

A Deplorable Death

A Report on the Department on Disability Services' Failure to Provide Services to an Eligible Individual in Need

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UNIVERSITY LEGAL SERVICES, INC

Since 1996, University Legal Services, Inc (ULS), a private, non-profit legal service agency, has been the federally mandated protection and advocacy (P&A) program for individuals with disabilities in the District of Columbia (D.C.). Congress vested the P&As with authority and responsibility to investigate allegations of abuse and neglect of individuals with disabilities. In addition, ULS provides legal advocacy to protect the civil rights of District residents with disabilities.

ULS staff directly serves hundreds of individual clients annually, with thousands more benefiting from the results of investigations, institutional reform litigation, outreach, education and group advocacy efforts. ULS staff addresses client issues relating to, among other things, abuse and neglect, community integration, accessible housing, financial exploitation, access to health care services, discharge planning, special education, and the improper use of seclusion, restraint and medication.

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INTRODUCTION

Mr. Johnson¹ died in squalor. On February 19, 2008, he was found alone and unconscious, laying in feces and urine in his roach infested apartment. He arrived at Providence Hospital's emergency room in a diabetic coma. Tragically, he never regained consciousness and died four days later on February 23, 2008.

As early as 2001, Mr. Johnson's representative payee, concerned about his inability to care for himself, attempted to secure services for Mr. Johnson through the Mental Retardation and Developmental Disabilities Administration (MRDDA) now called the Developmental Disabilities Administration (DDA).² That effort proved unsuccessful. In early 2007, growing concerns about Mr. Johnson's medical conditions and the deteriorating conditions in his apartment prompted Family and Child Services of Washington, DC, (FCS), a local social services agency, as well as his court-appointed guardian, to seek emergency supportive housing for him through DDA. Tragically, bureaucratic delays and an inexplicable lack of urgency at DDA resulted in a continued lack of services. Mr. Johnson passed away without appropriate services and neglected by a system created to assist him.

Mr. Johnson was sixty-five years old at the time of his death. He lived at home, under his mother's care until her death approximately 15 years ago. After her death he lived in the same apartment, alone. Reports describe him as socially isolated, chronically disheveled and sleeping in the living room since "he appear[ed] to have anxiety about sleeping in the bedroom formerly occupied by his mother." His apartment was infested with roaches; there were observations of feces smeared on the walls, dirty dishes in the sink and trash strewn around the apartment and astonishingly he was once observed to have roaches crawling on him at a doctor's appointment.

Mr. Johnson had a complex medical history which included the diagnoses of heart failure, diabetes, high blood pressure, facial skin cancer and prostate disease. Realizing that Mr. Johnson's deteriorating living conditions were placing him at grave risk, in October 2006, FCS contacted DDA regarding obtaining services and housing for him. Throughout the lengthy application and approval process, concerns were voiced by his social worker and representative payee that Mr. Johnson was not able to take his multiple medications correctly and that he could not recognize when he needed assistance should his medical condition deteriorate. His medical doctor emphasized that Mr. Johnson was not able to take care of himself and that 24 hour supervision in a residential facility was needed.

Repeated pleas and warnings, from June 2007 until his death in February 2008, for an emergency placement due to Mr. Johnson's deteriorating ability to manage his multiple medical conditions and inability to care for himself went unheeded by DDA. For more than a year, DDA was informed about Mr. Johnson's declining condition, yet the services that he so desperately needed were never provided, despite ultimately being approved for services in November 2007. Had Mr. Johnson received the services he needed in a timely manner his quality of life would have been much improved and it may have prolonged his life.

METHODOLOGY

In late January 2008, ULS was contacted by the now former guardian of Mr. Johnson. The guardian was troubled by the fact that Mr. Johnson, who later passed way on February 23, 2008, had yet to receive a single service from DDA, despite being found eligible for services and supportive housing on November 6, 2007. The guardian felt DDA neglected their duty to provide services to Mr. Johnson and requested that ULS investigate to determine why DDA had yet to provide services to Mr. Johnson despite his unequivocal need for emergency DDA intervention. As ULS began its investigation into the guardian's concerns, by requesting Mr. Johnson's records, Mr. Johnson was hospitalized and subsequently passed away.

