



FOR IMMEDIATE RELEASE

Egyptian Regional Human Rights Authority
Report of Findings
15-110-9012
Delta Center, Inc.

The Egyptian Regional Human Rights Authority (HRA) of the Illinois Guardianship and Advocacy Commission has completed its investigation concerning an alleged rights violation involving respite services provided by Delta Center, Inc. located in Cairo. There are approximately 45-50 families that are receiving respite services. The specific allegation is as follows:

The agency failed to provide adequate services for a child with a disability.

If substantiated, the allegation would be a violation of the Americans with Disabilities Act (28 CFR 35.130); and the Mental Health and Developmental Disabilities Code (405 ILCS 5).

Investigation Information

According to the complaint, a child with a disability was not provided with adequate respite services that had been approved. To investigate the allegation, the HRA Investigation Team, consisting of one member and the HRA Coordinator conducted site visits, spoke with the Executive Director of Delta Center, the child's mother, the child's school teacher and case worker.

I. Interviews:

A. Mother: The child's mother explained to the HRA that her son is non-verbal and has autism. He attends early education 2 hours a day for 2 days a week and the rest of the time it was up to her and her mother in law to care for him and stated that she "can't do everything". She stated that he was on a waiting list to attend a local autism center, however there was no way of knowing how long until he would be accepted. She stated that he had early intervention until he turned 3 years old which helped him tremendously, but now all he had was the early education at the local public school. The mother stated that she has had ongoing problems with the respite care provider, Delta Center, Inc. for the past year and a half prior to our interview. She stated that her son was approved by the grant funded program through the Department of Human Services 2 years ago to have up to 260 hours of respite care each year, resetting in July. She was told by the case coordination caseworker that the only agency to obtain a respite worker from in her area is Delta Center. She contacted them and obtained a respite worker that worked with her son for about 6 months. The mother stated she was very good and they had no problems with

her. However in July or August of 2013, that worker told the mother one day that it was her last day of work because she was moving. The mother stated she was given no prior notice from either the worker or Delta Center. At the time of our interview, her son had been without a respite worker for about a year and a half. The mother explained that since the Director that she had originally contacted at Delta Center left and the new Director took over, she has had several problems obtaining a replacement worker. She explained that her son is 5 years old and weighs about 60 pounds which, she stated, poses additional concerns regarding respite care workers because he has to be lifted frequently and the workers that Delta Center sent her to interview could not “physically handle” her son. One worker she interviewed stated she could not lift her son and also worked another job and could not work the hours needed. Another respite worker she thought would work out came and worked one day and offered to walk her son to the park but they were back in 10 minutes. Her son was crying because he had to come back home. The mother asked the worker if she wanted to continue working or if she needed to leave and she left. After that there were 3 or 4 workers that applied but the mother did not approve of them because they were older and she was afraid they could not lift her son. Delta Center told her that she needed to find someone that she knows who would be willing to do the job and they could apply through Delta to become his respite worker. The mother stated that her sister and mother in law applied along with 2 other workers but Delta Center stated that they never received the applications. She stated that her mother in law eventually became his respite worker but that took 8 months to accomplish. She stated that her mother in law applied in July, 2014 and became his respite worker in February, 2015.

B. Executive Director (Director): The HRA met with the Director who explained that Delta Center provides a number of services for the community. Some examples given were behavioral health services, residential services for people with mental illness, respite care, school counseling and community based youth services. For respite services, they receive referrals from a community case coordination agency, the program manager meets with the parent who completes an application for services and finally they look at the respite plan for the individual. There are exceptions to being approved for services: the client cannot be in the home based waiver program and the home environment has to be safe for the respite worker. Workers can be excluded due to location, hours of availability and finally, the respite worker has to agree to work in the home and the parent has to approve the worker. When hiring a respite worker, an application has to be submitted, they conduct a background check, screening and training prior to assigning them to a client. The respite workers receive orientation to the agency policies and procedures, reporting, confidentiality etc.. They also receive program specific training such as logging hours, reporting and the boundaries of services. Once these things have been accomplished, the supervisor and staff go into the home of a potential client at least one time, possibly more, to see what the client’s needs are and make sure everyone is comfortable. The majority of their respite workers are women and the facility has no policy stating that the parents cannot be in the home during the time that services are being provided.

