



FOR IMMEDIATE RELEASE

Egyptian Regional Human Rights Authority
Report of Findings
16-110-9013
Coleman Tri-County Day Training Facility

The Egyptian Regional Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission has completed its investigation concerning an alleged rights violation involving Coleman Tri-County Day Training Facility (Coleman) located in Harrisburg. There are approximately 70 individuals served by Coleman in three different locations. The individuals served range from having severe/profound to moderate intellectual disabilities, 10 are also in wheelchairs and some are visually impaired as well. The specific allegations are as follows:

- 1. Recipients were discriminated against based on their disabilities.**
- 2. There was inadequate care and treatment.**

If substantiated, the allegation would be a violation of the Americans with Disabilities Act (28 CFR 36 et al); the Rehabilitation Act (45 CFR 84 et al.) the Mental Health and Developmental Disabilities Code (405 ILCS 5/2-100 and 102) and Vocational Regulations in the Illinois Administrative Code (59 IL ADC 119 et al.)

Investigation Information

According to the complaint, several individuals were excluded from attending a spring dance that had previously been open to all recipients of services. When staff were questioned as to why some were excluded, the responses seemed discriminatory in nature. The issue of adequate treatment was also raised because some recipients had social goals in their treatment plans and by being excluded from the dance; those recipients had lost an opportunity to work towards attaining their social goals. Although this complaint involved several recipients, the HRA was only able to attain releases of information from 6 of the individuals' guardians. Therefore, our investigation will focus on those specific individuals and their treatment plans in place.

I. Interviews:

A. Caseworkers: Upon receipt of the complaint, the HRA contacted a community case coordination agency that has several caseworkers involved in the recipients' care. The caseworkers attend treatment meetings where individual service plans (ISP) are developed and progress is monitored. They ensure that services are provided for the recipients. The caseworkers also conduct quarterly visits at the community integrated living arrangement (CILA) homes and day training (DT) facilities. The caseworkers serve as advocates for people

of all ages with developmental disabilities and mental illnesses. The caseworkers explained that this dance has been held annually for as long as they can remember and they had not previously had an issue with some recipients being allowed to go and others not. When the caseworkers questioned staff at the DT facility as to why some were not allowed to go, they were told that it was due to some not being able to feed or toilet themselves, they were non-ambulatory (in wheelchairs) and that the DT was short staffed that day and could not provide enough supervision for everyone. However, they later learned that other recipients with similar disabilities were allowed to go. One person in particular they mentioned is high functioning mentally, but has hand and arm restriction, is in a wheel chair and has to be fed and he was allowed to attend the dance. Another caseworker explained that one of her clients who had to stay at home loves music and would have loved going to the dance to hear the music but he was not allowed to attend. To her knowledge, none of the clients in his same CILA home were allowed to go due to PICA behavior (eating inedible things such as dirt or paint that have no nutritional value) even though house staff offered to go to the dance to provide additional staffing so that their clients could also attend. The caseworkers also mentioned another recipient who “had a major behavior” at the dance last year was allowed to go again this year. It was explained that the dance is held at a location separate from the DT facility, which is handicap accessible, and some of the recipients involved in this case are in wheelchairs so there was no elopement risk and lunches could have been sent to the dance for those on special diets just as they are when they attend DT.

Another concern the caseworkers mentioned was that approximately 2 weeks prior to the dance, some clients were instructed to bring a white T-shirt to DT so they could tie-dye them for the dance, however other clients who were not going to attend the dance did not get to tie-dye T-shirts. Additionally, at a recent ISP meeting, a guardian of an individual had asked about vacation days being taken away from her ward. The question was raised because they usually would go out of state on vacation and the guardian was concerned because now when they go, her ward would not get paid for that time. The DT staff explained that vacation days were being eliminated because they were going to have more “fun days” and activities in lieu of vacation days so that more money could be “in the pot” for activities. However, when they plan these activities such as the dance, they did not include all of the clients. The HRA inquired about other activities that are done at DT and it was explained that they have parties every holiday which usually consists of DT staff bringing in cookies, cupcakes or McDonald’s food that day. Some of the Coleman DT facilities also took clients across the street to a gas station to get coffee or soda, some also go to a fast food restaurant or the dollar store to shop, but other Coleman DT facilities did very little. The caseworkers mentioned a “haunted forest” fundraiser that is held at Halloween time by the DT; some of the recipients are allowed to go to that and some help make decorations for it. The HRA inquired if the recipients who were not allowed to go to the dance had an alternative activity they were offered to attend that same day and the caseworkers stated that there was no alternative, if they did not attend the dance they stayed at home that day. The HRA questioned if community or social goals were in the ISPs of these individuals. All of the recipients involved in this case have social goals in place. According to the ISPs the home is responsible for the community/social goals and DT is responsible for meeting their vocational goals but the DT facility is aware of the community/social goals and they are to reinforce them at DT. It was explained that community outings logs used to be kept but now they do not keep logs on 2 of the 4 individuals we discussed. Two of the DT facilities don’t generally have outings

other than going to the gas stations and fast food but only the “higher functioning” wards get to attend those. The 4 individuals we discussed with the caseworkers do not attend any outings other than the dance. They went last year and the house manager reported to the caseworkers that they had a good time. The caseworkers also mentioned that Coleman DT had asked for it to be placed in the ISP that their clients did not want to attend the dances, but the caseworkers refused to agree to include that in the treatment plans because their clients might change their mind/preferences from one event to another.

