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HUMAN RIGHTS AUTHORITY - PEORIA REGION
REPORT OF FINDINGS

Case # 10-090-9015
The Arc of Rock Island County

INTRODUCTION

The Human Rights Authority (HRA) opened an investigation after receiving a complaint of possible rights violations at the Arc of Rock Island County, a developmental disability provider. Complaints alleged the following:

- 1. The Arc inconsistently applies practices and policies.**
- 2. The Arc charges fees for services that may be funded.**
- 3. The Arc attempted to assign fees based on parental income and assets.**
- 4. The Arc's Board of Directors is not accessible to clients and parents and Board practices have changed with regard to parental access to Board meetings and parent leadership on the Board and in committees.**
- 5. During a period of time when state funding was in question, many services were abruptly and inconsistently ended until funding resumed.**
- 6. The agency has recruited non-disabled individuals to work at jobs that Arc clients can do.**
- 7. There is a general lack of information shared with clients, parents, other family members and the Association membership; there is also a lack of accountability to these stakeholders as well.**
- 8. The agency has an inadequate grievance process.**

If found substantiated, the allegations would violate Illinois Department of Human Services (DHS) regulations that govern developmental training programs (59 Ill. Admin. Code 119.235, 119.300, 119.210, and 119.200), regulations in regard to ending services, grievances, grants, and transportation (59 Ill. Admin. Code 103.210), the Mental Health Code concerning adequate and humane treatment in accordance with their individual service plan (405 ILCS 5/2-102), and the agency's own Constitution, policies and by-laws.

The Arc of Rock Island has approximately 300 clients participating in various programs such as supported employment, day training, and respite. The Arc has 265 employees who are mostly residential and an 18 member volunteer Board. The Arc primarily serves the Rock Island Community.

To investigate the allegations, HRA team members met and interviewed staff members and reviewed pertinent documents. All documents were reviewed with the guardian's/ service recipient's written consent.

COMPLAINT STATEMENT

According to the complaint, the provider inconsistently applies practices and policies among the clients. Examples include one vocational client receiving additional services while others are not receiving these services, facilitating the medical needs of one resident while another resident was placed in a nursing home, and some clients paying transportation fees and others are not. Also during this time, some clients were allowed to attend programs, while others were not. The complaint also states that the Arc charges fees for services that may be funded. Fees are said to cover staff time as well as transportation. There is a question of how the funds received from fees are used and there is also a question of how the fees are even charged in some settings, such as in an ICF/DD. In one instance an activity was cancelled and the parents were not notified but if a client or parent cancels there is a \$10 cancellation fee. The complaint also states that the fees were being based on parental income and assets; one family would pay more than the other based on parental income. Another client was considered "active" because of a job and was asked to pay a higher fee for services. The complaint states that the Arc's Board of Directors is not accessible to clients and parents and board practices have suddenly changed. In the past, the board meetings were always open; now, the meetings are usually closed, particularly if a parent arrives at the meeting. Also, the agency welcomed parent participation with past board committees; recently, two parents were asked to end committee participation. Parent leadership on the board has now diminished. The complaint also states that during a period of time when state funding was in question, many services were abruptly ended, but, there was inconsistency in ending services; some individuals continued to receive services while others did not. There is a question as to whether or not the abrupt end of services placed client safety in jeopardy. The services were resumed when the state funding questions were addressed. The complaint also states that the Arc hired non-disabled, temporary employees to do the work that the clients could do. The complaint states that there is a general lack of information shared with clients and a lack of accountability to clients, parents, other family members and Association membership. Finally, the complaint states that the agency has an inadequate grievance process. When individuals attempt to pursue concerns or complaints, the concerns are disregarded.

FINDINGS

The HRA began its investigation by meeting with Arc administrative staff members and a member of the volunteer Board. Regarding the complaint that states that the Arc inconsistently applies practices and policies, the staff explained these inconsistencies may be due to various eligibility requirements and different programs. The staff explained that whether transportation is paid is based on the programs; for example transportation is not funded for grants but long-term care has funding. The staff explained that they have three different job programs for which the consumers may be eligible. The first is the vocational work program, which is the largest