The Director stated they currently have 45-50 people receiving respite care. She explained that their program has had a 32% reduction in funding since 2008. Since their funding is low, they cannot pay good wages for respite care workers. Therefore, they do not have many workers from which to choose. They have about 30-40 workers for 45-50 clients that need the services and most of the 30-40 workers are specific family members or friends that only work for

one particular client. She explained that they are the only agency in the lower 10 counties of the state that provides respite care.

She opened this child's case in February, 2013 and stated that he had a worker for approximately 6 months; 8/31/13 was the worker's last day. In September, 2013 the previous Director took in a new respite worker and the mother was upset because her child would not go outside to the park with the worker that day. Therefore, the mother stated that she would find her own worker but that never happened prior to the previous Director leaving the agency in December, 2013. In January, 2014 the mother emailed the Director stating that no worker had been provided; the Director explained that they were waiting to hear from the mother since she stated she would find her own worker. She explained that this happened throughout the entire time she was working with the mother, staff would attempt to contact her several times with no response then they would get an email from the mother wanting to know why nothing had been done. In February, 2014 the mother informed her that her mother in law was going to apply to be the child's respite worker and that she would be sending in her application. Approximately 6 days later, a worker was going to meet with the mother to be a temporary worker until the mother in law could become certified. After that meeting, the mother sent a "nasty email" about the meeting stating the lady was too heavy and too old to care for her son and she told them they were fired. The Director explained that the mother made the decision to deny the workers that Delta Center tried to provide, this worker in particular had no limitations on lifting and if she had temporary limitations she would not have been allowed to work. The workers that Delta Center sent as possible candidates were 57 years old, 68 years old and 58 years old. Approximately 7 days later, the Director sent a letter to the mother explaining that if she will be appropriate, then they will meet and discuss providing future services when her son was at school so they could talk. In March the Director contacted the mother again asking for the dates and times that her son was in school so they could meet because the mother had stated it would be easier to meet when he was in school. The mother never responded to that email. At the end of April, the mother contacted her stating that her sister would apply to become his respite worker. However, when Delta Center interviewed her, she stated that she did not want to do it but did not want to tell the mother that. She wanted Delta Center to tell the mother that she did not meet criteria. The Director explained that she could not do that but she would tell the mother that it did not work out and if she had further questions, she would have to contact her sister directly. From April through July the Director was trying to schedule a meeting with the mother but was unsuccessful. In July the mother in law went for finger printing and then turned in her application in September. The Director began processing it, however she stated that the mother in law was not sure if it was a good idea and asked that they delay hiring her until after she finished her semester of schooling. She started as the child's respite worker in February, 2015.

C. Teacher: The HRA met with the special education teacher at the public school. She has 25 years' experience in the special education field. She has had the child in her class for 3 years. He attends 5 days a week for 2½ hours each day. She stated that he has good attendance and only misses when he is sick. The child has the diagnosis of severe Autism and he is non-verbal. She stated that compliance was the first thing they worked on. He would scream, cry and run around the first year and a half but they worked on that behavior and it has improved. He is not aware of danger and was a risk to elope; therefore he had to have an adult with him at all times when he was at school. The teacher explained that the child is big for his age; he is 5

years old and weighs approximately 110 pounds but stated he is “not overweight just solid.” When she had him in her classroom, he weighed 60-70 pounds and it took 2 adults to lift him when needed. He had no social skills but enjoyed books and puzzles but that was about all he could do academically. His fine motor skills were not at his age level. He utilized Occupational Therapy (OT), Behavioral Analysis (BA) and Speech therapies at school. At the time of our interview, the child had graduated to Kindergarten and was attending full days, but could not be in the regular education classroom partly due to his verbal outbursts, so he was in the Special Education room all day. They are working on picture communication, but stated that he has a hard time with that.