B. Executive Director (Director): The Director explained that her role is to oversee all the programs which include vocational, respite, early intervention, visually impaired, CILA and day training (DT) programs. She also carries a small caseload. The DT serves approximately 70 individuals at 3 locations. One is a “working” site and the other two are mostly activities as most are not interested in work but the option is there should they choose to work. She has 14 staff members at the DT site we visited that organizes the dance. Another location has 9 staff and the third location has 17 staff. The Director explained that each site plans its own activities and she is involved in that. The DT activities she described to the HRA included this dance which has been held once a year for 9 or 10 years, fundraising events for client activities and to cover the cost of a big Thanksgiving and Christmas meal, they have a picnic, play bingo and attend local fairs. There was no alternative activity offered the day of the dance because the DT facility closes due to all of the staff attending the dance to help with recipients as some are on 1:1 supervision that day due to space and a meal being served. The building was described as one open room therefore if a recipient would have a maladaptive behavior, there is no separate room they can be taken to in order to calm down. This year approximately 150 people total attended the dance, 30 were staff and the rest were recipients. The dance is held at a community building; they decorate and have a Disc Jockey play music and recipients can dress in theme if they choose. The Director stated that some recipients did choose to tie dye T-shirts for this dance. When questioned as to why some attended and others did not, the Director explained that some of the recipients’ guardians did not want them to attend the dance. All recipients have been tried at the dance more than once and either had maladaptive behaviors or did not like the strobe lights; some are medically fragile, one had PICA and the guardian agreed to not have him attend, and one client was fairly new and did not care if she went so she stayed home with family. She had not previously been tried at the dance due to having severe behaviors to the extent that other DT facilities won’t accept her. When the HRA inquired as to 4 specific individuals that were involved in this case as to why they did not attend, the Director offered the following explanations: Recipient 1 has attended the dance off and on from 2003 – 2012 and requires 2 staff for a safety issues due to PICA, has seizures and a maladaptive behavior of spitting. His overall age equivalent is 9 months. At DT he typically chooses to stack blocks on the floor. Recipient 2 had attended the dance in 2013 and 2014 and had no reaction and was not really interested in it. Recipient 3 also has seizures, had also attended the dance in 2013 and 2014 and did not enjoy it. Recipient 4 attended the dance in 2011 and crawled on the floor and people fell over him. He was not interested in being there.

C. Home Staff: The HRA contacted several staff at different CILA homes. The first staff person stated that one of the clients was able to go to the dance but the rest stayed at home, no reason was given as to why one could go but the others could not. Previously, all clients had attended. The staff person stated that the clients left at home had not previously had any maladaptive

behaviors when attending the dance in prior years. The staff person stated that no notice was given ahead of time that some would not be able to attend. The staff person could not remember for certain, but stated as memory serves, none of those left at home had any maladaptive behaviors that were out of the ordinary that day but stated that the behavior plan goal sheets should have it documented if they did. The typical maladaptive behaviors of the recipients involved in this case were explained as self-injurious behavior, one has PICA but none are physically aggressive. When questioned about DT activities, this staff person stated that they are typically off campus approximately 1 or 2 times per year. When the HRA inquired if any of these recipients had social integration plans, the answer was, yes. One example was that the recipient would choose an outing to the best of his ability at least once per month but the home staff tries to take him out weekly. It is primarily the home's responsibility to help the recipients work towards their community/social goals.

The next staff person stated that a fax was received from the DT facility approximately a week prior to the dance advising of when it was scheduled and notifying the home to have the recipients ready to go that morning. This staff person thought all recipients in the home were going, but found out the morning of the dance upon reporting to work that three were left at home. When questioning other staff as to why, they stated that no explanation was given to them, just that one could go and the others could not. The staff immediately contacted a supervisor at the DT facility to inquire as to why the others were not going and was told that they were short staffed that day. This staff person explained to the supervisor that if prior notice had been given, arrangements would have been made for home staff to attend the dance so that all of the recipients could attend. The supervisor apologized and stated that they would try to touch base better next time. This staff person proceeded to contact other home staff to see if anyone was available to attend the dance but was unsuccessful so the Qualified Intellectual Disabilities Professional (QIDP) of the home was called in to work and this staff person and the QIDP stayed at home with the three recipients who were left behind. This staff person did not recall any out of the ordinary maladaptive behaviors from the recipients at home that day.