program and includes training and work support. Transportation for this program is coordinated but the Arc does not have to provide the transportation. The second largest job program is called regular work and there are no rules specified for the transportation other than it is a grant funded program and, as stated before, transportation is not funded for grant programs. The third program is called supported employment, which is grant funded unless the consumer has a Medicaid waiver. Different consumers are eligible for different job programs. The process of deciding eligibility for work opportunities consists of assessing the individual. An admission committee then reviews the consumer's files for experience. Then the Arc examines available funding for the consumer and reviews the consumer's service plan. When a program is identified, the consumer works the job for a few days as a trial period. If the consumer is considered a good match for the job, the job is written into the service plan. If the job is inside Arc, then it is not added to the service plan. Family and consumers are part of the entire process. Also, the staff stated that there is a waiting list for job openings and job placement. The placement of consumers is based on seniority. Also, due to the economy, the Arc has had trouble maintaining work. The slow down in work has not reduced the work days or work week, only the actual work being done. The Arc still offers job training on days when there is no work.

The Arc staff also explained the grant funding. The staff explained that if a program is funded by a State Grant, they can assign sliding fees. If it is a community grant, then the fee is flat. The staff also explained that if the program benefits the consumer, then the Arc would pay the fee. If the program benefits both the consumer and the family, such as a respite, then the family would be accountable for paying the program fees. Also, grant programs can have co-pays if there is partial funding for the program. The Arc staff explained that a grant can be used for different programs than the grant was originally being used for and it is a board decision to move the money around. They stated that they have no obligation to say which program the grant money is funding. The Arc staff explained that they had financial problems between September 2009 and February 2009 due to grants being cut and during that time, they terminated some of the programs that they offered. They stated that they had taken money from another program to put into recreation. When that grant was terminated, they moved recreation to a sliding fee. The Arc staff went on to explain that almost all of the programs are funded by state grants and they are concerned that many grants will be cut soon.

The Arc staff explained that a typical social activity they would sponsor would be a trip to a baseball game, bowling, or a day trip to Galena. The staff stated that the typical cost with a trip like this would be admission/activity cost, transportation cost, and there could be a cost for staff support depending on the activity. They stated that these activities are not part of the CILA rate but rather for people who live at home with their family. They stated that these types of activities would now, without grant funding, be based on a sliding scale and the scale would be based on a family's income. The Arc staff also stated that there is a 24 hour cancellation fee if consumers back out of the event during that period.

The staff stated that consumers are not using the social programs and the programs have often been cancelled. The Arc stated that they are now offering more center based activities such as Wii tournaments, cooking skills classes, or going to a local theater for a movie. They charge a \$5 fee for transportation to their home and then some possible money for the cost of supplies.

The Arc stated that they try to get volunteers to help with center based programs but none are available for entertainment. They stated that many of these programs are not continuing.

In regard to the complaint that there are inconsistencies in medical care, the Arc staff stated there are provisions on how long a consumer will get care. The Arc stated that they do not have services for skilled care, so a patient that needed skilled care would go to a different facility and, if they become healthier and change to a level that the Arc could manage, they could come back to the Arc. They also stated that each case is individualized.

In regard to the complaint that the Arc's Board of Directors is not accessible to clients and that the policy has changed concerning parent access to the board meetings, the Arc staff explained the board procedures. The Arc stated that it has monthly Board meetings, except for July and December, and there is the capacity to call a special meeting. The Board members have a constitution that dictates the actions taken by the Board and also the movement on the Board. The Board Constitution dictates that the Board includes three of the following classes of representatives: parents, consumers, and community members. The Constitution also states that at least one-third, but not more than one-half, of the members of the Board of Directors can be parents. The Constitution also states that the officers of the Board of Directors should consist of a President, a First Vice-President, a Second Vice-President, a Secretary, and a Treasurer. The current President has been on the Board for 9 years total and 4 years as President. The rest of the Board members are on 3-year terms. The officers are voted on by members of the Association, which are families and consumers of the Arc who pay the Association fee. The Arc staff stated that they are close to being at 50% capacity with family members on the board, which the Arc stated is high representation. The Board also consists of three consumers. The Board members chair different committees and it is the President's prerogative to appoint different chairs to the committees. They like to rotate committee members to keep fresh ideas in the committees. If a parent wants to speak at a board meeting, they have to contact the Board to be added to the meeting agenda. The Arc staff stated that the meetings generally start as open sessions and then go into closed, executive sessions to discuss confidential issues such as finances. They stated that guests at the meeting, such as parents, may not be involved in the executive sessions. The staff stated that there were conflicts regarding board members and the board changed. They stated that a board member was moved off the board due to breaching confidentiality.