The HRA questioned the teacher about the kind of relationship she had with the mother. She stated that the first year was the hardest and admitted that the mother can be quick tempered because she does not want the child to miss out on anything, but the teacher also felt like she and the mother had built a rapport over the 3 years she had this child in her classroom. The mother does not attend his IEP meetings but his grandmother, who is a social worker, does. Reportedly, his mother felt intimidated at the meetings and does not understand everything, so she just felt better if the grandmother attended the meetings. If the mother had any questions or concerns, she would call the teacher or talk to her during pick up time. The teacher stated that the child was always neat and clean and the mother seemed concerned about him and does the best she can for him, but it did not seem like he was “worked with” at home to improve skills but stated she had no concerns of neglect. She stated that he still takes a bottle at night because his mother said he sleeps better when he is given a bottle. She stated that he can feed himself and drinks out of a cup, which is a skill they taught him at school. He is a very picky eater, but is not on a special diet. The child is always happy to see his parents and grandparents when they pick him up and will run to them. The mother had expressed difficulty as the child gets older; he is quick, unaware of danger and does not respond to commands. She stated that the child did not respond to her at first but she had seen improvement, he now will get on the bus and walk quietly in the hallways. He does play independently but overall she felt like he had transitioned well to Kindergarten.

D. Caseworker: The HRA interviewed the case coordination worker over the telephone. She stated that her only involvement with this child was to put him on the Prioritization for Urgency of Need for Services (PUNS) list which is a statewide database that records information about individuals with developmental disabilities who are potentially in need of services. The State uses the data to select individuals for services as funding becomes available, to develop proposals and materials for budgeting, and to plan for future needs. Each year, the caseworker sends a letter to the mother to renew the child’s need to remain on the list; otherwise he has to be removed. She stated that Delta Center is the only agency in the area that provides respite services for state funded programs like the child has. She stated that she does not know who is in charge of the respite program now, but she does know of others that have complained about the services being lacking. She could not divulge those names to the HRA due to confidentiality reasons. She gave an example of one family who receives 3 days of respite care for their child and the family stays home with the child and respite worker. She did not believe this was using the program for its intended purpose, to give the family members a break. Then, there are families that are really stretched thin and stressed out that are not receiving needed services due to lack of respite workers available to provide those services.

II. Chart Review:

A...Application for Respite Worker: The HRA reviewed the sister's application for employment. There were no questions on the application form that asked about any restrictions or limitations, lifting or otherwise. The application included sections for employment history, educational background, references, criminal history, ethnicity, veteran status and a pre-employment inquiry release. The sister had written the following note in the "additional information you would like us to consider" section "*[name] is my nephew and his mom is my sister, very familiar with situation and would love to help them.*" The sister signed it and the mother witnessed the signature on the application.

B. Respite Client Activity Logs: The first log dated 3/30/15 was completed by the respite worker that the child had initially; her age was 58 at the time. This form documented that the visit was from 10:00 a.m. until 3:00 p.m. The child was in a happy mood, had a good appetite with hand over hand feeding; they played with his toys, watched television and went on an outing to the park. The worker also bathed him and brushed his teeth and hair. It was documented that the home was clean and the affect of the family is noted as relaxed mood. The second log dated 8/31/13 was completed by this same worker and documented the visit was from 9:00 a.m. until 1:00 p.m. It was noted that the child was in a happy mood and that they played in the back yard. The home was clean and the family was in a relaxed mood. The last log reviewed was dated 2/14/15 and was completed by the new respite worker, the mother in law. The visit was from 12:00 p.m. until 7:30 p.m. It was noted that the child was content and happy. They played, read books, watched movies, colored and completed puzzles. The home was noted to be clean and the affect of the family is listed as "NA" which the HRA assumed meant that they were out of the home.

C. Emails and interactions between the mother and Delta Center: The HRA reviewed several emails between the mother and Delta Center staff dated February, 2014 through April, 2015. The first email dated February 12, 2014 was a summary of attempted contacts by the previous Director to the mother which was provided to the current Director for historic purposes. The actual emails summarized in this one were viewed by the HRA as well to corroborate. The first documented notification from the mother that she was without a worker was on 1/20/14. The Director at the time replied stating she had no knowledge that she was without a worker and started coordinating days and times services were needed. The Director attempted to contact the mother 4 more times without success but was working on obtaining a worker and had documented that. On 2/3/14 the mother left her a voice mail and provided two other contact numbers. The mother had emailed the days she needed service to the main agency's account instead of the Director's email. On 2/4/14 the Director called one of the numbers provided and left a voice mail and the mother returned her call. This was the first and only time this Director was able to speak to the mother. During this conversation, the mother mentioned that her mother in law might be interested in becoming his respite worker and the two coordinated what was needed for her to apply. Later that night, the mother sent an email notifying the Director she had contacted her mother in law and stated the mother in law would call. On 2/5/14 the Director emailed the mother notifying her that she had no contact from the mother in law yet. The mother replied to the email at 7:30 p.m. and said she would follow up and wasn't sure why she had not

