A VOICE IGNORED:

REPORT ON A DEATH AT A NURSING FACILITY

October 2013

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220 I Street, NE Suite130
Washington, D.C. 20002

The Protection and Advocacy Agency
for the District of Columbia

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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SUMMARY

Mr. Benning[1] was in his mid-fifties[2] at the time he fell to his death from a fourth floor window of a nursing facility in March 2012.[3] Neither the police nor an investigation by the District's Department of Health determined why he fell – whether it was an intentional suicide or an accident. One thing is certain – he wanted to leave. His death serves as a dramatic and troubling reminder that we should respect an individual's choice to live and participate in the community and that we must act in accordance with federal law to make this desire a reality.

Mr. Benning was admitted to Deanwood a year and a half before, with a primary diagnosis of "Failure to Thrive."[4] His weight at the time he entered Deanwood was 112 pounds.[5] The initial intake documents described a man with no emotion – "exhibits flat affect."[6] He was, however, described as able to "make his needs known" and "to make clear judgments."[7] Without explanation, the initial document listed his discharge potential as "poor."[8] Deanwood completed the District's Pre-Admission Screen/Resident Review for Mental Illness and/or Intellectual Disability ("PASRR") on October 29, 2010. The form indicated that he had a major mental illness ("schizophrenia") but had been checked "no" to the question of whether the mental illness "resulted in serious functional limitations in major life activities within the past 3 to 6 months."[9] The case manager completing the form did not refer him to the D.C. Department of Mental Health ("DMH") for a Level II screening[10] as required by federal law.

Nevertheless, a DMH provider was involved in Mr. Benning's life. Before entering Deanwood, Mr. Benning had been receiving assertive community treatment ("ACT") services from the Green Door, a community mental health core service agency ("CSA"), and Green Door continued to provide treatment to Mr. Benning after he entered the nursing facility, visiting him regularly.[11] Though Deanwood continued to claim in its forms that Mr. Benning did not verbalize any desire to leave,[12] he repeatedly told Green Door that he desperately wanted to leave.[13] Then on February 7, 2012, one month before his death, Green Door discharged Mr. Benning from its rolls, meaning that he would no longer have access to their mental health services. There was no clear explanation for closing his case except that he had a "Nursing Home Placement."[14] His final Individual Treatment Plan, completed on January 16, 2012, had

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[1] The name has been changed to protect the confidentiality of the individual.

[2] Deanwood Admission Record, dated 6/7/2011 at 17:30.

[3] Memo to Sharon Williams Lewis, Program Manager, from Tamara Freeman, Nurse Consultant, and Eddy Wolff, Sanitarian, D.C. Department of Health, Health Regulation and Licensing Administration, undated ("DOH Report") at 1; Metropolitan Police Department ("MPD") WACIIS Investigative Supplement Report dated 3/9/12 at 2.

[4] Deanwood Social Services Department Initial Assessment Psychosocial History dated 10/15/10 at 1.

[5] Resident Summary dated 10/15/10 at 3.

[6] Deanwood Social Services Department Initial Assessment Psychosocial History dated 10/15/10 at 2.

[7] Id. at 1.

[8] Id. at 3.

[9] PASRR dated 10/29/10 at 1.

[10] Id. at 2.

[11] Green Door Multi-Service Progress Notes dated 9/11/09 to 3/9/12.

[12] See Elopement Risk Assessment Tool dated 6/11/11, 9/6/11, 12/6/11, and 3/6/12 at 1.

[13] See discussion *infra* 6 - 8.

[14] Green Door Discharge Summary dated 2/8/12 at 1.

been written to extend until July 14, 2012.[15] At the time, the documents state that Mr. Benning was independently ambulatory.[16] Moreover, he weighed 182 pounds[17] - no longer reflecting a "Failure to Thrive" diagnosis.

ULS's review of the records revealed that neither Deanwood nor Green Door took active steps to address Mr. Benning's tremendous desire to leave Deanwood. Deanwood staff failed to heed his expressed interest in transitioning to the community, and failed to properly record his desire in his records. Instead, staff incorrectly or falsely indicated that Mr. Benning did not want to leave the nursing facility and that he was incapable of expressing his opinion, even though he very clearly told Green Door that he longed to leave. This failure resulted in his prolonged stay at Deanwood and potentially his death. Deanwood staff neglected Mr. Benning by failing to adequately assess his ability and desire to live in the community. Green Door failed to take steps to enable his discharge though he made his desire known to its staff. Ultimately, Green Door stopped visiting Mr. Benning and discharged him from the Green Door rolls because the "nursing home would be taking care of all his needs."[18] Had Deanwood and Green Door acted on his expressed desires by facilitating his discharge, Mr. Benning might be living in the community today as he desired.

METHODOLOGY

Under federal law -- the Protection and Advocacy for Individuals with Mental Illness ("PAIMI") statute, 42 U.S.C. § 10805, P&As have the authority to investigate complaints of abuse and neglect, including deaths involving people with mental disabilities. For this report, ULS reviewed records provided by the District of Columbia Metropolitan Police Department ("MPD"), the Green Door, Deanwood Rehabilitation and Wellness Center, and the D.C. Department of Health ("DOH"). ULS expresses its appreciation to the Green Door and to Deanwood for their quick response to ULS' record requests. ULS reviewed the MPD reports provided; the DOH Report; the Deanwood PASRR report, physicians' orders, initial intake forms, Minimum Data Sets, psychiatric evaluations, and behavioral records; as well as Green Door's Individual Recovery Plans, assessments, LOCUS forms, Discharge Summaries, and progress notes.