In regard to the complaint that Arc has an inadequate complaint process, the staff stated that the grievance process is given to the consumers on admission. The staff stated that, if there is a complaint, the consumer or consumer's family is encouraged to go to the QMRP first. The QMRP will try to resolve the issue. If they cannot resolve the issue, the complaint goes to the Quality Assurance Director. From there, if the issue cannot be resolved, it goes to upper management for resolution. The Arc staff stated that no complaint was brought to the QMRP regarding any of the complaints listed in this case and the Arc has not fielded a complaint this year.

The Arc staff also mentioned other events where they ask family members to participate. They hold a meeting where the parents are asked to have tea with the Executive Director of Arc and the Board President. They also have a meeting called "In The Know" that parents are invited to as well as Association Meetings that paying association members can attend. The Arc also has an annual meeting and other events such as a Thanksgiving potluck, picnics, etc. The Arc

sends out a Quarterly Newsletter with meeting information on the newsletter and an Annual Report. The Executive Director also sends out emails to families with information regarding the Arc.

In regard to the complaint regarding the termination of services, the Arc stated that they had an Association meeting to discuss the services that would end and sent out mailings to all families who may be affected by the service shut down. The Arc handed out a copy of the Department of Human Services (DHS) notice and shared a timeline of when programs would be terminated. The staff stated that services were discontinued for seven weeks and then the services were reinstated until December 31st. From then, the grant service has been extended on a month to month basis by the State. The Arc is anticipating that the grants will end on July 1st. The Arc staff have been working to switch consumers over to Medicaid and have successfully converted 79 consumers. 8 people from supported employment did not qualify for Medicaid and 2 people from regular work did not get converted but they were offered private pay. Arc stated that they even laid off staff to put money towards services.

In regard to nondisabled workers being hired to work jobs that Arc clients could do, the Arc stated that they had the need to hire temporary workers for jobs that clients could not do because of their disabilities. Specifically, there was a Hoseworker Job that they felt no Arc consumers could manage. The Arc stated that their non-disabled employees represent 10% of the workforce which is less than the National Industries for the Severely Handicapped (NISH) standard. NISH's website defines that organization as "... one of two national, nonprofit agencies designated by the Committee for Purchase From People Who Are Blind or Severely Disabled [a federal government agency] to support nonprofit agencies participating in the AbilityOne Program which provides employment opportunities for people who are blind or have other significant disabilities by procuring federal contracts for goods and services."

Record Review

With consent, the HRA obtained and reviewed documents pertinent to the investigation. Written correspondence between the Arc and the Arc consumers reads that DHS is terminating funding for programs on July 1st of 2009 and that the Arc will allow all members of the program to attend the programs until July 14th of 2009. On August 21st, a letter from the Executive Director of the Arc to the Association members states that the grant funding had been reinstated on a temporary basis through December 31st, 2009. On March 3rd, 2010, a letter was sent to the New Directions activities program participants reminding them that the agency is in the process of converting the consumers to Medicaid Waiver programs. The letter states that "When DHS finalizes this conversion, it will result in the loss of the current Client Family Support grant that has supported New Directions." The letter goes on to read that "They [the Arc's Business Committee] have decided to implement a private pay program with a sliding fee schedule for continued activities to be offered this fiscal year." The letter also states that "If you are interested in participating in activities at a reduced rate, you will need to verify your household income level." Attached with the letter is a New Directions Fact Sheet that explains what New Directions offers and how to access the program and a sheet with fee structure and payment options for the New Directions program. On that sheet, there is a sliding fee scale where the family can determine how much they will pay per hour based on family income and the number

of people in the family. There is also a Private Pay Option where an individual can pay \$27.54 per hour for a one-on-one activity or \$10.00 per hour for activities with three or more individuals. The sheet also states that "In addition to the above rates, individuals must pay any activity admissions and a \$5.00 transportation fee home. All participants must supply their own transportation to the Respite Center before the activity."