Under the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), P&As have the authority to investigate reports of abuse and neglect and deaths involving people with developmental disabilities. See 42 U.S.C. § 15043. To aide in its investigation, ULS requested and obtained Mr. Johnson's records from DDA, his court-appointed guardian, FCS and the medical examiner's external examination report from the DC Medical Examiner's office. An autopsy was not performed.

ULS received and reviewed the following records to prepare this report: DC Medical Examiner's External Exam Report dated April 17, 2008, Psychological Evaluation dated June 7, 2007, Psychological Evaluation dated January 29, 2008, Family and Child Services of Washington, DC records, DC Arc records, DC Institute of Mental Hygiene records, Department on Disability Services records, physician correspondence dated October 26, 2007, November 2, 2007 and January 8, 2007, DC Superior Court Petition for Guardianship dated October 2, 2007 and DC Superior Court Findings of Fact, Conclusions of Law and Order dated November 1, 2007.

RECORDS REVIEW

Social/Medical History

According to a June 2007 Neuropsychological Evaluation (2007 Neuropsychological Report), Mr. Johnson's mother never sent him to school and he was apparently never employed. However, a February 2008 Social Work assessment (2008 SW Assessment) drafted by DDA, states that Mr. Johnson did attend elementary school in Washington, DC. Nevertheless, when DDA attempted to obtain Mr. Johnson's records from DC Public Schools (DCPS), they claimed no records could be found.

Mr. Johnson was reportedly hit by a bus between the ages of 3 and 4 and sustained a traumatic brain injury (TBI) resulting in a diagnosis of mental retardation (MR).³ The 2007 Neuropsychological Report revealed that Mr. Johnson functioned in the extremely low range and below the 1st percentile for individuals his age. In addition, his verbal intellectual abilities, including reasoning and judgment, working memory, nonverbal intellectual abilities and adaptive behavioral functioning were also extremely low. The 2007 Neuropsychological Report shows a diagnosis of MR and Mixed Receptive-Expressive Language Disorder. Additionally Mr. Johnson's records show that

between 1987 and 1991, he attended the District of Columbia ARC⁴ and received services from the DC Institute of Mental Hygiene. There is no indication of why or when services from the DC Institute of Mental Hygiene were discontinued.

With no known living relatives, Mr. Johnson was assigned a volunteer representative payee through the American Association of Retired Persons (AARP) Legal Counsel for the Elderly program following his mother's death who assisted him in paying bills, grocery shopping and light housekeeping. The representative payee, who saw Mr. Johnson approximately twice a week, observed decreases in Mr. Johnson's ability to care for himself according to the 2007 Neuropsychological report. In addition, Mr. Johnson had difficulty living independently, cleaning his apartment, attending to his personal hygiene, and cooking; in the past he had received a bad burn on his arm after attempting to cook on the stove.

In November 2006, Mr. Johnson received a notice from his property manager regarding the conditions of his apartment. According to FCS records, FCS was able to arrange for a home health agency to assist Mr. Johnson and for a professional cleaning service to deep clean the apartment. However, by December 2006, the home health agency had terminated Mr. Johnson's case because of the continued unhealthy condition of his apartment. However, according to FCS records, the home health agency rethought their decision and continued to provide services to Mr. Johnson. In March 2007, they reported his need for intervention to Adult Protective Services (APS). Following the referral to APS, arrangements were made to again have the apartment professionally cleaned and fumigated and for Mr. Johnson to continue receiving services from the home health agency. In a letter to MRDDA dated June 2007, Mr. Johnson's FCS social worker reported that Mr. Johnson was unable to maintain the cleanliness of the apartment and that the home health agency refused to work in such unsanitary conditions and closed his case.