contacted them and stated she also had another person who might be interested. Therefore, the Director was waiting on information from the mother before pursuing a worker. Approximately 2 hours later the mother emailed again stating she did not think her mother in law was interested but asked the Director to contact her to make sure. The mother also stated that if her other person was no longer interested either, then she would “move onto a stranger that she doesn’t even know.” On 2/6/14 the Director left a message for the mother in law to call her back to let her know if she was interested or not. The next day the mother called and left a message with the secretary. She very upset because she did not have a worker yet. Staff informed her that they were still waiting to hear back from the mother in law or the other person the mother mentioned. The mother was informed that the Director would call back later that day. The Director attempted but was unable to reach the mother, however a clerical staff person later that day was able to reach the mother. On Sunday 2/9/14 the Director spoke with a respite worker who wanted more hours. Although this worker could not work every day after school due to her other job, she could work on Saturdays and some afternoons to help the mother. A pre-respite visit was scheduled for 2/12/14. On 2/11/14 the Director spoke with a community caseworker who also worked with this family and advised the Director that the mother had contacted them to get help stating that Delta Center had not done anything to help them with respite. It was explained that the agency had no control over the respite program and reminded her that it can take time to find a worker. The caseworker further discussed her difficulties working with the family due to an ongoing issue of not being able to get in touch with the family. They have 3-4 numbers but never answer any of them. That agency had a similar issue with the mother calling them upset because she felt like nothing was being done to help her and her son and wanted something done as soon as possible. On 2/12/14 the Director received a call that her staff and the potential respite worker were “chewed out and thrown out of the mother’s house by her.” The staff stated that the mother was very rude with the worker and upset that Delta did not bring more than one worker for her to choose from and was “just unhappy in general.” When the staff member made a suggestion that the mother consider talking to a counselor to talk through and deal with the stress she was experiencing, the mother was “greatly offended” and told them to leave her home; however, there were about 5 locks that had to be undone on the door in order for them to leave and the mother continued to scream at them to leave while they were attempting to do so. Later that same day, the Director spoke with the Executive Director who had also received several emails from the mother since the situation at her home had occurred. The situation was discussed and it was decided that Delta Center would not respond to any calls, emails etc... at that time and would save all messages left from that day forward and document the entire experience working with this family. The Executive Director was to contact the Developmental Disability Division of the Department of Human Services to discuss the case and would notify the family that at that time they would be unable to serve them based on the safety and security of their workers. The Director provided the HRA with copies of written accounts of the incident by both the respite worker and the Delta staff who attended this meeting.

The respite worker’s written account stated that the mother seemed frustrated and stressed upon arrival and was not happy with Delta Center. The worker stated that the mother talked bad about the former Director and was unhappy that she was still without a worker. She continued to say that the mother “*took one look at me and said I couldn’t take care of her son, she didn’t think I knew how to.*” The worker heard the mother mumbling in the other room and stated she would not give the staff person a chance to speak. Finally the staff informed the mother that the worker

had been with Delta Center for 10 years and had taken care of her own disabled son for 18 years. The worker noted that she had offered the mother different times she could work but the mother did not seem happy with them. She stated that the Delta Center staff person was nice and was attempting to help the mother with finding help and services but the mother was *“very rude”* to both of them. As they were about to leave, the mother became very angry and *“ordered us to get out of her house.”*