The HRA reviewed the Arc's Constitution and Bylaws. The Constitution and Bylaws state that the Board of Directors should include three classes of representatives, one of which being Parents. The Constitution defines Parents as persons "who are parents, step-parents, aunts, uncles, grandparents, legal guardians or siblings of a person living or deceased with mental retardation." The Constitution also states that "At least one-third, but not more than one-half, of the members of the Board of Directors shall be parents." The Bylaws also state that "The election of Board officers will be conducted according to the applicable Bylaw procedures for the election of directors." The Bylaw procedures allow members to vote on Board members at the annual meeting as well as nominate Board members. The Bylaws also state that "No director shall be elected for more than three consecutive terms of office, commencing with the first slate of directors elected after the adoption of these Bylaws." The "Qualifications and terms for officers" section of the Bylaws reads "All officers serve for one year commencing on July first" but the Bylaws do not state that there are term limits for the officers.

The HRA reviewed the Arc's Consumer Complaint Resolution Procedure. The procedure states that if the individual has a complaint, to first "Contact the individual's QMRP [Qualified Mental Retardation Professional] and explain your concern." The QMRP in this case acts as a caseworker for the consumer. The document states that next "The QMRP will investigate the matter and contact you with a reply." The third step states that "If you are not satisfied with this response, submit your complaint in writing to ... [Quality Assurance Director's Address]." The fourth step in the process states that "Within two weeks from receipt of your complaint, you will receive a written response from the Arc Management." The final step states that "If the agency has not resolved your complaint to your satisfaction, you may file an appeal with the Human Rights Advisory Committee of the Arc Board of Directors." The Arc also has a handout titled "Individual Complaint Resolution Procedure" that defines steps taken by the QMRP such as "For complaints not involving modification of the individual's IHP, the Quality Assurance Professional shall personally contact responsible site personnel to discuss the issue and resolve the complaint." This handout defines steps taken in the appeal procedure such as "All appeals must be filed within ten (10) working days of the complainant's receipt of the Management response or discharge of service." The HRA reviewed a copy of the individual's rights which is given to the individual on admission and signed by the individual/guardian as well as the QMRP. The document states that "The Arc shall apprise the individuals of their rights, rules and regulations, and complaint procedures. A copy of these documents shall be given to the individual, legal guardian, or to a responsible person upon admission." The document also states that "An individual, or his/her representative may present grievances to the Guardianship and Advocacy Commission, Equip For Equality and/or file an Individual Complaint Appeal with the Arc Human Rights Advisory Committee without threat of discharge or reprisal in any form or manner whatsoever. Individuals in CILA should also contact the Department of Human Services. The individual or his/her representative shall be provided with assistance in contacting these groups upon request." The document provides the address and phone number of the Arc's

Human Rights Advisory Committee, Equip for Equality, Guardianship and Advocacy Commission, and Department of Human Services. The document also gives the phone numbers for Long Term Care Ombudsman, Office of Inspector General, Department of Public Health Hotline and phone numbers for the Police Departments of Rock Island, Moline and Milan.

The HRA reviewed the Work Services Handbook, which outlined information such as when to take breaks, absentee policy, what to do in downtime, etc. Within the handbook, there is no mention of tasks that consumers could not do or tasks that would be farmed out to temporary workers.

The HRA reviewed a letter sent out to clients on June 30th, 2009 stating that DHS has notified the Arc that it will be terminating all funding and support for the Respite Program, the Supported Employment Program, and the New Directions program. The letter states that "It is with deep regret that I am writing to inform you that the Department of Human Services has notified us of its intent to terminate all funding and support for the Supported Employment/Respite/New Directions programs effective July 1, 2009." The letter goes on to state that "In an effort to try and provide you with some transition, The Arc will allow you to continue to attend up through July 14, 2009, and the Arc will absorb all losses associated with service up until that date." This letter leaves the consumer with a 14 day advance notice that the programs are being terminated.

The HRA examined a letter from a consumer's file regarding a meeting between parents and the Arc concerning a consumer's eligibility for a CILA program. The letter states "A meeting was held with [consumer's] Guardians to discuss the one male CILA vacancy which was offered to [consumer] through the conversion process from grant to Medicaid Waiver." The letter states that "Since [consumer] has seniority, the CILA placement was offered to him." This letter illustrates the lack of openings within the CILA program at the Arc and also that they do take steps with their consumers to determine eligibility for various programs.

The HRA reviewed a consumer's Employment Eligibility form which requests information about the consumer's work skills, mobility, communication, employment history, etc. This completed form is necessary to determine eligibility for any work services available through the Arc.