According to a 2008 Psychological Evaluation (2008 Psychological Report), conducted by DDA, despite being able to toilet himself, Mr. Johnson's representative payee observed feces on the wall of his bathroom and wet spots on the floor of the apartment of unknown origin. FCS and Mr. Johnson's representative payee reported that his apartment was disorganized, challenged by odors of unknown origin and infested with roaches. Astonishingly, a September 2007 FCS Social Work Assessment (2007 SW report), indicated that during a doctor's visit Mr. Johnson had roaches crawling on him. The report states that:

[d]espite the heavy house cleaning and several exterminations, there are roaches everywhere in the apartment. Client does not take out his trash which only perpetuates the roach infestation . . . [C]lient's hygiene is unacceptable . . . It is unclear how often client bathes. On one occasion SW [social worker] met . . . client for client's medical appointment and client had roaches crawling on him in the doctor's office. Rep payee reports . . . that he has found feces on the wall of the client's bathroom.

In addition to being diagnosed with an intellectual disability, Mr. Johnson had from multiple medical conditions including high blood pressure, diabetes, heart disease and skin cancer of the face.

His medical conditions were being managed by his primary physician, who prescribed seven daily medications. Both the 2007 Neuropsychological Report and the 2008 Psychological Report state that Mr. Johnson's compliance with his medication regime varied and at times he did not take his medications. A January 8, 2007 letter from his primary care physician states:

It is my impression that the degree of mental retardation is moderate to severe, and that he is not able to take proper care of himself. On numerous occasions he has presented to the office in a disheveled state and does not have acceptable hygiene. It is my recommendation that Mr. [J] have 24 hour supervision, in a residential facility . . .

The 2008 Psychological Report further emphasized the need for 24 hour supervision due to Mr. Johnson's inability to take his medications and to recognize symptoms of his illness worsening.

Medically, he relies on his care givers to pick up his medications . . . however, it is not known if Mr. [J] in fact complies with the medication. . . . He is not aware of when to seek medical help in cases of emergency and does not understand the directions for health care procedures or medical treatment Mr. [J] has a history of poor compliance with his medications prescribed to treat his various medical ailments.

Mr. Johnson could not call for help when his medical condition worsened as the 2008 Psychological Report indicates that Mr. Johnson was not able to use a telephone. The volunteer representative payee found Mr. Johnson unconscious in his apartment on February 19, 2008, in the middle of feces and urine. According to a review of Mr. Johnson's medical records from Providence Hospital, it is difficult to determine how long Mr. Johnson had been at home in this condition. Mr. Johnson had deteriorated to the point of being unconscious and in critical condition when he was found. He arrived at the hospital in an extremely unstable condition with severe diabetic ketoacidosis (diabetic coma), hyperglycemic, sepsis, hypotensive (low blood pressure), and anuremia (no urine output.) He required intubation and was placed on a breathing machine. He never recovered from his critical condition and remained unstable throughout his hospital stay. He died four days later on February 23, 2008.

APPLICATION FOR SERVICES

2001 Application for Services

Mr. Johnson's representative payee applied to MRDDA on Mr. Johnson's behalf sometime between 2000 and January 2001. (Though requested, DDA did not provide ULS with a copy of this application). In a January 2001 letter to Mr. Johnson's representative payee, an MRDDA representative stated that they needed additional information regarding Mr. Johnson's diagnosis of MR or DD, and requested a copy of his most recent health assessment and photo identification card as well as a psychological assessment showing his MR or DD diagnosis prior to his eighteenth birthday. These documents would need to be provided before MRDDA could process the application.

In a letter dated May 2002, DDA' acting intake chief informed Mr. Johnson that his application for services was denied because of a lack of pre-eighteen diagnostic information. There is no indication from the record that MRDDA assisted Mr. Johnson or his volunteer representative payee in obtaining the pre-eighteen diagnostic information nor is there any indication if anyone requested a review of MRDDA's decision or what, if any, services anyone arranged in lieu of MRDDA services.

