



FOR IMMEDIATE RELEASE

METRO EAST HUMAN RIGHTS AUTHORITY

REPORT OF FINDINGS

HRA CASE # 20-070-9004

**DEPARTMENT OF HUMAN SERVICES-DIVISION OF REHABILITATION
SERVICES**

The Metro East Regional Human Rights Authority (HRA) has completed its investigation of a complaint concerning Department of Human Services' (DHS) Division of Rehabilitation Services (DRS). According to their website, DHS's Division of Rehabilitation Services (DRS) is the state's lead agency serving individuals with disabilities. DRS works in partnership with people with disabilities and their families to assist them in making informed choices to achieve full community participation through employment, education, and independent living opportunities.

The allegation being investigated is: The agency violates consumers' rights when it denies certain types of services; and the complaint and grievance process is inadequate.

If found substantiated, the allegation represents violations of the Mental Health and Developmental Disabilities Code (405 ILCS 5), regulations regarding Early Intervention Services (89 Il Admin Code 500, 510, 677.80 & 676.30, 679) and DRS policies and procedures.

METHODOLOGY

To pursue the investigation, the HRA interviewed the recipient's guardian, the DRS Rehabilitation Services Supervisor (RSS), the Home Care Ombudsman, and the Ombudsman supervisor, as well as reviewed records, reviewed the recording of the appeals hearing, and obtained and reviewed agency policies and procedures.

FINDINGS

The complaint states that a customer's newly appointed guardians applied for DRS services and the customer was approved for Respite hours. However, after learning about the availability of Personal Assistant (PA) services, from an outside agency, the guardians inquired about being reassessed for PA services, but the request was denied.

The guardians were unfamiliar with the service options available to the customer, as the customer recently experienced the loss of her main caregiver, her mother, in another state. She moved to Illinois to be cared for by her father and stepmother, which were her newly appointed guardians. The customer requires total care and is unable to be left alone. Obtaining all new providers and services for the customer was extremely time consuming and both guardians temporarily stepped away from their employment to focus on establishing the appropriate level of care for the customer.

According to DRS case notes listed below, the customer's initial assessment occurred at her home on June 27, 2019 and she was approved for 20 plan hours per week. The plan was to provide respite care and was to begin on June 27, 2019. The guardians were to arrange for an agency or a PA to provide care for the approved hours. The guardians could not decide upon a PA or agency and continued to care for the customer as they had been and did not use the respite hours. Both parents returned to work, and in September, the guardians were asked by a case manager at another agency why the stepmother was not acting as the customer's PA since she is a Certified Nurse Assistant and works as Direct Support Personnel. The guardians called the DRS case manager to see if this was a possibility and were allegedly told that they do not pay parents to care for their children. The parents were advised by the case manager at the other agency to continue to investigate the stepmother's eligibility. The stepmother reached out to the RSS on 9/19/20, and she informed the RSS that she and the father had returned to work and she would like a reassessment because they were both now back to work. According to the case notes, she was told to send in proof of employment to show the situation had changed, and then DRS would reassess. The RSS then notified the parents that they received the information regarding employment and would be contacting them for a reassessment. The caseworker called the family on 10/4/19 and inquired about hours being worked and the hours did not currently overlap, and one parent is always home. The caseworker said she would have to speak with her supervisor as it still seems the respite hours would be sufficient. On 10/16/19, the RSS notes that she returned the mother's call. She told the mother that they would not be reassessing because the parents were still in the home providing care. The mother asked for appeal paperwork at that time. On 10/23/19, the family had not yet received the appeal paperwork and contacted the RSS. The paperwork was then emailed by the RSS. On 1/15/20, the appeals hearing was held by phone. According to the parents and the ombudsman, the administrative law judge heard the details of the appeal and advised the parents that they needed to state that they are no longer able to provide the same level of care that they had provided previously in order to receive a reassessment. The ombudsman and parents explained on the call that they were unable to provide the care. The caseworker advised that she would have to call Adult Protective Services since the family stated they would no longer care for the customer. The judge advised the caseworker that was not the case and that this is not what is occurring, the family did not say they would no longer care for the customer, rather they could not provide the same level of care. It was decided that a new assessment would be completed by a new caseworker and the family would withdraw their appeal. The DRS caseworker called APS and reported that the family stated they could not or would not care for the customer any longer. An APS investigation was conducted. The case notes from the DRS caseworker on that date state, "The parents did withdraw their appeal after the parents and Ombudsman stated the parents will no longer care for customer because they want the stepmom to be paid to be the PA and the hearing officer stated that this is the only way to get a redeterm [redetermination] at this time since both parents are currently assisting with her care and are available. This was their main goal during the hearing, this is a concern since HSP doesn't provide 24 hour care so there will be times when it appears the customer isn't cared for. This was expressed by DRS during the hearing. DRS also

stated this causes a concern of why the stepmom should then be paid since she is saying she will no longer care for customer. The father stated he no longer feels comfortable doing her care, so he can't assist. This is a big concern for the customer's safety. The customer can't manage a PA or care for herself, so both parents stated they want the stepmom to be paid as a PA and the dad will manage her since customer can't. Since it is a managed care case, they will have to make the decision whether they would pay the stepmom since they say they can't/won't care for her unless she is paid. The customer is at school during the day."