A staff person at a different CILA home stated that three of the recipients in their home were not allowed to attend the dance. It was explained that workers at the home received a call from the day training workshop that three recipients would not be attending the dance, but no reason was given. The workers could not recall the name of whom they spoke with at the workshop. There was one recipient from that home who was allowed to attend but that person was picked up and driven to workshop, like a typical day, and then left from workshop to go to the dance. This staff person contacted the CILA home manager about the situation and was told that the home staff could take the recipients to the dance, however this staff person was alone at home with the three recipients who were left behind and could not provide adequate supervision of them alone at the dance. This staff person took the three who were left at home on an outing in the van to get ice cream and drove around the community. This staff person did not follow up further on the dance situation because a case worker stated that she would take care of it with workshop staff.

The CILA home manager was also contacted. It was explained to the HRA that the manager was aware that two of the recipients were not going to the dance due to "being total care" so it was assumed that they were left behind due to a "safety issue." The manager did

speak with the home supervisor about the other recipients not being allowed to attend the dance. The supervisor did not know why those recipients could not go and they both were unsure as to whether or not those left behind had attended the dance in the past or not because they were fairly new. The home manager stated that staff could take those left behind to the dance but was told there was not sufficient home staff to provide adequate supervision because no prior notice was given so that arrangements could have been made for staff coverage at the dance. The home manager assumed that the primary reason for some not being allowed to attend was due to budget/funding cuts to staff so it was a “staff issue” primarily. One house manager did attend the dance to provide assistance to another female recipient who was “having an issue” at the dance so that she could stay at the dance. The home manager stated that the supervisor at the DT facility was contacted after the fact and they discussed the communication breakdowns that occurred and agreed that they would work toward having the dance more organized in the future.

D. Guardians: The HRA questioned the state guardian for these individuals who indicated that she did not request that any of these 4 recipients not be allowed to attend the spring dance. This guardian also confirmed that some of her other wards in wheelchairs who have higher mental functioning as well as wards with significant maladaptive behaviors did attend the dance.

E. DT Manager: The HRA spoke with the DT manager and asked about the decision to exclude some recipients from attending the dance. It was explained that the decision was made by herself, another staff member and was approved by the Executive Director. All recipients had gone to the dance previously and either did not act like they enjoyed the dance or they had behaviors. Specific behaviors from previous years were noted as one “ate off the floor”, one “went across the table” and the others “were nervous.” She explained that they had been having this annual dance since approximately 2006 and had never had any issues in the past with recipients being excluded. She stated that in years past, those not attending the dance attended DT and had the same food at DT as they were serving at the dance and had special activities that day. This year she was unable to do that due to having 5 less staff than in previous years. The Manager also explained that another DT staff called the CILA homes on April 22nd and told staff there who would not be attending the dance. A memo was also sent on April 20th to the homes advising them when the dance was and that memo included a note to the bus company that stated what recipients would not be attending the dance. The secretary prepared the memo so the HRA spoke with her also and she told the HRA what the memo said and stated that a hand written note was at the bottom to the bus company advising which recipients would not be picked up that day. She could not recall if the handwritten note was included in the fax when it was sent to the CILA homes. The DT Manager did say that after the fact the CILA home manager spoke with her and stated that residential staff would have attended the dance to help if advance notice would have been given. They agreed to have better communication in the future. The HRA did receive and review a copy of the fax that was addressed to consumers and the bus company from the secretary dated April 20, 2016 which stated that the dance would be held on April 26th and it states “all consumers will be picked up at regular time and returned home at regular time...” This memo also described the theme for this year and what food would be served. There was a hand written note at the bottom that was addressed to the bus driver which listed which people from each home would not be on the bus for pick up and drop off that day. All consumers involved in this complaint were listed as staying at home.

A follow up call was made to the CILA home staff. The first home's staff explained that they did get a memo via fax but that person did not recall if specific names of who would not attend the dance were hand written on the memo when they received it. That staff searched for the memo but did not find a copy that had been retained. The next CILA home's staff did not receive a fax and stated that if another staff had received it, it was missed by her but other staff in the home did not mention receiving a memo, just that they received a call the day of the dance stating that 3 recipients would not be attending the dance. She also pointed out that the recipients in this CILA home were on their way to board the bus for the dance before staff was told that they would not be attending; therefore she assumed that no one else had received a fax advising who would not attend. The final CILA home's staff that the HRA spoke with stated that they did know approximately one or two days ahead of time that some of their recipients would not be attending the dance. The exact method of notification could not be recalled, but she stated that she thinks it was via a note in the communication book from DT. Staff coverage for this day was not an issue because this home has some clients that do not attend DT so they always have staff throughout the day.