Referral to Family and Child Services of Washington, DC

In January 2006, Mr. Johnson was referred to FCS for an assessment of his continued ability to live alone. He was assigned a social worker who attempted to enroll Mr. Johnson in a community residential facility (CRF). However, the social worker learned that Mr. Johnson could only afford this type of supportive housing by receiving this service through MRDDA. This resulted in FCS 'attempt to apply for services through the MRDDA system on Mr. Johnson's behalf.

2007 DDA Application for Services

Beginning in October 2006, FCS attempted to contact DDA to provide services and supportive housing to Mr. Johnson. According to FCS records, Mr. Johnson's social worker met with a DDA intake case worker and obtained a DDA application on February 8, 2007.⁵ At that time, the case worker stated that Mr. Johnson was a previous DDA consumer but that his case was closed.

The case worker informed the FCS social worker that Mr. Johnson needed to be diagnosed via a psychological examination with mental retardation or a developmental disability prior to his eighteenth birthday and would need to see a psychologist for updated Intelligence Quotient (IQ) and Adaptive testing. In an attempt to provide DDA with the pre-eighteen diagnostic information they required, Mr. Johnson's physician referred him for a Neuropsychological Evaluation which confirmed the mental retardation diagnosis. While this was occurring, FCS notes indicate that his social worker attempted to figure out a way to move him more quickly through the system, but none were found.

On June 26, 2007, a completed DDA application was submitted to DDA along with a letter from FCS requesting immediate action in light of Mr. Johnson's deplorable living conditions and his need for emergency supervision and intervention. Included in the application was a copy of the 2007 Neuropsychological Report diagnosing Mr. Johnson with moderate MR with onset before the age of eighteen. Mr. Johnson's case was assigned to a DDA case worker.

According to DDA case notes, Mr. Johnson's application was deemed incomplete because it did not include information showing a pre-eighteen mental retardation diagnosis, despite the submittal of the 2007 Neuropsychological Report discussed above. DDA suggested that Mr. Johnson should enroll in the Elderly and Physical Disabilities waiver program (EPD) in lieu of receiving services through DDA. According to DDA case notes, FCS attempted to enroll Mr. Johnson in the waiver program, but was unsuccessful. On August 13, 2007, DDA requested Mr. Johnson's records from DCPS in an attempt to locate records showing Mr. Johnson's pre-eighteen mental retardation diagnosis. DCPS was unable to locate any records related to Mr. Johnson.

DDA Case Conference

Following continued pressure from FCS and APS, DDA held a status conference for Mr. Johnson on September 18, 2007. DDA did not provide an emergency placement; instead they recommended more neurological testing to determine Mr. Johnson's pre-eighteen diagnosis of mental retardation or a statement from a neighbor attesting to Mr. Johnson's MR diagnosis. In addition, they recommended Mr. Johnson obtain a court-appointed guardian and a psychiatric evaluation.

Pursuant to DDA's recommendations, FCS continued to search for records showing Mr. Johnson had a diagnosis of an intellectual disability prior to his eighteenth birthday. They also contacted Mr. Johnson's physician to obtain any pre-eighteen mental retardation diagnostic records. The physician provided FCS with a letter verifying his treatment of Mr. Johnson and that in his medical opinion Mr. Johnson's diagnosis of mental retardation was congenital and present prior to the age of eighteen. The doctor's letter was forwarded to DDA on October 30, 2007. Also in keeping with DDA's recommendations from the September 2007 case conference, FCS, with assistance from a student attorney at Catholic University's Columbus School of Law, filed a petition for guardianship for Mr. Johnson on October 2, 2007, in DC Superior Court. The guardianship hearing was held on November 1, 2007, at which time a permanent general guardian was appointed for Mr. Johnson.