The HRA examined a newsletter titled "The Challenge" which featured articles about Arc members, consumers and staff. Within a copy of one of the reviewed newsletters (Winter 2010), there is a section titled "Mark Your Calendars" that gives the dates and names of Arc events that Association members can attend such as "Worker Recognition Event," "In The Know Meeting," and "Arc Association Annual Meeting." On the back page of the newsletter, there is an article titled "Introducing ... In the Know" which describes the new program and gives a monthly agenda of presenters. The Arc provided the HRA with a copy of its online newsletter titled "Fusion" that deals with similar issues as "The Challenge." The HRA also reviewed email correspondence between the Executive Director and the Association. The topics of these emails ranged anywhere from a social get-together for mothers of children with autism (January 13th, 2010) to an update regarding the entering of the 2nd half of the fiscal year (January 4th, 2010).

The HRA spoke with a Department of Human Services representative regarding the ability to charge sliding scale fees to the clients and the families of the client. If a provider is not receiving grants for a program from the DHS then they are not under the jurisdiction of the DHS, and the agency's ability to charge is not monitored by the DHS. If a provider is running a day program, or any other program, regardless of DHS grants, they still must follow Rule 119 and be certified with the DHS. The Department of Human Services representative stated that the Arc of Rock Island does have a day training program that is licensed and registered. The Department of Human Services representative also stated that when a provider receives grants, they must use the grant money for that specific program or they must contact DHS if they want to move the grant money from one program to another. The Department of Human Services also states that it is permissible to have non-disabled employees working in a vocational program but the DHS grant money cannot fund the non-disabled employees; the facility must pay their salaries.

The HRA reviewed a letter regarding a group of concerned family members who spoke to the Arc Business Committee regarding fees. The letter is from the Arc's Executive Director and states that the concerned family members attended the meeting and voiced their concerns. The Executive Director responded to the family members by saying the Business Committee determined to suspend the current fee schedule and apply an hourly fee of \$2 per hour through December 31st, 2009 which is the hourly rate the group proposed in the letter.

The HRA reviewed the meeting minutes from the September 15th, 2009 Board of Directors Meeting at which two guests were present. The meeting started with one of the guests presenting concerns regarding committee assignments and whether or not the meetings are open to observers. The meeting went into executive session at 7:10PM after the guest spoke and returned to regular session at 7:40PM. The rest of the meeting consisted of updates from the various Arc committees such as the Residential Committee and the Membership Committee.

Consumer File Review

With consent, the HRA reviewed four consumers' files as a part of the investigation. Consumer One lives at home and is a client of the Arc work program. The consumer was not impacted by the loss of grants to the Arc programs and did not lose access to the Arc's services. A review of Consumer One's treatment program showed that the family was part of the consumer's treatment team meeting and there is no evidence of a complaint from the family or the consumer regarding the Arc.

Consumer Two is involved in developmental training which is covered under Rule 119. The consumer lives at the Arc residential program and there is no evidence that the consumer is paying fees for Arc programs because she receives all programming and services through the Arc as a residential and vocational client. There is evidence of information exchanged between the family and the Arc.

Consumer Three is part of a grant funded program and was offered conversion into a Medicaid funded CILA program in December 2009 but the family refused. Consumer Three also received a notice letter on 6/30/2009 from the Arc explaining the DHS funding was cut for several Arc programs and the programs would no longer be offered. The letter stated that the

programs funded by the DHS grant were supported employment, New Directions, and the respite program. Consumer Three also received a letter of program reinstatement on 8/21/2009. On 9/20/2009 Consumer Three received a letter requesting income information from the consumer's family but the information was for public aid medical assistance and not for a lower, sliding scale payment for activities.

Consumer Four received a letter on 6/30/2009 regarding termination of the Arc's respite and New Directions programs. The Consumer also received a referral notice from the Arc after being laid off from his position with them. The referral does not state that the consumer received supported employment but, during the staff interview, it was stated that the consumer is part of the supported employment program.

The individual consumer files do show inconsistencies in treatment but these inconsistencies are based on the funding that each consumer receives rather than inconsistent practices or policies. For example, Consumer One was unaffected by loss of grant funding because the consumer was a part of the developmental training program, but Consumer Four was a part of the supported employment program and was laid off due to lack of funding.