The HRA met with the RSS on 1/27/20 at the DRS office. The caseworker was not present. The RSS stated that during the appeal, the family said "they are not caring for the customer any longer" but the RSS admitted she was not on the call and had not heard the recording. She had received this information from the caseworker. Per the case notes, the RSS received an email on 1/16/19 from the ombudsman that stated, "Today during the formal hearing for customer regarding the appeal of her respite hours only service plan, it was determined that the DRS office would complete a new DON [determination of need] assessment based on the fact that parents are not able to provide the level of care they previously were providing to customer during the assessment done in June 2019. Can we schedule a three way call with you to discuss scheduling a new DON assessment...". RSS told the HRA that during the initial assessment, the family stated they were doing everything for the customer and it was determined that respite care was needed. When asked why a reassessment was not completed when the parents went back to work and requested it, she stated that they do not pay family members to care for customers and that they would need a change in condition to be eligible for a reassessment. She stated that they had concerns that a parent would want to be paid to care for their child, and now they are refusing to care for the customer. The HRA advised her that the ombudsman, the ombudsman supervisor and the recording of the call, all dispute the fact that this was said by the family. The HRA explained that it was documented that the family stated they could no longer provide the same level of care now that they are employed, and the father feels uncomfortable providing certain types of care. The HRA asked if a supervisor was involved when APS was called on a family by a caseworker and she explained she was not and that the caseworker is a mandated reporter and is required to report cases of suspected abuse or neglect. The HRA voiced concern that APS was called when it was stated the family would no longer provide the same level of care, not that they would no longer care for the customer as the caseworker alleges. The RSS stated that a new assessment will occur after 2/1/20 and will be done by a new caseworker.

DRS CASENOTES:

"6/27/19 Home visit completed. Applicant was sitting in a chair that looked like a bean bag chair on the floor and was watching TV. She is nonverbal. Her stepmom provided most of the information. Her Dad did participate a little. Applicant has a diagnosis of Cerebral Palsy and developmental delays. She is nonverbal. She is dependent on her parents for all activities. She can ambulate if she walks behind you and holds on to you. Her parents don't work and provide her care. They are willing to continue, but are interested in respite hours to give them a break. There

are 4 other kids in the home and the older ones work and the others also go to school. I did explain this and the HSP [home services plan] to them. The DON was completed and she scored the points to be eligible. All forms were completed. A ROI [release of information] was signed...I gave the applicant HSP 1, appeal form and privacy notice.” (caseworker)

“7/18/19 (caseworker) completed a Formal Respite Service Plan for applicant.Total plan hours are 20.0 and total cost of services for the plan are \$3235.20. The plan start date is June 27, 2019. Case status moved from Application to Formal Eligibility.”

“7/18/19 (caseworker) called guardian and let her know I certified customer for respite hours and that I would be mailing the plan and a PA packet to her.....”

“8/22/19 Returned a call to mother. She wanted to switch to an agency as she hasn’t found a PA. I explained she could call [PAS agency]and see if they can give her names. I gave her the number and she will call them. I explained that we can’t go back and forth between an agency and PA that it has to be one or the other.”(caseworker)

“8/30/19 Mother called to say the person originally to be the PA can not perform the job due to already receiving social security. Mother called LINC [independent living services] for a PA list but a worker from LINC asked her why she could not be the PA. Mother called to inquire about this. We discussed respite services and the purpose and yearly hours. She verbally agreed that this is what (caseworker) talked about at the home visit. (Another agency) is mailing mother a list and I offered to assist with the PA packet if she needed it.” (another caseworker)

“9/6/19 Mother called at 4pm.....I told her that we are home services, applicant by the assessment that took place, she has been approved for in home services. Mother confirmed the hours and I agreed. She said that if she did not go this route with the program was there something else. I advised her to speak with caseworker and had her leave a voicemail message.” (another caseworker)

“9/9/19 I returned the call to mother and left a voicemail letting her know that all questions need to be referred to MCO (managed care organization).” caseworker.