The worker’s written account documented that they arrived around 9:20 a.m. and could not get an answer at the door. The mother finally came to the door after the staff had called her telephone and stated they were still sleeping. She noted that although the mother had just woken up, she appeared *“very stressed”* and appeared *“agitated and frustrated throughout the meeting.”* The mother escorted them to the living room and immediately stated she did not think the worker was capable of doing the job because her son was a big boy and very difficult to manage. The mother stated that she was not happy with Delta Center due to a lack of a worker and then left them to go check on her son. Upon return, the mother again stated that the worker would not be able to do the job. She attempted to have the mother complete the training sheet regarding the routine and instructions, but noted that the mother was in and out of meeting the entire time and it was *“very difficult to keep mom on task with providing needed information as she was in and out of the living room and kept returning to her dissatisfaction with Delta Center and her disappointment in the choice of worker.”* It was also noted in her account, that the mother *“was clearly struggling with the amount of stress she was experiencing,”* therefore, when the worker stepped away to take an important phone call, the Delta staff suggested to the mother that she may benefit from counseling or stress management techniques. The mother was not pleased with these suggestions and stated *“How dare you come to my house and judge me; you don’t know what it’s like.”* The mother then asked the Delta staff why she had brought a *“fat, old woman”* to the meeting when it was obvious she could not do the job requirements. At that point, the staff person felt it was necessary to end the meeting and told the mother the reason why was because she was being very rude. The mother became more agitated and stated she no longer wanted their services and stated they were fired. The mother’s voice was raised and she told them to get out of her home. The staff person attempted to provide contact to her supervisor and grievance information but the mother would not listen to anything she had to say. She also noted there were about 5 locks on the door and once they were able to get out of the door, the mother slammed the door behind them and continued to yell and curse at them with the door closed.

The Executive Director wrote a letter to the mother dated 2/19/14 which informed her that they did not currently have workers that were available and willing to come into her home based on the last interaction. The Executive Director stated that she was *“very hesitant to place a worker in your home because I won’t have my staff subjected to being verbally attacked and/or disrespected.”* However, the Executive Director informed her that if the mother would identify an individual willing to come into her home that meets their hiring criteria, they may be able to provide services but she also informed her that she would not even be willing to consider that unless the mother was willing to do a face-to-face meeting with her and discuss her behavior on 2/12/14 and assure her that this type of thing would never occur again. She concluded the letter by stating that *“If I don’t hear anything back from you within the next 14 days, I’m going to assume that as you indicated to our staff on 2/12/14, you are no longer interested in our*

services.” This letter was sent certified mail and signed for by the mother on 2/20/14. The mother did respond via email on 3/4/14 around 8:30 p.m. and was in agreement to meet but stated they could not travel due to not having insurance or registration on their automobile. On 3/6/14 around 7:20 p.m. the mother sent another email stating it was her last attempt to “*express how important this situation has become*” and stated that her son had begun new, more difficult behaviors and “*We HAVE NO HELP WHAT SO EVER, and we are doing the best with what is happening with our non-verbal disabled autistic 4 year old, but the stress of not having a break at all is REALLY REALLY REALLY taking a toll on both [name’s] father [name] and myself.*” The mother continued that if they did things the way Delta suggested it would be the end of June and “*all the hours that they so desperately need are just going to be gone.*” The Director responded to this email on 3/11/14 and agreed to come to the mother’s home but thought it would be best while her son was at school and asked that the mother provide days and times he attends school and they would schedule around that. It was 4/11/14 when the mother responded providing the days and times her son attended school.

The HRA reviewed several emails after this that were provided by both the mother and the agency documenting several communications between them as they tried to work out the specific details of obtaining a respite worker. An email dated 4/28/14 did document the Director responding to the mother regarding her sister’s application and she stated that “*after my staff spoke with her this morning, it appears it is not going to work out with her as a possible respite worker for you-since that is an employment issue and is considered confidential, I can’t share any details with you. You would have to ask those questions directly to your sister-in-law.*” She continued in this email to clarify that her son is eligible for a certain number of hours each fiscal year but those are not entitlement hours and therefore, he would not be getting a full year of hours by June 30th. The most hours any one worker can provide are 30 hours per week. There were several other emails reviewed by the HRA, some of which were simple communications and others were from the mother expressing her extreme frustration with the process and at times using all capital letters as if she was yelling via email. Delta Center continued to attempt to remain in contact with the mother; sometimes she responded and other times she did not.