II. Chart Review:

A. Recipient Charts: Recipient 1 has diagnoses that included severe/profound mental retardation, Angelman's syndrome, seizure disorder, carnitine deficiency, hypothyroidism; PICA; Aggressive behavior; anxiety; and excess salivation related to severe/profound MR. His IQ is estimated at 21 with a functioning level of approximately 5 months. He is in the Pre-vocational skills program 5 days per week. He has goals of being cooperative and attempting an assigned vocational task at 95% of trials with 1 verbal cue and 1 physical assist for 3 consecutive months. He was unable to achieve this goal due to inconsistent progress, throwing training materials, and frequent absences due to illness. A future goal recommendation was listed in the Annual Review of Goals as "*continue improvement shown in completing a vocational task without throwing program materials. Follow simple instructions. Personal Living Skills: Toileting, Grooming, Social Interaction.*" He was able to learn a new task of assembling a tumbler. His annual DT staffing notes state that he may be fed by staff if he is unable to feed himself with a regular spoon. He also uses a sippy cup and has directives to cut his food in small bite size pieces and to use a gait belt at all times when ambulating. It was noted in staffing notes that he likes music. Behavior data shows a decrease in maladaptive behaviors that were being monitored as follows: spitting went from 175 to 73 times; chewing fingers went from 75 times to 59 times and inappropriate behavior went from 90 times to 16 times in 3 weeks' time of data collection. PICA was documented at 6 times and mouthing at 28 times but it was noted that 20 times was in the first day he moved in. The Functional/Vocational Assessment Report stated under the community activities/special events/cultural education section that this recipient "*appears to enjoy the seasonal decorations and parties within the program; he smiles and becomes excited...*" This section also noted that he does not always actively participate in activities offered. The Individual Service Plan (ISP) lists his overall objective/goal as "*to develop personal living, social and community orientation skills, knowledge and attitudes that will allow [name] to lead a happy, self-sufficient and socially responsible life in the least restrictive environment.*" Some of his "must haves" are listed as help with PICA, Spitting and Inappropriate playfulness; staff assist with a gait belt when on his feet, assistance getting dressed, bathing and other ADL's, including assistance when eating. Some of his "strong preferences"

are listed as *“I like to watch music videos and commercials on TV...I like to dance...”* It was also noted in the ISP that this recipient’s medical condition has been stable, with no major medical concerns noted. Under the social service/behavior section it stated that the recipient enjoys any TV program or video with music and will stop what he is doing while the music is playing. His community integration long term goal is to *“choose a place to go in the community that interests him 100% of trials with 1 verbal cue across 3 consecutive months by 1/13/17”* The short term goal is to *“choose between 2 places in the community to visit 25% of trials with 4 verbal cues across 3 consecutive months.”* Monthly activity sheets documenting what specifically this recipient participated in were not found.

Recipient 2 has diagnoses which included profound mental retardation, convulsive disorder, spastic Quad, developed language disorder and cerebral palsy. His level of functioning is described as having an IQ of 17 with an overall age equivalent of 4 months. His overall objective/goal is listed as *“to develop personal living, social and community orientation skills, knowledge and attitudes that will allow [name] to lead a happy, self-sufficient and socially responsible life in the least restrictive environment.”* He attends the DT In house program at the facility. His ISP contained a community integration goal of *“will show preference between two places in the community, the park and a retail store, by refraining from tapping his mouth with his hand repeatedly 25 times or less per one minute period with 4 vc [verbal cues] and 4 pc[physical cues]per month consistently over a 3 month period.”* The plan stated that whichever location the recipient showed fewer instances of self-injurious behavior (SIB) is the one that he prefers. There were also data collection sheets to document instances of SIB in his care plan; no other behavior plans were found in the ISP. His non-negotiables (must have) includes custom made wheelchair, in an upright position while eating with chin tucked, help with behavior to prevent self-injury, total assistance in all self-care areas, and pureed food due to choking risk. His strong preferences included built up coated spoon and plate, hand over hand for eating, van rides, and going to the park. The plan stated that the QIDP is responsible for implementing this recipient’s goals. The DT facility also had monthly activity notes for this recipient. Monthly activity notes were found for this recipient. In February no community outings were documented; other activities included movies, sensory activities, and holiday parties. The comments section noted a Valentine’s Day party at DT. In March, no community outings were documented; activities included movies, sensory, leisure, and music programs/therapies, cultural education and holiday parties. The comments section noted a St. Patrick’s Day party and Easter [illegible] singing. The April activity notes documented participation in movies, sensory and music program/therapy, there were no community outings. In May, activities included movies, sensory and the comments section noted talking books, and banana splits. Again, no community outings were documented. In June, this recipient participated in movies, sensory activities, cultural education, Flag Day and client management. There were no community outings documented.

Recipient 3 has diagnoses that include profound mental retardation, severe epilepsy, encephalopathy due to prematurity and spastic quad. His level of functioning is listed as within the profound range of mental retardation. His IQ is 19 with an overall age equivalent of 4 months. His overall objective/goal is listed as *“to develop personal living, social and community orientation skills, knowledge and attitudes that will allow [name] to lead a happy, self-sufficient and socially responsible life in the least restrictive environment.”* His non-negotiables (must

have) included custom made wheelchair, extensive help with things like dressing, eating, bathing, etc., and pureed diet with total staff assistance. His strong preference included playing peek-a-boo, watching TV, van rides, and listening to music and TV. This recipient is nonverbal and it was noted that he does not consistently respond to conversational level of speech and is unable to cooperate with any thorough testing. It was noted in his social service/behavior section that he prefers to sit alone in a quiet place and does not enjoy group activities but rather to sit by himself and listen to music, TV etc. No reason is documented as to how this determination came about (ie maladaptive behaviors in group settings etc...). It was noted that he is not on any behavior development plan at this time. It was documented that he is completely dependent upon staff for all ADLs (activities of daily living) and needs complete staff assistance for bathing and eating. His community integration goal states that he *“will cooperate with 4 sensory stimulation activities in the community for a total of 2 minutes per activity at 60% of trials per month consistently over a 3 month period.”* The QIDP of the home is responsible for the review of the goals. His individual activity schedule for his DT room documented that he is to work on the following skills while at DT from 8:00 a.m. to 3:00 p.m.:

Functional: following instructions; eating skills

Program Awareness: client management; client focus council; entitlements; sensory activities; human relations; safety; cultural diversity

Daily Living/Independent: Toileting schedule

Community Development: pedestrian safety/outings

Vocational: vocational skills/tasks

Mobility: Alternative positioning; exercise/chair; recliner

Leisure: Talking books; crafts; art; group activities; music therapy

The activity schedule for his classroom at DT stated what general activities the class would work on as a whole and during what time during the day but not specifically how they would work on them. For example, from 9:30-10:15 on Monday the schedule listed attendance, nail care, break, task, communication and toileting. From 10:15-1:00 the schedule listed money skills, sensory, lunch, leisure, activities, toileting pre-vocational task. From 1:00-2:30 the schedule listed exercise, leisure and toileting. Monthly activity notes were kept on this recipient at the DT facility. In February, this recipient had one community outing for Pedestrian Safety skills; worked on craft project/special event decorations, movies, sensory, music program/therapy, leisure, holiday parties, sports/exercise; addressed safety and cultural education and provided client management.

Recipient 4's diagnoses included profound mental retardation, growth failure, scoliosis, peg tube, SIB and anxiety. His level of functioning was documented as being within the severe range of mental retardation with an IQ of 23. His overall age equivalent is 5 months. His non-negotiables (must haves) include attending DT training, assistance with meals and ADLs, have depends on at all times, and being upright for an hour and a half after his tube feeding. His strong preferences include going on van rides in the community and lounging in a rocker or in pajamas. His community integration goal is listed as *“go into the community at least once per month and possibly purchase something if he goes to a retail shop 50% of trials across 3 consecutive months.”* His speech and language development section stated that his communication level is limited to hand over hand sign language. He knows his immediate environment by crawling and feeling for the chair he wants. He does have a behavior support

plan in place for SIB of hitting himself in the head or striking his head against objects like the walls. It is documented that this behavior typically occurs when his wishes/demands are not met or the word, no, is used. He also exhibits SIB when he has difficulty communicating his desires or as a means of escape. Monthly DT activity notes were found for this recipient. In April of 2015 it was documented that he did attend the spring dance and no comments were listed as to him having any difficulty with attending. In January, 2016 activities he participated in were documented as New Year's Day, movies, sensory, individual project, leisure, exercise, safety, music program/therapy, client of the day, senior programming and client management.

Statutes & Definitions

Americans with Disabilities Act (ADA) regulations (28 CFR 36.201) prohibit discrimination on the basis of disability and in the receipt of services and states *“No individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any private entity who owns, leases (or leases to), or operates a place of public accommodation.”* Section 36.104 defines public accommodation as *“Public accommodation means a private entity that owns, leases (or leases to), or operates a place of public accommodation.”* Section 36.202 states this about activities *“(a) Denial of participation. A public accommodation shall not subject an individual or class of individuals [on the basis of a disability or disabilities of such individual or class, directly, or through contractual, licensing, or other arrangements,] to a denial of the opportunity of the individual or class to participate in or benefit from the goods, services, facilities, privileges, advantages, or accommodations of a place of public accommodation. (b) Participation in unequal benefit. A public accommodation shall not afford an individual or class of individuals ... with the opportunity to participate in or benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to other individuals. (c) Separate benefit. A public accommodation shall not provide an individual or class of individuals...with a good, service, facility, privilege, advantage, or accommodation that is different or separate from that provided to other individuals, unless such action is necessary to provide the individual or class of individuals with a good, service, facility, privilege, advantage, or accommodation, or other opportunity that is as effective as that provided to others.”*

The Mental Health and Developmental Disabilities Code (405 ILCS 5/2-100) guarantees that *“No recipient of services shall be deprived of any rights, benefits, or privileges guaranteed by law, the Constitution of the State of Illinois, or the Constitution of the United States solely on account of the receipt of such services..”*

The Code (405 ILCS 5/2-102) states that *“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. The Plan shall be formulated and periodically reviewed with the participation of the recipient to the extent feasible and the recipient's guardian, the recipient's substitute decision maker, if any, or any other individual designated in writing by the recipient”*

The Administrative Code (59 IL ADC 119.100) requires that *“Developmental training programs shall prepare adults 18 years of age or older who are developmentally disabled to live and function in integrated social settings.”* Section 119.205 provides that *“A minimum level of*

skill development shall not be required for entry into a program... At least annually, the team shall assess the individual's skill level and review the current placement to determine if it is meeting the individual's needs”