“9/9/19 Early morning, mother, came to the office with PA packet. PA packet completed except no photo ID or social security...Mother spoke about the possibility of she and her husband returning to work and needing different services for applicant mentioning a daycare center or possibly a group home. Mother spoke about the difficulty with these decisions and needs of another daughter with disability. I advised mother to call MCO for resources and discuss applicant’s needs.” (another caseworker)

“9/16/19 Left voicemail to (PA) to inform her she is approved to begin working for customer She needs to call back for her Santrax ID.” (another caseworker)

“9/16/19 I returned a call to ...at...MCO. She said that the mom is wanting to be paid as a PA now and she asked if this could be done since it's respite. I explained the respite hours are for someone to come in and stay with the customer while the parents have free time away from the home. I explained the parents told me they don't work and are available to assist the customer and will continue to do this. They only wanted respite hours. She then said the mom told her she was told she could be paid, so she said they need more income, so she'd like to be a paid PA as her job. I told her I had concerns about this and we don't go out and do a new assessment because someone wants to be paid as she said there were no changes in the customer's condition. I also explained the customer can't manage a PA and the mom was supposed to be managing the PA she was going to hire, so if she is hired, she can't manage herself...”(caseworker)

“9/19/19 Customer's mother called ABC..., and he called RSS to return the call. Mother explained the situation with customer. She then informed RSS that she had gone back to work, and the customer's father had as well. She is asking for a re-assessment due to the fact they are both working now. However, it appears that mother is wanting to work for customer as well. RSS told her she would get back with her.” (RSS)

“9/20/19 RSS spoke with customer's mother and asked her if she could get us documentation of their work to show that the situation has changed, and then we would do a reassessment. She stated that it would not be a problem. (RSS)

“9/24/19 RSS returned call to mother, to inform her that the office had received the verification of employment verifying both her and her husband's employment, and they would be contacted soon to set up another assessment.” (RSS)

“10/4/19 I called mother to get the hours that she and her husband work before scheduling a redeterm. She only works Sat and Sun from 6am-2pm and her husband is home during this time. He works as a bus driver for the school and his hours are M-F from about 6am-8am and then he is home and goes back around 1:30-4 or 5pm and she's home. I told her I'd have to speak to my supervisor as it still seems the respite hours would be sufficient.” (caseworker)

“10/16/19 RSS spoke with customer's mother on this date, returning her call. Mother wanted a reassessment because customer case was determined Respite based on the information shared at the time of the DON. RSS explained that since they were still in the home and providing the service to the customer, we would not be doing a reassessment on the customer. Mother had indicated that the father had a job outside the home, so they needed assistance to provide the care for customer when they were at work. However, they are working different days and times and a parent is in the home, so customer's needs are still being met. RSS explained to mother again that we must look at the resources in the home when doing DON. Mother asked for appeal paperwork, which RSS mailed to her.” (RSS)

“10/17/19 Customer's mother called this afternoon and wanted a copy of her service plan. I explained she would have to get this from her MCO.”(caseworker)

"10/23/19 Customer did not receive appeal rights in mail. RSS spoke with mother and she requested appeals rights to be sent to her...Emailed on this date." (RSS)

"11/6/19 Customer mom filed for appeal as she wants to be paid to be the PA." (caseworker)

"1/15/20 Hearing held today. They did withdraw their appeal after the parents and Ombudsman stated the parents will no longer care for customer because they want the stepmom to be paid to be the PA and the hearing officer stated that this is the only way to get a redeterm at this time since both parents are currently assisting with her care and are available. This was their main goal during the hearing, this is a concern since HSP doesn't provide 24 hour care so there will be times when it appears the customer isn't cared for. This was expressed by DRS during the hearing. DRS also stated this causes a concern of why the stepmom should then be paid since she is saying she will no longer care for customer. The father stated he no longer feels comfortable doing her care, so he can't assist. This is a big concern for the customer's safety. The customer can't manage a PA or care for herself, so both parents stated they want the stepmom to be paid as a PA and the dad will manage her since customer can't. Since it is an MCO case, they will have to make the decision whether they would pay the stepmom since they say they can't/won't care for her unless she is paid. The customer is at school during the day." (caseworker)

"1/24/20 I called and spoke with the customers stepmother. We scheduled a reassessment for 2/10/20..."(new caseworker)

"3/2/20 I attempted to meet with the customer's mother at the Welcome center on the Airforce base. However, she was not present as she stated she would be. I called her and she stated that she left a pass for me at the desk. I attempted to get the pass but was told that the computers were down for at least another 30 minutes. I called the customer's mother back and rescheduled for Wednesday at 3:00. At this point she informed me that the ombudsman was also going to meet with us today and had driven down from Springfield for this meeting. I explained that I was not aware that ombudsman was going to be a part of the meeting and I appreciate if they let me know this information prior to appointments in the future. I spoke with ombudsman about the appointments and suggested that they contact [MCO] to get the services that they wanted. I reminded her that I am unable to create a service plan for this customer and she stated that she is aware but wants a DON that has a score in the 'need' column." (new caseworker)

"3/4/20 the appeal was withdrawn so that a new DON could be completed." (new caseworker)

"3/5/20 I met with the customer at her home in... Air Force base. Also present was her step mother and... (ombudsman). The meeting was held at their kitchen table. The customer scored a 57 on the DON. I gave her a copy of the privacy notice and the redetermination agreement form. Mother explained that she is not interested in being the PA now because she has a part time job. She starts her new job this weekend and hopes to hire someone soon." (new caseworker). A note on 3/12/2020 stated that a service plan was completed and submitted for authorization and the note also states that the Mother is interested in being the primary PA."