III. Policies

A. Annual Agreement of Mutual Responsibilities for Respite Services: The HRA reviewed this form which outlines responsibilities of both parties and by signing, the participants agree to said guidelines. Some examples of the parent responsibilities is to participate in a pre-respite visit with the respite care provider and program coordinator, provide all needed supplies (food, mediations, diapers etc...) and “*authorize Delta Center, Inc. to select the most appropriate temporary replacement Respite Care Provider if the original Respite Care Provider is unable to follow through on his/her commitment or if there is an emergency during the Respite.*” Some of the Program Coordinator’s responsibilities are to coordinate the pre-respite visit with the family, provide an individual respite plan with an annual review, furnish the respite worker with sufficient client information to provide needed services, train and monitor workers and “*assist in searching for an appropriate alternative services if an emergency situation arises with the Respite Care Provider or if the Respite Care Provider is deemed unable to care for the client. [sic].*” The last responsibility listed states the coordinator will “*provide a respite care provider who will:* A. *Participate in a Pre-Respite visit with the parents/guardian and/or Respite Program*

Coordinator. B. Provide close supervision and take all possible precautions for safety. I also agree not to subcontract Respite care services. C. Provide support for the individual's physical and emotional needs during Respite Care services. D. Administer medications according to written instructions provided by the parents/guardians. E. Notify the parents/guardians of any illness or injury requiring medical treatment. I further agree to follow designated procedures if the parents cannot be reached. F. Provide recreational/social activity during the stay, per agreement with the parents/guardians. G. Provide for maintenance of skills as specified in the Individual Respite Plan. H. Release and hold the parents/guardians and the Delta Center, Inc. from liability for any accident or injury, or property damage occurring during the contracted stay. I. Notify the parents/guardians and/or Delta Center, Inc. of any emergency or inability on my part to care for the assigned individual. I further agree to allow Delta Center, Inc. to select the most appropriate alternative Respite care provider.” Although the last few agreements stated seem to refer to the respite worker not holding the parent or Delta Center, Inc. responsible, there is no signature line for the respite worker, only the parent and Delta Center's respite program coordinator. The mother did sign this form along with the program coordinator.

B. Respite Program Participant Guidelines: Program participants have at least 14 requirements which are listed on this form that the parent or guardian signs. Some of those are as follows: *1. Provide individual client based training to all prospective Respite Care Providers prior to Respite care being provided by that individual...6. Return at scheduled time to relieve Respite Care Provider of his/her duties...8. Treat Respite Care Provider with respect...Provide a safe and clean working environment for Respite Care Provider...14. Be an active participant in service planning and delivery.”* The form concludes with a signature line which states the participant has *“received explanation of and understand the Respite Program Participant Guidelines. I agree to follow these guidelines while a participant of the Respite Program.”* This form was signed by the mother on 2/6/13. An addendum letter was sent on 10/9/13 which the mother signed on 10/25/13 which notified her of two new procedures in the Respite Program to ensure safety of both program participant and staff. The first was that the staff are not allowed to participate in any water related activities with clients, except for bathing if required as part of their in home respite care and only if documented in the client's respite plan and after the staff are trained in the specifics pertaining to each client. The second was that prior approval would be needed for any out of the home activities with the exception of staff accompanying the respite family on in town trips for shopping or doctor's appointments. Program participants and respite staff are required to agree on the activity before the request is submitted and signed by the parent. Both policies are listed as “effective immediately.”

C. Client Bill Of Rights: This form listed the standard rights that are guaranteed under statutes such as the right to appropriate treatment and related service, the right to be actively involved in your treatment, the right to keep your personal freedoms, including being free from harm, abuse neglect and misuse of your funds and the right to complain without fear of negative consequences from the agency. The right listed as “Right to Continuity of Services and Treatment” states the following *“A. You have the right to remain in a program or receive treatment appropriate for you or reside in a facility appropriate for you for as long as Delta Center continues the program, makes available the treatment or maintains the facility. B. You have the right not to be transferred without your voluntary written consent to another agency or organization, which would provide the same services or treatment to you that Delta Center is*

providing at the time of the proposed transfer, without reasonable notice of the intended transfer, and an opportunity to be heard and assert your objections to the same.” Also listed in this form is a section entitled “Certain Limitations of Your Rights.” One example listed within this section in which the client’s rights might be restricted is for the facility to “*Refuse to treat or furnish services contrary to professional judgment arrived at in an appropriate staffing procedure. Discharge a client from a program or facility when such person or provision of an appropriate treatment or services are or have become impossible as the result of such person’s refusal to consent to such treatment or services...*” The mother signed this form on 2/6/13.