Section 119.120 defines exclusion as “*Preventing an individual's entrance or continuation in a program due to the individual's disability, medical condition, or maladaptive behavior, or due to lack of space in the day program.*” Section 119.210 states that “*a) Exclusion, suspension or discharge may occur due to:*

- 1) The individual's desire to stop participation;*
- 2) The individual's attainment of the exit criteria;*
- 3) The individual's physical disability or medical condition which places the individual in danger; or 4) Maladaptive behavior that places the individual or others in serious danger....*

c) The provider shall refer all proposals excluding, suspending or discharging an individual to the team which shall determine whether the criteria in subsection (a) of this Section have been met, recommend alternative services and determine the criteria under which the individual may enter or re-enter the program.

d) Before exclusion, suspension or discharge, the team shall discuss, summarize and place in the individual's record the date and reason for this action.

e) A provider shall not suspend or discharge an individual from a program without at least a 10-day written notice to the individual or guardian except when it is documented that the individual is dangerous to himself or herself or others and the behavior cannot be corrected through special training procedures.

f) An individual shall have the opportunity to appeal to the agency representative the provider's decision to exclude, suspend or discharge him or her in accordance with the procedures required in Section 119.235(e) of this Part”

Section 119.215 requires the following staff ratios “*1) the provider shall maintain staff ratios that will meet the individual's program needs. The Department's calculation of provider cost is based on the following ratios, but the provider will be given flexibility in grouping individuals to meet the individual's needs.*

A) For individuals who have mild deficits in adaptive behavior as defined in Classification in Mental Retardation...and who have physical disabilities, mental disabilities or behavior disorders, the provider shall maintain on-duty trainers and instructors at a ratio of 1:10.

B) For individuals who have moderate deficits in adaptive behavior as defined in Classification in Mental Retardation and who have physical disabilities, mental disabilities or behavior disorders, the provider shall maintain on-duty trainers and instructors at a ratio of 1:8.

C) For individuals who have severe or profound deficits in adaptive behavior, as defined in Classification in Mental Retardation and who have physical disabilities, mental disabilities or behavior disorders, the provider shall maintain on-duty trainers and instructors at a ratio of 1:5.

D) The provider may request additional staff for individuals whom the team has assessed and who require and who are receiving specialized services stated in one of the following levels:

i) *Level I. For individuals requiring and receiving staff assistance for the following specialized care: aids or appliances for visual or auditory deficits or both; aids, appliances or equipment for physical disabilities; in dwelling catheterization; insulin injections for stabilized diabetics; cardiovascular or respiratory medications and multiple daily monitoring; incontinence care and assistance in personal care; seizure medication and monitoring of unstable condition; or a moderately serious level of maladaptive behavior as measured by the Inventory for Client and Agency Planning (ICAP) (DLM Teaching Resources, One DLM Park, Allen, Texas 75002, 1986);*

ii) *Level II. For individuals requiring and receiving staff assistance for the following specialized care: personal care and assistance with transfer and movement about the facility; insulin injections for diabetics who are not stabilized; ostomy care; or a serious level of maladaptive behavior as measured by the ICAP; or*

iii) *Level III. For individuals requiring and receiving staff assistance for the following specialized care: intermittent catheterization; wound care; respiratory care; tracheotomy care; tube feeding; or a very serious level of maladaptive behavior as measured by the ICAP.”*

Individual services plan is defined as “A written plan which includes an assessment of the individual's strengths and needs, a description of the services needed regardless of availability, objectives for each service, the role of the individual, guardian, significant others, and the family in the implementation, if the individual agrees to their participation. The plan shall also include a timetable for the accomplishment of objectives, and the names of the persons responsible for their implementation.” Section 119.230 requires that a individual services plan is developed within 30 days of admission to a program and requires the following “g) *At least monthly, the QMRP shall review the plan and document in the record that:*

1) Services are being implemented; and

2) Services identified in the plan continue to meet the individual's needs or require modification or change to better meet the individual's needs.

h) The team shall review the plan, at least annually, and shall note the status of the individual including any progress or regression which might require modification to the plan.”

Section 119.235 addresses individual rights and states that (the purpose is) to “*insure that individual's rights are protected and that all services provided to the individual comply with the laws cited in subsections (a) and (b) of this Section, providers shall assure that:...e) providers have procedures that permit the individual or guardian to present grievances and to appeal decisions to deny, modify, reduce or terminate services up to and including the authorized agency representative...g) the individual is **not excluded**, suspended or discharged from services **and services are not reduced for exercising any of his or her rights.***”

The Rehabilitation Act of 1973 (45 CFR 84.4) prohibits discrimination and states “*No qualified handicapped person shall, on the basis of handicap, be excluded from participation in, be denied the benefits of, or otherwise be subjected to discrimination under any program or activity which receives Federal financial assistance. Section 84.3 defines recipient as “any state or its political subdivision, any instrumentality of a state or its political subdivision, any public or private agency, institution, organization, or other entity, or any person to which Federal*

financial assistance is extended directly or through another recipient, including any successor, assignee, or transferee of a recipient, but excluding the ultimate beneficiary of the assistance.”