MANDATES/REGULATIONS

The Department of Human Services regulations regarding service providers states “The following individuals shall not be paid through HSP to be a Customer's service provider. a) The Customer's responsible family members (89 Ill. Adm. Code 676.30), including the Customer's spouse, a parent of a child who is under age 18 or a legal guardian of an individual who is under age 18; b) The Customer's minor child (under age 18); c) The Customer's foster parents if the Customer is under age 18; or d) The Customer's stepparents, if the Customer is a minor child (under age 18)” (89 Il Admin Code 684.30).

The Department of Human Services regulations also state “a) DHS-DRS shall make the grievant aware, in a language that is understandable to the grievant, of the right to appeal pursuant to this Part, at the following times or events: 1) upon application for services; 2) upon denial of application; 3) after the initiation, or change, of services; 4) upon termination of a service; 5) upon closure; 6) upon enrollment in a DHS-DRS school; and 7) upon entrance into the Business Enterprise Program for the Blind” (89 Il Admin Code 510.40). The regulations also state “The following may be appealed under this Part: a) DHS-ORS' refusal to provide any service it is authorized to provide; b) modification of any service currently provided to the customer by DHS-ORS, termination of a service or case closure, unless agreed to by the customer and DHS-ORS” (89 Il Admin Code 510.20). Additionally “a) Any Customer served under the Medicaid Waiver for Persons with Physical Disabilities shall have his/her eligibility redetermined whenever there is a change in his/her condition or situation that may affect his/her continued eligibility, but if no such change, at least every 12 months” (89 Ill. Adm. Code 682.410)

The Adult Protective Services Act (Chapter 320 ILCS 20/1 et seq.) defines neglect as follows: “(g) ‘Neglect’ means another individual’s failure to provide an eligible adult with or willful withholding from an eligible adult the necessities of life including, but not limited to, food, clothing, shelter or health care. This subsection does not create any new affirmative duty to provide support to eligible adults. Nothing in this Act shall be construed to mean that an eligible adult is a victim of neglect because of health care services provided or not provided by licensed health care professionals.”

CONCLUSION

The first complaint alleges that DRS violates consumers’ rights when it denies certain types of services. The HRA **substantiates** this portion of the complaint. The HRA reviewed the records and policies and the HRA saw no evidence in Section 686.10 Personal Assistant Requirements that excludes a family member from becoming the PA for a child over the age of 18. Additionally, the Code (89 Il Admin Code 684.30) specifically states that a step parent cannot be paid to become a PA for a child under the age of 18, but there is no limitation documented over the age of 18. The HRA also notes that after the administrative hearing, a redetermination was completed which proved successful in the customer receiving PA services provided by her step mother. The family was told on multiple occasions that the step mother could not be the PA but this statement is not accurate in accordance with the law.

Regarding the second complaint, the guardians inquired about becoming PA over using Respite services, and as stated above, they were told that was not an option due to the relationships. The DRS representatives also told the HRA, as well as the guardians, that there had to be a change in need in order to receive a redetermination, which is not accurate in accordance with the Code (89 Ill. Adm. Code 682.410). Although it appears that the guardian was made aware of the appeal process upon admission per the Code (89 II Admin Code 510.40), by being give copies of the Home Services Program Appeal Fact Sheet (HSP1 R-10-12) and IL 488-2450W (R-03-14) The Home Services Program Application and Redetermination of Eligibility Agreement which clearly state the customer can request a redetermination when there is a change in condition or need. The customer requested a redetermination based on need and it was denied on multiple occasions, a clear violation of The HSP Application and Redetermination of Eligibility Agreement. The HRA requested copies of the redetermination, grievance and personal assistant eligibility policy which were never provided. The HRA is also concerned that the guardians requested the appeals paperwork to be mailed to them on 10/16/2019 and they never received it. They had to request it again on 10/23/19 and it was finally emailed to them. In accordance with DRS mandates (89 II Admin Code 510.20), an appeal can be made when a customer is denied services available through DRS or when services are modified. As stated above, the services were said to be available when they were not and the parent was requesting modification. Additionally, considering how many times the mother asked about PA services, DRS representatives should have encouraged her to file a grievance for a thorough review to take place, but through this process, the action did not occur. When there was an appeal and discussion, the determination was made to allow the step parent to be PA. Because of the lack of action taken with the appeal process, the HRA finds this complaint **substantiated**.