D. Community Services Agreement between the Department of Human Services and Delta Center, Inc. For Fiscal Year 2015: When the HRA inquired about policies governing the respite program, the Director advised us that this agreement with the state is what they have which governs their funding and services to be provided by their agency, respite care being one of those services. The scope of services section pertaining to respite care states “*The in-home respite (87D FFS) program provides intensive or non-intensive support services to help maintain individuals with developmental disabilities in their homes. The services are provided to adults and children age twelve or older who need care because of their developmental disability, and children ages eleven and younger whose developmental disability requires care by a worker with special skills or training beyond the skills and training required of any worker qualified to care for non-disabled children...The provider shall provide intensive or non-intensive support services to help maintain individuals with developmental disabilities in their homes. Report services monthly via the report of community services database...expected outcomes: A decrease in the need for institutional placement or other types of long-term residential support services by assisting the individual or the family in maintaining in-home residence.*”

Statutes & Definitions

Americans with Disabilities Act regulations (28 CFR 36.201) prohibit discrimination on the basis of disability and in the receipt of services.

The Mental Health 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*”

Conclusion

The complaint alleged that Delta Center, Inc. failed to provide adequate respite services for a child with a disability. Upon review of the investigative information, the HRA found several documentations, including emails and other written communications, that there was some difficulty in reaching the mother which delayed services being provided in some instances. In another instance, a worker was refused by the mother due to her age and weight as the mother

felt like she could not provide the job duties that would be required, even though this worker had 10 years' experience working with a child with disabilities and had no limitations on how much weight she could lift or any other duties that might be required. One of the steps taken in placing a worker with a family is having a pre-visit and ensuring the worker and family are all comfortable with the placement. However, both the case coordination caseworker and Director of Delta Center explained the shortage of respite workers and agencies able to provide those services due to budget constraints and lack of interest. Therefore, the mother's refusal of at least 2 workers made it difficult to find another replacement from such a small pool of workers. Although the contract does state that the parent agrees to let Delta Center find an appropriate replacement if an emergency comes up or the worker needs to be replaced, the mother stated her preference on several different occasions to find her own worker, which she did. However, it was also documented that the mother in law and sister asked to either not be chosen or to delay the start date for their respite employment to begin. Delta Center staff also documented difficulty in working with the mother, therefore the HRA made further inquiries. The school teacher did say at first she and the mother had some difficulty and the mother could be quick tempered, but they had built a rapport over the years and had a good relationship by the time the child graduated out of the preschool program. The Client Bill of Rights does state that Delta Center can "*Refuse to treat or furnish services contrary to professional judgment arrived at in an appropriate staffing procedure.*" In this case Delta Center did follow proper procedures when reviewing the incident with the potential respite worker. After that incident Delta continued to attempt to provide services with stipulations on the mother's behavior toward respite workers and eventually placed the mother in law as the worker.

The HRA concluded that Delta Center made several attempts to provide a respite worker for this family but other circumstances such as the family's disapproval of workers, shortage of respite workers available to provide the service and the mother's inappropriate behavior towards a potential respite worker prevented this from being accomplished in a more timely fashion. The allegation is **unsubstantiated** however the HRA offers the following **suggestions** for best practice. Although, the HRA has since learned that Delta Center was forced to close due to the lack of a state budget.

1. The application for respite worker contained no questions regarding restrictions or limitations that a worker might have. The HRA suggests this be included on the application form.
2. The Annual Agreement of Mutual Responsibilities for Respite Services included statements that seemed to refer to the respite worker not holding the parent or Delta Center, Inc. responsible. However, there is no signature line for the respite worker, only the parent and Delta Center's respite program coordinator.
3. The HRA suggests that the form be revised to either include the respite worker's signature or the wording of section E, H and I be revised from first person wording so as to prevent any confusion.
4. Consider disability specific training prior to placing workers as well as training on parent/guardian and worker interactions.

5. Consider the development of a more formal grievance process in the client rights statement as well as a formal discharge process.