MANDATES

The HRA researched state and federal mandates in accordance with the complaints raised within this report. The Department of Human Services states that "Agencies may transfer funds between programs within the agency plan guidelines distributed by the Department. Agencies desiring to reallocate funds in excess of agency plan guidelines must request this reallocation in writing prior to the expiration of the grant agreement" (59 Ill. Admin. Code 103.210). The Department of Human Services defines an "Agency Plan" as "The agency plan when fully executed as part of the grant agreement, serves as the formal statement of mutual expectations between the Department and the agency regarding contracted levels of service, costs and funding levels. The agency plan is a combination service plan and budget. It identifies what services will be provided, to what target group and the geographical area to be served. In addition, it identifies how the services will be financed, and through what budget items and funding sources. It becomes formalized documentation of the agreement between the Department and the agency through mutual execution of the grant agreement" (59 Ill. Admin. Code 103.150).

In regard to the complaint that the agency has inadequate grievance practices, the Illinois Administrative Code states that "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" (59 Ill. Admin. Code 119.235 e).

In regard to the complaint that services were abruptly and inconsistently ended until funding resumed, Department of Human Services Rule 119 states that "When a provider decides to terminate operation of a program, it shall notify the following of its decision at least 60 days in advance of the termination." The rule goes on to state that the bodies who need notified are the Department of Human Services, individuals who must be transferred or discharged, the individual's guardian and members of the individual's family, and, when applicable, the contractual staff and subcontractors working with affected individuals. Rule 119 also states that

"The provider shall advise individuals on available alternatives and shall assist them in securing alternative services. If the provider is unable to find an alternative, the Department shall assure placement for those individuals funded by the Department" (59 Ill. Admin. Code 119.320 a b c). Rule 119 applies to any developmental training programs offered but does not cover regular work programs, supported employment programs, or entertainment activities offered.

Rule 119 states that "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 that the behavior cannot be corrected through special training procedures" (59 Ill. Admin. Code 119.210 e).

Rule 119 also states that "Transportation required for individuals shall be the responsibility of the provider" (59 Ill. Admin. Code 119.200 d).

Also, The Mental Health Code reads "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" (405 ILCS 5/2-102).

CONCLUSION

Complaint #1: The Arc inconsistently applies practices and policies.

The complaint states that the Arc inconsistently applies practices and policies. The Arc stated that some individuals are not eligible for certain programs due to their ineligibility to receive Medicaid waivers and also due to the fact that they do not have seniority or are not eligible for certain work opportunities. The Arc stated an assessment determines if someone is eligible for work service plan, funding, program vacancies, etc. The HRA reviewed a questionnaire given by the Arc that is part of the eligibility process for vocational services. The HRA also examined meeting notes between a client's family and the Arc regarding an individual's eligibility at a CILA due to seniority. In regards to transportation funding, in accordance with Rule 119 transportation is the responsibility of the provider, but the HRA found no requirements regarding transportation for programs that are not covered under Rule 119. Also, the Regular Work and Supported Employment services were cut from the Arc due to funding but the Vocational Work program was still in place, which may have given the appearance that some clients were allowed work while others were not. The HRA did discover inconsistencies, but the HRA viewed these more as individualizations with the consumers based on their different funding methods rather than inconsistencies based on practices and policies. Due to the fact that the Arc has eligibility systems based on standards and guidelines, the HRA finds the complaint **unsubstantiated** but offers the following suggestion:

- If there are instances in the future regarding funding loss and programs being shut down, the reasons why some consumers are working while others are not should be communicated to the parents and family members more clearly. Also, the eligibility process for any program should be shared with the parents and the family members. The sharing of this information may eliminate some misunderstandings regarding complaints of inconsistent policies and practices.

- Consider holding treatment plan meetings for consumers impacted by funding so that individual needs and alternative resources are reviewed.

Complaint #2: The Arc charges fees for services that may be funded.

The complaint states that the Arc charges fees for services that may be funded. Through researching with the DHS, the HRA found that a provider is allowed to take grant money that was initially provided for one grant and place it with another grant with DHS notification and approval. The New Directions program was initially terminated due to a grant being cut, and then it was brought back with a private pay option that was more expensive due to grant cuts. Also, because of the nature of the program, it is not considered a registered DHS program but rather an extra program offered by the Arc. This type of program is also not under the jurisdiction of the DHS. Due to the fact that the HRA found no evidence that the Arc charges fees for services that may be funded, this complaint is **unsubstantiated**, but offers the following suggestion:

- Communicate to the Association and family members funding arrangements for various programs. Communicating openly regarding business and finances may eliminate concerns when charging fees for funded programs.

Complaint #3: The Arc attempted to assign fees based on parental income and assets.