Also of concern for the HRA is that DRS representatives were very wrapped up in the status of the parents' employment and the fact that the mother was requesting to be the PA when it is clear to the HRA that this family needed support. The HRA questions why the DRS representatives did not suggest a referral to the community-based program vs. respite which might have been a better fit for the consumer and family. As explained to the HRA by the DRS RSS, community based programs help to keep consumers out of more expensive state-funded program such as group homes and institutions; if the family is able to be paid for the hours, it saves the state money, allows the customer to be cared for by people who know her, and provides the least restrictive care option. The DRS caseworker and RSS attempted to keep the customer from receiving PA services that would have kept her in her own home and in the presence of caregivers that know her and in the least restrictive environment possible and the HRA is very troubled by this.

When the family tried to get support by explaining their needs in the hearing, an APS report was filed, and the mothers' statement was misquoted in the report. The Adult Protective Services Act (Chapter 320 ILCS 20/1 et seq.) defines "Neglect" as "another individual's failure to provide an eligible adult with or willful withholding from an eligible adult the necessities of life including, but not limited to, food, clothing, shelter or health care." The Act also designated Department of Human Service employees as mandated reporters and specifies: Sec. 4. Reports of abuse or neglect. (a) Any person who suspects the abuse, neglect, financial exploitation, or self-neglect of an eligible adult may report this suspicion to an agency designated to receive such reports under this Act or to the Department. (a-5) If any mandated reporter has reason to believe that an eligible adult, who

because of a disability or other condition or impairment is unable to seek assistance for himself or herself, has, within the previous 12 months, been subjected to abuse, neglect, or financial exploitation, the mandated reporter shall, within 24 hours after developing such belief, report this suspicion to an agency designated to receive such reports under this Act or to the Department.... (a-7) A person making a report under this Act in the belief that it is in the alleged victim's best interest shall be immune from criminal or civil liability or professional disciplinary action on account of making the report, notwithstanding any requirements concerning the confidentiality of information with respect to such eligible adult which might otherwise be applicable." The HRA is troubled by the report of neglect made by the DRS caseworker as no signs of abuse or neglect were ever documented in DRS files and the report was inaccurate in the details of what the mother stated.

RECOMMENDATIONS

The HRA **recommends** that the facility train staff in eligibility for PA and redetermination per Code requirements (89 Il Admin Code 674.30 & 682.410). The HRA also **recommends** that staff be retrained on the complaint/grievance and appeals mechanisms per regulations (89 Il Admin Code 510.40). When a customer questions or disagrees with the services provided, DRS representatives should remind or inform the customer of the appeals mechanism and offer them the appeals form as well as any necessary assistance in completing the form. In this instance, the mother requested or inquired about a redetermination at least 8 times before an appeal was filed.

SUGGESTIONS

The HRA strongly suggests that DRS work with its consumers and their families to find the most appropriate fit to meet the consumer's needs, including whether or not the home base program was a better fit and the extent to which family can provide and be paid for service hours given their knowledge of the consumer and the fact that they would otherwise need to seek outside employment. The HRA suggests that DRS implement an annual policy/training that mandates DRS representatives work with customers to ensure that they are receiving optimal services for their unique needs. This should include a provision that every customer is to be informed of all available options for care and that they are reminded of those options annually and as their needs change. This would require all staff, including supervisors, to be up to date on the rules and regulations regarding all available care options and when and how those options can be denied.

The HRA requested policy regarding grievance, eligibility and redetermination that were never provided. If the facility does not have policy regarding the topics, the HRA **strongly suggests** creating such policy so that it is easily accessible by staff.

The HRA also strongly urges DRS to examine this incident with regard to APS notification particularly when access to services is contingent upon a family's inability to provide care

The HRA would like to add that it finds the lack of responsiveness troubling and bordering on discrimination with decisions for this family potentially being based on personal judgements versus regulatory requirements.

RESPONSE

Notice: The following page(s) contain the provider response. Due to technical requirements, provider responses appear verbatim in retyped format.

REGIONAL HUMAN RIGHTS AUTHORITY

HRA CASE Numbers 20-070-9004

SERVICE PROVIDER: Department of Rehabilitative Services

Pursuant to Section 23 of the Guardianship and Advocacy Act (20 ILCS 3955/1 *et seq.*), we have received the Human Rights Authority report of findings.

IMPORTANT NOTE

Human Rights Authority reports may be made a part of the public record. Reports voted public, along with any response you have provided and indicated you wish to be included in a public document will be posted on the Illinois Guardianship and Advocacy Commission Web Site. (Due to technical requirements, your response may be in a verbatim retyped format.) Reports are also provided to complainants and may be forwarded to regulatory agencies for their review.

We ask that the following action be taken:

We request that our response to any recommendation/s, plus any comments and/or objections be included as part of the public record.

We do not wish to include our response in the public record.

No response is included.