According to FCS records, DDA continued to delay granting Mr. Johnson services, and, in November 2007 inexplicably requested an MRI of Mr. Johnson's brain to determine a diagnosis of pre-eighteen mental retardation. A second letter, dated November 2007 and submitted to DDA by Mr. Johnson's physician, stated that an MRI of his brain would not determine the duration of Mr. Johnson's mental retardation. He again asserted his medical opinion that Mr. Johnson's mental retardation was congenital and not acquired after Mr. Johnson's eighteenth birthday. When confronted with this information, DDA psychologist, Dr. Bradby, requested a copy of Mr. Johnson's brain injury report. (There is no such report included in any of the records ULS obtained from DDA, FCS or Mr. Johnson's guardian). FCS case notes report that a brain injury report never existed to their knowledge.

APPROVAL FOR SERVICES

Mr. Johnson was finally found eligible for DDA services on November 6, 2007. Despite the urgency required, DDA did not request a date for the pre-Individual Support Plan assessments until November 28, 2008. These assessments were to be used to determine what services Mr. Johnson needed. Without explanation, Mr. Johnson's assessments were not scheduled until January 17, 2008. It is unclear why the assessments were not expedited, nor is it clear why emergency housing was not immediately arranged given the overwhelming evidence that Mr. Johnson's situation required emergency intervention.

Assessments and ISP Meeting

On January 17, 2008, Mr. Johnson underwent assessments by a DDA social worker, dentist, nutritionist and psychologist. The DDA psychologist, Dr. Lockwood, stated she was quite concerned about Mr. Johnson, and asked the DDA case worker if an emergency placement was available. The DDA case worker responded that DDA was not using emergency placement because of funding. The DDA case worker informed Dr. Lockwood that an Individual Service Plan meeting would be scheduled before the end of January. Mr. Johnson remained alone in his apartment, without the emergency housing DDAs' own psychologist recommended.

From January 18, 2007, through January 31, 2007, FCS and Mr. Johnson's guardian began contacting DDA to request a date for the Individual Service Plan. Finally, on January 31, 2008, they were able to speak with Carole Davis, a DDA supervisor, regarding their requests for an Individual Service Plan meeting date. The Individual Service Plan meeting was finally scheduled for February 4, 2008. This information was then forwarded to the Individual Service Plan writer. The DDA case worker also informed the Individual Service Plan writer that Mr. Johnson's case was in turmoil and that Ms. Davis and DDA Director, Judith Heumann were now involved. At the Individual Service Plan meeting, DDA recommended that Mr. Johnson be placed in an ICF-MR and receive day habilitation from a senior day program.

Approval for DC Medicaid and Prior Authorization for ICF-MR

Mr. Johnson was found eligible for DC Medicaid long-term care at an ICF-MR on February 12, 2008. Tragically, there is no evidence that any further action was taken to actually provide the critical services Mr. Johnson needed.

MR. JOHNSON'S DEATH

On February 19, 2008, Mr. Johnson was found unconscious in his home by his representative payee. He was brought by ambulance to Providence Hospital's emergency room. He arrived in critical condition and required immediate placement of a breathing tube. The hospital progress notes state he was unresponsive. Upon learning of Mr. Johnson's hospitalization, The DDA case worker visited the Providence Hospital Intensive Care Unit (ICU) to check on Mr. Johnson's status. She was escorted off the unit because she was not family, but was informed that Mr. Johnson was in critical condition and still in a coma. Sadly, Mr. Johnson never regained consciousness and died on February 23, 2008. Mr. Johnson's guardian informed the DDA case worker on February 29, 2008, of Mr. Johnson's death. The DDA case worker was apparently shocked by the news, and DDA offered to obtain funding for Mr. Johnson's funeral through the burial assistance program. If this in fact occurred, it would be the only actual service DDA ever provided to Mr. Johnson

DDA notified the Metropolitan Police Department Special Victims Unit and the Medical Examiner's office following Mr. Johnson's death. According to an e-mail from a DDA intake specialist to the DDA case worker on March 3, 2008, DDA's Incident Management Investigation Unit (IMEU) scheduled a meeting with Mr. Johnson's guardian and requested the DDA case worker's presence at the meeting. According to the e-mail, the DDA intake specialist cautioned the DDA case worker to answer IMEU's questions and to "[g]o according to record." It is unclear why the DDA case worker

needed to be cautioned to “[g]o according to record,” whether this meeting occurred or the outcome of the meeting.