The complaint states that the Arc attempted to assign fees based on parental income and assets. The HRA reviewed a letter from a Arc staff member explaining that they are implementing a private pay program regarding the New Directions program. The letter goes on to read "If you are interested in participation in activities at a reduced rate, you will need to verify your household income level." Attached to the letter is a grid of income levels and amount of members in the family. This sliding scale fee presented as a measure for families to save money when participating in the Arc's program. The HRA spoke to a DHS representative who stated that if a program is not receiving DHS funding, there are no requirements from the DHS on how fees are charged to the consumer. Also, the HRA found no other evidence through federal or state regulations regarding sliding fees. Due to the fact that the HRA found no mandate disallowing the assignment of fees based on parental income for grant funded programs, the HRA finds this complaint **unsubstantiated**, but offers the following suggestion:

- Part of the underlying issue with the fees presented to the parents and family, and part of the reasoning for charging on a sliding scale, is due to the fact that the fees are being raised to a substantially higher level that may cause many members to opt out of the programs. The HRA would like to stress the possibility of lowering prices for these activities through the use of volunteers instead of staff members, less costly activities, possibly attempting to find a reduced rate by inquiring with the venue if there is a group rate or if the organization can receive a lowered rate, etc.

Complaint #4: The Arc's Board of Directors is not accessible to clients and parents and Board practices have changed with regard to parental access to Board meetings and parent leadership on the Board and in committees.

The complaint states that the Arc's Board of Directors is not accessible to clients and parents and that board practices have changed with regard to parental access to Board meetings and parent leadership on the Board and in committees. The HRA reviewed the Board of Director's meeting minutes, which the Arc stated is open to members, parents, and family to attend, and saw that the specific meeting that was presented did have a guests present who expressed concerns regarding the Arc. The Arc did go into executive session at 7:10 and returned to regular session at 7:40. The Arc expressed that they only go into executive session to discuss matters that are confidential to the board such as finances. Also, the Arc Constitution and Bylaws state that at least one-third, but no more than one-half, of the members of the Board of Directors shall be parents. The Arc also stated that the Board is one person less than 50% of the Board consisting of family members. The Constitution states that it was adopted in 1995 and has no dated updates to the document which means that the practices have been in place for 15 years. Also, the Arc stated that every Association Member has a vote on who presides on the Board so it is up to the Association to create the Board and leadership. According to the Bylaws, the Officers are also voted on by the Association but the Bylaws do not state that the Officers have term limits. Also, the HRA reviewed a letter from the Executive Director regarding a group of concerned parents who attended an Arc business committee meeting on November 12th, 2009. The Arc did state that the committee members being appointed are solely the responsibility of the Board Chair. Due to the fact that the board practices have consistently been in place for 15 years, that there is parental leadership on the board, and that the meetings are open for guests to speak, the HRA finds this complaint **unsubstantiated** as a recipient rights violation, but offers the following suggestions:

- During Board Meetings, explain the reason for the Board entering executive session with the meeting guests without exposing any of the confidential information. This may alleviate concern that the Board is entering the session to eliminate parental involvement.
- Develop protocol to disseminate info and have one contact person that the parents come back to regarding the information.

Complaint #5: During a period of time when state funding was in question, many services were abruptly and inconsistently ended until funding resumed.

The complaint states that during a period of time when state funding was in question, many services were abruptly and inconsistently ended until funding resumed. The HRA reviewed a letter that was sent to program participants that gave them a 14-day notice regarding the programs being terminated. Rule 119 states that "When a provider decides to terminate operation of a program, it shall notify the following of its decision at least 60 days in advance of the termination" and goes on to identify those who need contacted as the DHS, the individuals who must be transferred or discharged, the guardian/family and, when applicable, the contractual staff and subcontractors working with the individuals. This rule covers developmental programs only and would not cover the New Directions or the Respite program. As stated in the Consumer File Review, Consumer Four was laid off from his position with the Arc but he was participating

in the supported work program, and therefore not covered by Rule 119 and therefore did not need the 60 days advance notice. The only consumers that would be covered by Rule 119 would be Consumers One and Two who are in the developmental training program; however, these consumers's services were not disrupted. Due to the fact that the consumers and programs affected by the service ending were not covered by 119, the HRA finds this complaint to be **unsubstantiated** and offers the following recommendations:

- Even though consumers may not be covered under Rule 119, any advance notice would be beneficial to the consumer along with treatment planning meeting to discuss other service options.