Rahnee K. Patrick

NAME

Director, Division of Rehabilitation
Services, Illinois Department of Human
Services

TITLE

June 9, 2020

DATE



JB Pritzker, *Governor*

Illinois Department of Human Services

Grace B. Hou, *Secretary*

Division of Rehabilitation Services

June 9, 2021

Dr. Karen Kelly, Chairperson
Regional Human Rights Authority
Metro East Regional Office
4500 College Avenue, Suite 100
Alton, IL 62002-5051

Re: Human Rights Authority Case #20-070-9004-IDHS/DRS/HSP response

Dear Ms. Kelly:

Thank you for the additional time that you granted for the Illinois Department of Human Services (IDHS), Department of Rehabilitation Services (DRS) Home Services Program (HSP) (hereinafter referred to as HSP) to respond. We appreciate the opportunity to work with the Metro East Regional Human Rights Authority of the Illinois Guardianship and Advocacy Commission to identify issues that may need to be improved within the HSP. As you know, the HSP takes all customer concerns seriously including customer rights when there has been a denial of services, and the complaint and grievance process.

The first complaint alleges that a customer's newly appointed guardians applied for HSP services and the customer was approved for respite hours. However, after learning about the availability of Personal Assistant (PA) services, from an outside agency, the guardians inquired about being reassessed for PA services, but the request was denied. The HRA substantiated the first complaint that DRS violated the customer's rights when it denied certain services. DRS agrees that 89 Ill Admin Code 684.30 and 89 Ill. Adm. Code 676.30 sets forth who cannot be paid as a Family Service Provider, aka Personal Assistant (PA).

HSP services are determined by the Determination of Need (DON) assessment. If there is no need found in the assessment, the services are limited to respite services based on the DON score. Information for the assessment is provided strictly by the customer and/or guardian or informant. In this case, the parents provided the information for the DON, which indicated no need score, so respite services were provided.

The HRA was correct that, under the rules, the customer's step-mother would be eligible to be the PA. However, HSP respectfully disagrees that the stepmother was told that she could not be a PA but only that she could not be paid to be the respite worker. As you know, the HSP has many customers who have family members working for them. However, in a Respite case, the family members seeking Respite cannot also be the providers of the service. So, it is accurate that, since this was a Respite case, the stepmother could not be the PA.

The second complaint alleged several items including the following

1. The DRS representatives told the HRA, as well as the guardians, that there had to be a change in need in order to receive a redetermination. 89 Ill. Adm. Code 682.410.
2. The guardian was not immediately made aware of the appeal process upon admission per the Code, 89 Ill Admin Code 510.40, and was given copies of the HSP Appeal Fact Sheet and IL 488 -2450W (R-03-14) which states that a customer can request a redetermination when there is a change in condition or need and it was denied on multiple occasions which is a violation of The HSP Application and Redetermination of Eligibility Agreement.
3. The HRA requested copies of the redetermination, grievance and PA eligibility policy which were never provided.
4. The HRA was concerned that the guardians requested the appeals paperwork to be mailed to them on 10/16 /2019 and they never received it. They had to request it again on 10/23/19 and it was finally emailed to them.

The HRA substantiated the second complaint because of the lack of action taken with the appeal process. The HSP respectively disagrees that it did not inform the parents of their appeal rights. When the parents informed the HSP office that they had obtained part-time jobs, it was our understanding that there was still a parent in the home 24 hours a day and they planned to continue to provide care for the customer. The first time the HSP knew that there was a change in need or situation was at the appeal hearing, when the parents stated that they would be unable to provide the level of care they had been providing to the customer and it was at that point, a reassessment was scheduled.

The reassessment took place on June 27, 2019 and, at that time, the parents received a copy of the appeal paperwork. (see case note dated 6/27/2019). On October 16, 2019, when the supervisor talked to the stepmother and informed her that she could file an appeal, the supervisor personally mailed the appeal paperwork to the parents. When they had not received it by 10/23/19, the paperwork was emailed to them on that date.

Copies of the Redetermination and Grievance process were provided to the HRA in an email on 1/27/20, along with the application for services, case notes, and a transcript of the appeal hearing (on 2/5/20 from Bureau of hearings), at the request of the HRA. DRS has no record of request from the HRA for a PA eligibility policy, or that would have been provided as well. We apologize that it was not sent, it is enclosed with this response.

HRA's additional areas of concern included the status of the parents' employment in relationship to the support that the family needed, and why the HSP allegedly did not suggest a referral to the community-based program vs. respite.

We agree that there were many discussions about the parents' employment and the family need. The DRS counselor needed the employment information to determine when the

customer had unmet need due working outside the home. The parents' work schedules showed that there was a parent in the home with the customer 24 hours per day therefore there was no change in the customer's need.

HSP agrees that a person is better served in the community, if that is possible. The mission of the IDHS/DRS/HSP is to assist individuals with disabilities in achieving their goals in the areas of employment, education, and independent living. HSP does not provide community-based programs (this is provided by Division of Developmental Disabilities (DDD)); we provide home-based services. The HSP program is designed to provide services in the home, so that the customer does not have to go into a nursing home to receive the services needed. On May 18, 2018, the DRS counselor did suggest a referral to DDD for their Community Based Services Waiver. We are unsure whether or not the parents ever followed up with DDD. The family can make the referral to DDD at any time.