(b) Discriminatory actions prohibited.

(1) A recipient, in providing any aid, benefit, or service, may not, directly or through contractual, licensing, or other arrangements, on the basis of handicap:

(i) Deny a qualified handicapped person the opportunity to participate in or benefit from the aid, benefit, or service;

(ii) Afford a qualified handicapped person an opportunity to participate in or benefit from the aid, benefit, or service that is not equal to that afforded others;

(iii) Provide a qualified handicapped person with an aid, benefit, or service that is not as effective as that provided to others;

(iv) Provide different or separate aid, benefits, or services to handicapped persons or to any class of handicapped persons unless such action is necessary to provide qualified handicapped persons with aid, benefits, or services that are as effective as those provided to others;

(v) Aid or perpetuate discrimination against a qualified handicapped person by providing significant assistance to an agency, organization, or person that discriminates on the basis of handicap in providing any aid, benefit, or service to beneficiaries of the recipients program or activity;

(vi) Deny a qualified handicapped person the opportunity to participate as a member of planning or advisory boards; or

(vii) Otherwise limit a qualified handicapped person in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.

(2) For purposes of this part, aids, benefits, and services, to be equally effective, are not required to produce the identical result or level of achievement for handicapped and non-handicapped persons, but must afford handicapped persons equal opportunity to obtain the same result, to gain the same benefit, or to reach the same level of achievement, in the most integrated setting appropriate to the person's needs.

(3) Despite the existence of separate or different aids, benefits, or services provided in accordance with this part, a recipient may not deny a qualified handicapped person the opportunity to participate in such aids, benefits, or services that are not separate or different.

(4) A recipient may not, directly or through contractual or other arrangements, utilize criteria or methods of administration (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity

with respect to handicapped persons, or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common administrative control or are agencies of the same State.

(5) In determining the site or location of a facility, an applicant for assistance or a recipient may not make selections (i) that have the effect of excluding handicapped persons from, denying them the benefits of, or otherwise subjecting them to discrimination under any program or activity that receives Federal financial assistance or (ii) that have the purpose or effect of defeating or substantially impairing the accomplishment of the objectives of the program or activity with respect to handicapped persons.

(6) As used in this section, the aid, benefit, or service provided under a program or activity receiving Federal financial assistance includes any aid, benefit, or service provided in or through a facility that has been constructed, expanded, altered, leased or rented, or otherwise acquired, in whole or in part, with Federal financial assistance.

(c) Aids, benefits, or services limited by Federal law. The exclusion of non-handicapped persons from aids, benefits, or services limited by Federal statute or executive order to handicapped persons or the exclusion of a specific class of handicapped persons from aids, benefits, or services limited by Federal statute or executive order to a different class of handicapped persons is not prohibited by this part.”

Conclusion

The first allegation was that recipients were discriminated against based on their disabilities. The specific allegation was that several recipients were allowed to attend a spring dance while others were not due to being in wheelchairs and/or needing full care. According to the Director, the four individuals involved in this complaint have attended the dance off and on from 2003–2015. Some explanations given for these four not attending the dance this year are as follows: one recipient requires 2 staff for safety issues due to PICA and has a maladaptive behavior of spitting; another recipient had no reaction and was not really interested in the dance; another recipient has seizures and did not enjoy the dance in previous years when he attended; and, the fourth recipient crawled on the floor and people fell over him hence causing safety issues for others attending and the Director stated that he was not interested in being there. Upon review of their charts, only one had documentation of attending the dance in previous years. It was not documented that he had any problems the previous year while attending the dance such as maladaptive behaviors to indicate he did not enjoy it, and there was nothing indicating he caused any safety concerns for others in attendance. The charts documented that all of these recipients were noted to be in the severe/profound level of mental retardation and were nonverbal. The caseworkers stated that some other individuals with similar physical disabilities, but higher mental functioning, were allowed to attend the dance. The guardians of these individuals indicated that they did not ask that their wards not be allowed to attend the dance nor were the guardians consulted on any decisions related to participation. It was documented in the ISPs that some these individuals either like to dance, enjoy music videos or listening to music and one chart noted that the recipient would stop what he is doing while the music is playing. One recipient did have documentation that he does not enjoy group activities, but it was not stated as to how that determination was made and it was noted that he did not currently have a behavior plan in place for any maladaptive behaviors. Some people interviewed mentioned that

low staff levels were the reason for exclusion. However, section 119 of the Administrative Code requires staff ratios for clients with moderate deficits in adaptive behavior be 1:8 and individuals who have severe or profound deficits in adaptive behavior be 1:5. The Director stated that approximately 150 attended the dance which includes 30 staff which provided a staff to client ratio of approximately 1:4.