CONCLUSION

Although DDA was well aware of Mr. Johnson’s urgent need for services as early as 2001, over six years had passed before he was finally approved for services. For at least the last year of his life, Mr. Johnson continued to live in squalor with roaches infesting his home, and without services and supports to ensure that his fragile medical condition was being managed properly. Even after the application was complete, and in spite of DDA’ knowledge of the urgency, DDA took approximately five (5) months to approve Mr. Johnson for services and almost another two (2) months more to schedule and hold the assessments, the Individual Service Plan meeting, and finally authorize Mr. Johnson for supportive housing.

It is clear that DDA refused, on numerous occasions, to provide even interim emergency assistance as far back as 2001. Despite evidence that Mr. Johnson received services from the DC Arc and DC Institute of Mental Hygiene as far back as 1991, DDA failed to accept this documentation as preliminary evidence of Mr. Johnson’s eligibility pending further evaluation. Moreover, they failed to assist Mr. Johnson’s volunteer representative payee in obtaining the needed documentation of a pre-eighteen mental retardation diagnosis and denied Mr. Johnson services.

In June 2007, DDA again attempted to deny services to Mr. Johnson for not producing records showing a pre-eighteen mental retardation diagnosis, despite the fact that a 2007 Neuropsychological Report clearly showed that in light of Mr. Johnson’s subnormal intelligence and adaptive behavioral impairments, he was an individual with mental retardation, with an onset before age eighteen. This diagnosis concurred with Mr. Johnson’s own physician who also believed, in his medical opinion, that Mr. Johnson was an individual with mental retardation and that the mental retardation was congenital and present prior to age eighteen. DCPS’ failure to maintain records was also used to delay eligibility.

It was only with the continued persistence of Mr. Johnson’s FCS social worker, his volunteer representative payee and later, his court-appointed guardian that DDA finally approved Mr. Johnson for services based on the documentation accompanying Mr. Johnson’s DDA application in June 2007. Following approval for services, DDA should have immediately offered emergency supportive housing for Mr. Johnson, as suggested by DDA psychiatrist, Dr. Lockwood, during the DDA psychiatric assessment in January 2008. Instead, DDA waited until Mr. Johnson was deceased before they provided a single service – assistance in obtaining funding for his burial.

RECOMMENDATION

Due to the egregious lapse in services for Mr. Johnson, ULS recommends that the Columbus Organization conduct a full investigation into why services were never offered to Mr. Johnson prior to his death and if his death could have been avoided if DDA had provided emergency housing and services to Mr. Johnson pending a finding of full eligibility.

In addition, DDA must review its eligibility criteria. DCPS' failure to maintain records or failure to appropriately diagnose or identify individuals with intellectual disabilities should not be used as a basis to deny services.

¹ This is not the actual name of the individual referenced throughout this report. ULS is using a pseudonym in accordance with the Health Insurance Portability and Accountability Act of 1996 (HIPAA).

² In January 2007, MRDDA became the Developmental Disabilities Administration (DDA) pursuant to the Developmental Disabilities Services Management Reform Emergency Amendment Act of 2006.

³ Although this report uses the terms "mental retardation" and the abbreviation "MR" because this label is part of the factual presentation; it is more appropriate and respectful to use the term "intellectual disability."

⁴ The DC ARC works to improve the quality of life of all persons with developmental and intellectual disabilities and their families through supports and advocacy.