The customer was not at immediate risk of nursing home placement because the parents told the counselor, at the initial assessment, that they were providing all of her care and planned to continue to do so. A parent was in the home with the customer at all times. There was no attempt to keep the customer off the program, as she was found eligible at the first meeting and assessment.

The HRA also strongly urged HSP to examine this incident with regard to APS notification particularly when access to services is contingent upon a family's inability to provide care. HSP agrees that based on the facts, we will look into this issue more thoroughly with our counselors.

In response to the recommendations of the Metro East Illinois Guardianship and Advocacy Commission, the HSP will take the following actions:

1. Continue to provide training to staff on eligibility for PA and redetermination per Code requirements. (89 Il. Admin. Code 674.30)¹ 89 Il. Admin. Code 679.30 & 682.410.
2. Continue to provide training to staff on the complaint/grievance and appeals mechanisms per regulations (89 Il. Admin. Code 510.40).
3. Continue to provide training to staff on the Waivers so that staff can advise customer and their families on the IDHS Waivers that most appropriately meet the customer's needs.
4. Continue to provide training to staff on appropriate referrals to APS .

The HSP thanks the Metro East Guardianship and Advocacy Commission for its thorough review of this case, the recommendations, and the concerns. We appreciate your consideration of the information we have shared regarding this case in this response.

¹ We were unable to find 89 Il. Admin. Code 674.30 of the Administrative Code but believe the provision should be 89 Il. Admin. Code 679.30
<https://www.ilga.gov/commission/jcar/admincode/089/089006790000300R.html>

Sincerely,
Rahnee K. Patrick
Director
Division of Rehabilitation Services
Illinois Department of Human Services

**TITLE 89: SOCIAL SERVICES
CHAPTER IV: DEPARTMENT OF HUMAN SERVICES
SUBCHAPTER d: HOME SERVICES PROGRAM**

**PART 686 PROVIDER REQUIREMENTS, TYPE SERVICES, AND RATES OF PAYMENT
SECTION 686.10 PERSONAL ASSISTANT (PA) REQUIREMENTS**

Section 686.10 Personal Assistant (PA) Requirements

In order to be employed by a customer as a PA (89 Ill. Adm. Code 676.30), an individual must:

- a) have a Social Security number and provide the Department of Human Services (DHS) with documented verification of this number;
- b) be a minor between 14 and 16 years of age who is not employed during school hours, has an employment certificate and meets all other requirements of the Child Labor Law [820 ILCS 205] and has an adult who is at least 21 years of age and who is legally responsible for the customer who will supervise the PA; be 16 years of age or older, enrolled in school and not employed during school hours; or be 17 years of age or older and not enrolled in school;
- c) have provided to the customer at least two written or verbal recommendations from present or former employers, the recommendation of a Center for Independent Living (CIL), or, if never employed, references from at least two non-relatives;
- d) be able to communicate with the customer to the satisfaction of the customer and counselor;
- e) be able to follow directions to the satisfaction of the customer and counselor;
- f) have previous experience and/or training that is adequate and consistent with the specific tasks required for safe and adequate care of the customer;
- g) if the customer has a contagious infectious disease, have a physician, health care institution (i.e., hospital, nursing home, home health agency), or CIL certify, in writing, that he/she has the knowledge of precautionary procedures for the control of contagious infectious diseases, if it is anticipated that he/she will come into contact with bodily fluids, or be evaluated by a Registered Nurse

licensed pursuant to the Nurse Practice Act [225 ILCS 65] to determine that he/she has knowledge of those procedures;

- h) complete an EMPLOYMENT AGREEMENT between the customer and PA that certifies the PA:
- 1) shall provide services to the individual in accordance with his/her SERVICE PLAN (IL 499-1049) (89 Ill. Adm. Code 676.30(u));
 - 2) shall submit a bi-monthly calendar listing actual hours worked each pay period (1-15; 16-last working day of the month), as verified by the customer and in accordance with the number of hours authorized by DHS. The PA shall not claim more hours than approved by DHS unless prior approval has been granted by the counselor to address a temporary increased service need;
 - 3) shall make available to DHS and other designated agencies those records described in subsection (h)(2);
 - 4) shall maintain all customer information as confidential and not for release, either in writing or verbally, to anyone other than those designated by DHS in writing;
 - 5) shall not subcontract to any other person, any of the services he/she has agreed to provide;
 - 6) shall provide services only while the individual is in his/her home or during the period covered by Section 684.60 (Provision of Services);
 - 7) shall agree that the customer is responsible for locating, choosing, employing, supervising, training, and disciplining as necessary the PA. Further, that the State of Illinois does not provide paid vacation, holiday, or sick leave; however, such absences shall be reported to the DHS counselor per the HOME SERVICES TIME SHEET (IL 488-2251) only for the purposes of processing payment;
 - 8) understands that DHS reports all payments made to a PA to the Illinois Department of Employment Security (DES) and that the PA may apply for unemployment benefits, but DES, not DHS, makes the determination as to whether the PA shall receive benefits;
 - 9) understands that he/she may apply for Workers' Compensation benefits through DHS and that some customers may carry such insurance

coverage; however, DHS maintains that the customer, not DHS, is the employer for these purposes; and