Everyone interviewed concurred that there were no alternative activities at the DT facility that day and that individuals who did not attend the dance just stayed at home. The ADA (28 CFR 36.201) ensures equal participation by stating that “A *public accommodation shall not afford an individual or class of individuals ... with the opportunity to participate in or benefit from a good, service, facility, privilege, advantage, or accommodation that is not equal to that afforded to other individuals...*(c) *Separate benefit. A public accommodation shall not provide an individual or class of individuals...with a good, service, facility, privilege, advantage, or accommodation that is different or separate from that provided to other individuals, unless such action is necessary to provide the individual or class of individuals with a good, service, facility, privilege, advantage, or accommodation, or other opportunity that is as effective as that provided to others.*” The Rehabilitation Act of 1973 (45 CFR 84.4) also prohibits discrimination by including the following as discriminatory actions that are prohibited “*Otherwise limit a qualified handicapped person in the enjoyment of any right, privilege, advantage, or opportunity enjoyed by others receiving an aid, benefit, or service.*” The Mental Health Code guarantees the right to adequate and humane care and services pursuant to an individual services plan with input from the recipient and guardian. Section 119.100 of the Illinois Administrative Code includes reference to integrated social integration in developmental training programs and Section 119.205 states that no particular skill level is required for general entry into a developmental training program. It appears that individuals with certain, similar characteristics were not included in a Center sponsored social event, nor were their interests honored pursuant to their ISPs, nor were their guardians consulted as per the Mental Health Code and no alternate comparable social activity was offered; all of this appears inconsistent with provisions of the ADA and Rehabilitation Act, the Mental Health Code and Rule 119. Therefore, this allegation is **substantiated** the following **recommendations** are made:

- 1. In the future, if there are events scheduled that might not be of benefit to or enjoyed by all individuals served, the treatment team should discuss this ahead of time, referencing the individual’s ISP preferences and involving the individual/guardian, and place in the individual's chart the date and reason for exclusion consistent with treatment planning provisions of the Mental Health Code (405 ILCS 5/2-102) as well as social integration programming referenced in the Administrative Code (59 ILADC 119.100.)**
- 2. When future events are scheduled that not all individuals served will be participating in (after discussion with the treatment team), the facility should offer an alternative activity for those individuals that is equally effective as the opportunity provided to others as required by the ADA (28 CFR 36.201).**

The following **suggestions** are also offered:

1. The HRA was concerned after discussion with the CILA home staff that although some stated they were notified ahead of time that some individuals would not be attending the dance, other CILA home staff were not notified until that day. This left some of the CILA homes understaffed for that day for the number of recipients who were left at home that are normally gone to day training during those hours. In the future, the DT managers should have better communication with the CILA home managers/staff when planning special events that might affect the home staff scheduling in order to prevent possible safety issues for both staff and residents.
2. Some people interviewed by the HRA were concerned that this complaint might prevent the dance, which has been held annually for at least 9-10 years, from being held in the future. The Director also mentioned to the HRA that they might not be able to hold this dance in the future if it is going to cause problems. Therefore, the HRA was also concerned that the event's continuation might be at risk due to the exercising of the right to file a grievance, which is a protected right under the Administrative Code (59 IL ADC 119-235). The HRA commends the program for sponsoring this event, which appears to be a client-favored means of meeting social integration requirements of Rule 119 as well as meeting the interests of so many clients.

The second allegation was that there was inadequate care and treatment. This allegation was a direct result of the first complaint alleging discrimination and was included for the HRA to explore if social goals were included in the ISPs of the individuals who were excluded from the dance. If so, the HRA wanted to investigate whose responsibility it was to implement programming to help achieve those goals and also to determine if treatment plans were not being followed by the DT facility to reinforce said social goals. The Rehabilitation Act of 1973 (45 CFR 84.4) includes the following as discriminatory actions prohibited “*may not, directly or through contractual or other arrangements, utilize criteria or methods of administration (i) that have the effect of subjecting qualified handicapped persons to discrimination on the basis of handicap, (ii) that have the purpose or effect of defeating or substantially impairing accomplishment of the objectives of the recipient's program or activity with respect to handicapped persons, or (iii) that perpetuate the discrimination of another recipient if both recipients are subject to common administrative control or are agencies of the same State.*” Upon investigation, the HRA learned that all these recipients did have some type of social/community integration goals in their ISPs. However, everyone interviewed concurred that it is primarily the CILA home's responsibility to help recipients work towards achieving those goals by planning outings and activities although the DT facility is made aware of those community integration goals and are to reinforce said goals at day training as well. The HRA reviewed monthly activity notes for some of these individuals which showed activities aimed at reinforcing at least the social aspect of said goals. Therefore this allegation is **unsubstantiated**. The following **suggestion** is offered:

1. Not all of the recipients involved in this case had monthly activity notes in their chart documenting specific activities that they participated in. The only documentation was what their classroom did, in general, which did not indicate whether or not those clients participated in classroom activities. It was explained to the HRA that a former employee was not properly documenting in recipient charts. However, no specific policy was in place requiring such documentation. The HRA suggests that staff involved in documenting activities be retrained on

the procedure required by administration of documenting specific activities or outings and that supervisors review charts frequently to ensure that proper documentation is in place. Administration should consider developing a formal policy for documentation of specific activities/outings which might prevent issues in the future if questions arise from treatment plans not being followed.