Complaint #6: The agency has recruited non-disabled person to work at jobs that Arc clients can do.

The complaint states that the agency has recruited non-disabled people to work at jobs that the Arc clients can do. The Arc has explained that, to complete a work assignment, at times they will hire temporary workers to complete the tasks that the Arc employees cannot complete. An example of this would be that Arc hired a non-disabled temp to work at a Hoseworker Job that no consumers could do because of mobility limitations. Based on the research, the HRA did not find any regulations or mandates that prohibit a vocational agency from hiring non-disabled workers to assist with contracts. Through researching with DHS, the HRA discovered that non-disabled workers are allowed to work within vocational programs as long as the facility is not funding their salary through DHS. The HRA finds the complaint to be **unsubstantiated** but offers the following suggestion:

- Document the Arc's standards for non-disabled employees and communicate them to the family members and the Association to alleviate any possible future misunderstandings.

Complaint #7: There is a general lack of information shared with clients, parents, other family members and the Association membership; there is also a lack of accountability to these stakeholders as well.

The complaint states that there is a general lack of information shared with clients, parents, other family members and the Association membership; there is also a lack of accountability to these stakeholders as well. The Arc has multiple meetings that can be attended by the Association Members, family members, parents and clients. Examples of these meetings include the Board of Director's Meeting, the "In the Know" informational and educational luncheon series for Parents and Guardians, the Arc Association Annual Meeting, and the meeting where members come for tea. The Arc also publishes a newsletter titled "The Challenge" that has articles regarding the Arc, the Arc staff, and Arc members. "The Challenge" also provides dates and times for meetings and events that are held by the Arc. The HRA also reviewed an online newsletter published by the Arc titled "Fusion" that deals with issues concerning the Arc. The HRA reviewed emails sent from the Executive Director to Association members dealing with topics such as the attending an autism awareness event, Medicaid reform, and updates concerning legislation and its affect on the Arc. The HRA also reviewed letters mailed to the members concerning fees and programs. Due to the various communication tools available to

the members concerned with the Arc and the opportunities given to obtain information, the HRA finds the complaint **unsubstantiated**.

Complaint #8: The agency has an inadequate grievance process.

The complaint states that the agency has an inadequate grievance process. The HRA reviewed "The Arc Consumer Complaint Resolution Procedure" that was given to all individuals, guardians, and family members. This document outlines the entire grievance procedure and appeal processes if the complaint has not been resolved to the individual's satisfaction. The HRA also reviewed the "Individual Rights" handout which is given to, and signed by, the individual. The form states that the Arc will "... apprise individuals of their rights, rules and regulations, and complaint procedures" and, on the back of the document, presents the option of presenting grievances to the Guardianship and Advocacy Commission, Equip for Equality, as well as the Department of Human Services, the Office of Inspector General, Long Term Care Ombudsman, and the Department of Public Health Hotline. The document also has the phone number for the Arc's Human Rights Advisory Committee Chairperson. The Arc stated that they have not received an internal complaint regarding this case and they have not received a complaint this year regarding any issues with the Arc. Due to the fact that the Arc has a grievance process in place as well as providing the information for outside agencies where the individual can voice a complaint, the HRA finds this complaint **unsubstantiated**, but the HRA offers the following suggestion:

- The HRA suggests that the Arc takes steps to promote its grievance process to the Association and family members. The Arc staff stated that they did not receive any grievances regarding the complaints in this report, nor have they received any grievances in the last year; however, multiple complaints came to the HRA in this case. This could be from a lack of communication between the Arc and its consumers which could be remedied with making the Arc population more aware of the grievance process and comfortable with using that process. An option for promoting the grievance process would be using the existing tools such as newsletters, emails, meeting, etc.

Overall, the complaints have a reoccurring theme of family members, consumers, and Association members lack of education on certain pieces of information such as why non-disabled employees are working for the Arc, why the family is being asked financial information for pricing, or why the Board goes into executive session. The Arc has multiple modes of communication, which would be excellent avenues for sharing and relaying information which would ease the parents with what is going on at the Arc, but overall some information is being held back as confidential. The HRA suggests that the Arc communicate more specific information with the parents regarding grant funding, where the funding is being distributed and why the money is being moved around, eligibility for programs, and why the Board goes into executive session during their meetings.