions regarding his medications.

On 01/19/09, a facility psychiatrist documented that the recipient informed him that he wanted to sign consents to receive medications rather than have court-ordered medications. According to the psychiatrist's note, the recipient stated that the medication was working and the shaking had improved. The psychiatrist documented that the recipient's facial movements were mild and his hand tremors had decreased to a level 1, which was not disabling for him.

According to a 02/16/09 psychiatrist's note, the recipient had informed him that he wasn't shaking as much and the condition could be worse. The psychiatrist documented that the tremors had decreased by 50%.

In a 03/16/09 and a 04/29/09 psychiatrist's notes, the recipient complained about the tremors in his face and hands. However, in 05/29/09 and 06/29/09 psychiatrist's notes, the recipient noted that the tremors had improved and voiced no complaints.

Documentation in the Progress Note indicated that the recipient had a visual exam on 05/18/09. The optometrist documented that the recipient did not relay any complaints concerning his vision and understood that there would be little benefit of issuing an order for glasses due to the trauma to his right eye. The optometrist recorded that the recipient seemed satisfied with the explanation and voiced no other concerns.

According to documentation, the recipient refused dental examinations on 07/04/09, 10/13/09 and 10/19/09.

Additional documentation indicated that the recipient met the criteria for transfer to a less restrictive environment on 01/27/10.

#### D... Information from emedicine.medscape.com website (website A)

According to information from the website A, Tardive Dyskinesias (TDs) are defined as "involuntary movements of the tongue, lips, face, trunk, and extremities that occur in patients treated with long-term dopaminergic antagonist medications. Although they are associated with the use of neuroleptics, TDs apparently existed before the development of neuroleptics. People with schizophrenia and other neuropsychiatric disorders are especially vulnerable to developing TDs after exposure to conventional neuroleptics, anticholinergics, toxins, substances of abuse, and other agents. TDs are common in patients with schizophrenia, schizoaffective disorder, or bipolar disorder who have been treated with antipsychotic medication for long periods, but TDs occasionally occur in other patients as well".

#### E...Information from MedicinePlus.com website (website B)

According to information from website B, dopaminergic antagonist medication is" related to, involved in or initiated by the neurotransmitter activity of dopamine".

Neuroleptic is a term that refers to "the effects of antipsychotic drugs on a patient, especially his or her cognition and behavior. In psychotic patients, neuroleptic drugs cause a reduction in confusion and agitation and tend to normalize psychomotor activity".

Anticholinergic is defined as "the action of certain medications that inhibit the transmission of parasympathetic nerve impulses and thereby reduce spasms of the smooth muscles".

# Summary

According to the complaint, Chester Mental Health Center had failed to address the recipient's "severe tremors". When the Team spoke with the recipient whose rights were alleged to have been violated, he stated that the tremors were caused by his long-term use of antipsychotics, and he had been informed that the condition was irreversible. The recipient expressed concerns regarding not having visual and dental care. Documentation throughout the recipient's clinical chart indicated that the recipient has Tardive Dykinesia, a condition that causes involuntary movement of the tongue, lips, face, trunk and extremities as a result of long-term use of anti-psychotic medications. Although the record indicated that the condition was irreversible documentation specified that medical staff frequently monitored the tremors and the recipient's psychiatrist made numerous changes in medications in an attempt to improve the problem. Documentation also indicated that the recipient had received a visual examination with findings that glasses would not be beneficial. The record indicated that the recipient refused offers of dental examinations. The recipient's TPRs indicated that the recipient had a problem with constipation and goals were incorporated in the plan to deal with the issue. Documentation indicated that the recipient was carefully monitored and appropriate measures were taken when the problem occurred. Additional documentation indicated that the recipient's medical issues were addressed, labs performed, and education provided pertinent to his medical issues and the medications that he was taking.

# Conclusion

Although it is unfortunate that the recipient experienced involuntary movements, facility medical staff addressed the benefits versus the problems associated with the use of anti-psychotics with the recipient, and the recipient acknowledged the benefits. Additionally, documented past history indicated that when the recipient did not take medications to deal with psychosis, his mental status markedly deteriorated causing him anguish and resulted in serious legal issues and repeated hospitalizations. Therefore, the allegation that the recipient has not been provided with adequate care and services is unsubstantiated. No recommendations are issued.