- 10) understands that DHS will withhold Social Security tax (FICA) from payments made to him/her. Federal and State income tax shall be withheld if the PA completes and returns to DHS two separate W-4 forms;
 - i) complete an I-9 Immigration form, which must be retained by the customer;
 - j) for PAs starting on or after April 13, 1992, complete a PA STANDARDS (IL 488-2112) to be returned to DHS;
 - k) as of April 13, 1992, at the time of redetermination of eligibility of the customer by which he/she is employed, have completed by the customer, a PERSONAL ASSISTANT EVALUATION (IL 488-2089); and
 - l) if requested by the customer, give permission and the necessary information for the customer to request a conviction background check from the Illinois State Police. This permission will require the prospective PA to sign the appropriate form provided by the customer.

(Source: Amended at 38 Ill. Reg. 11519, effective May 15, 2014)

**TITLE 89: SOCIAL SERVICES
CHAPTER IV: DEPARTMENT OF HUMAN SERVICES
SUBCHAPTER d: HOME SERVICES PROGRAM
PART 682 ELIGIBILITY
SECTION 682.410 REDETERMINATION TIME FRAMES**

Section 682.410 Redetermination Time Frames

- a) Any Customer served under the Medicaid Waiver for Persons with Physical Disabilities shall have his/her eligibility redetermined whenever there is a change in his/her condition or situation that may affect his/her continued eligibility, but if no such change, at least every 12 months.
- b) Any Customer served under the Medicaid Waiver for Persons with HIV/AIDS shall have his/her eligibility redetermined whenever there is a change in his/her condition or situation that may affect his/her continued eligibility, but if no such change, at least every 12 months.
- c) Any Customer served under the Medicaid Waiver for Persons with a Brain Injury shall have his/her eligibility redetermined whenever there is a change in his/her condition or situation that may affect his/her continued eligibility, but if no such change occurs, at least once every 12 months.

**SUBCHAPTER a: GENERAL PROGRAM PROVISIONS
PART 510 APPEALS AND HEARINGS
SECTION 510.10 GENERAL INFORMATION**

Section 510.10 General Information

General Provisions

- a) A grievant who is not satisfied with an action taken by DHS-DRS, or with the failure of DHS-DRS to take action, is entitled to a hearing. A customer of the Vocational Rehabilitation program may also request mediation.
- b) Any and all notices and communications to DHS-DRS made pursuant to this Part should be in writing. Nonwritten communications will be accepted if the information required in subsection (b)(6) of this Section is provided. All nonwritten communications shall be documented by DHS-DRS.
- c) A grievant may appoint a representative in accordance with Section 510.40(e)(2), who may exercise any right of the grievant on the grievant's behalf. A grievant may only designate one representative at a time. The designation must be in writing or on the record.
- d) All time periods related to communications arising under this Part commence on the date of receipt (receipt is presumed 5 days after the date of postmark or on the day of delivery for hand delivered items) or, if a nonwritten form of communication, on the date of receipt.
- e) A request for a hearing by any person not a "grievant" cannot be heard by DHS-DRS pursuant to this Part.
- f) The request for a hearing should include the specific determination and the date of the determination or, if appealing inaction, the date the action was requested, and specific identification of any other matter that is being appealed, but if this information is not readily available to the grievant, the grievant must supply sufficient information for DHS-DRS to identify the specific action or inaction that is being appealed.

- g) Should a grievant improperly request an appeal and other procedures for appeal are available, DHS-DRS will advise the grievant of the proper appeal process.
- h) Failure of a grievant to follow procedures as set forth in this Part or failure to request an appeal within the specified time frames found in Section 510.80 shall result in dismissal of the appeal except if the failure to follow procedure was a result of DHS-DRS failure to provide required notice or information.
- i) After a request for a hearing is filed, the grievant or DHS-DRS may initiate attempts to resolve the grievance informally. The grievant and the appropriate DHS-DRS employee may agree to resolve disputed issues, at any time during the appeals process, prior to the issuance of the hearing decision. If prior to the hearing there is mutual agreement on an issue under dispute, this will remove the need for a hearing on that issue.
- j) DHS-DRS, and the Department of Healthcare and Family Services in the case of Home Services Program (HSP) hearings, will assume all administrative costs of the appeal (i.e., interpreters, pursuant to Section 510.40(b), and record, pursuant to Section 510.80(e)) but will not assume costs personally incurred by the grievant because of the proceeding (e.g., legal fees, travel, witness costs, and room and board).

(Source: Amended at 32 Ill. Reg. 10047, effective June 26, 2008)