SUMMARY OF THE INCIDENT OF DEATH

On Friday, March 9, 2012, around 6:00 a.m. a nursing assistant went to Mr. Benning's room where he and three other men lived. She helped him to the restroom, then left the room. While she was in the room, "the window was closed."[19] A phlebotomist came in at around the same time to assist another resident in the room and saw Mr. Benning sleeping. "The window

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[15] Green Door Treatment Plan dated 1/16/12 at 1.

[16] Elopement Risk Assessment Tool at 1.

[17] Deanwood Weight Records dated 3/1/12.

[18] Green Door Multi-Service Progress Note date 2/17/12. Mr. Benning's final LOCUS score was done on January 4, 2012, which recommended continued ACT services (Locus Evaluation Report dated 1/4/12 at 1); nevertheless, he was discharged to the care of nursing home without explanation a little more than a month later. Multi-Service Progress Note dated 2/17/12.

[19] DOH Report at 6.

was closed."[20] An LPN Charge Nurse came into the room and performed a finger stick test on Mr. Benning, told Mr. Benning the results were good then she left. "The window was not open."[21] Moments later, a woman outside the Deanwood building heard someone "hollering then a thump." She saw Mr. Benning on the ground and then flagged down a nearby policeman. Emergency services were called.[22]

The police found Mr. Benning on the ground below his fourth floor window on top of the window screen – "unconscious, unresponsive, breathing with multiple broken bones."[23] Beside him was a New Testament Bible, a scripture pamphlet – Our Daily Bread, and one black tennis shoe.[24] None of the residents of the room had seen Mr. Benning go through the window. The curtains around each of their beds were pulled closed. One resident explained: "The curtains were pulled, I heard them [facility staff] talking when they were running in the room and they said he jumped out of the window. I felt the cold [air] after they came in the room. The window normally stays closed. . . . I didn't hear anything."[25] Neither the police reports nor the DOH Report stated whether the death was intentional or accidental.

<u>MR. BENNING WANTED TO LEAVE THE NURSING FACILITY</u>

Beginning in August 2011, Green Door clearly documented that Mr. Benning wanted to leave Deanwood and move back to the community. Notes of the Green Door case worker quoted him again and again – pleading to leave. Mr. Benning's own words provide a litany of the isolation and tedium he felt in the nursing facility:

> "Consumer continues to express difficulty living in close proximity to other resident, stating ***"I feel trapped and just have to stay and bear the situation out."*** . . . When asked what thoughts come to mind before falling asleep, consumer stated ***'I hope that I'll be able to leave there [nursing facility] one day.'"*** Multi-Service Progress Note dated 8/2/11.
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> "Consumer continues to express difficulty living in close proximity to other resident." Multi-Service Progress Note dated 8/9/11.
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> "Consumer continued ***'While I lie in bed I think of trying to get out of Deanwood somehow or another.'"*** Multi-Service Progress Note dated 8/23/11.
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> "Consumer reported ***'I mostly stay in room lying in bed wondering if I will ever get out of here.'"*** Multi-Service Progress Note dated 8/25/11.

[20] <u>Id.</u>
[21] <u>Id.</u> at 6-7.
[22] MPD Incident-Based Event Report dated 3/9/12 at 2.
[23] MPD Death Report dated 3/9/12 at 1; MPD WACISS Investigative Supplement Report dated 3/9/12 at 2.
[24] MPD Evidence Report dated 3/9/12 at 1.
[25] DOH Report at 8 (brackets in original).

"Consumer agreed to accompany recovery specialist on outing to increase activity and improve mood. Consumer stressed '***I'm just glad to be away from Deanwood for a little while. I still think about getting out of here.***'" Multi-Service Progress Note dated 9/13/11.

"When asked how he was coping, consumer stated: '***Just trying to hang in there, its [sic] difficult trying to avoid other resident.***' Consumer noted: '***I'm just not myself anymore. The biggest thing is not wanting to be there mainly.***'" Multi-Service Progress Note dated 10/6/11.

"Consumer stressed '***There's really not much to do during the day. I feel stuck here at Deanwood.***'" Multi-Service Progress Note dated 11/1/11.

"When encouraged to reflect on his thoughts, consumer stated '***At night I worry about what's going to happen next and ultimately whether I will get out of here or not.***' When asked what activities he was participating in during the day, consumer replied '***I've been going to bible study and watching movies. Besides that pretty much staying in my room.***' Consumer stressed '***It's disheartening having to go through the same things each day.***'" Multi-Service Progress Note dated 11/8/11.

"Consumer continues to isolate in room[.] Consumer stated '***I've been trying to get out of room, but mainly just be on the bed resting and thinking about whether I'll be able to get [out] of here [Deanwood]*** [this bracket in the original] ***or not.***' Consumer reiterated few activities to participate during the day, remarking '***Bible study is mainly it. I don't really care for it that much.***'" Multi-Service Progress Note dated 11/10/11.

"Consumer agreed to accompany recovery specialist on outing to increase activity and improve mood. Client continues to express desire to move to another facility." Multi-Service Progress Note dated 1/27/12.

"Client's mood appeared dysphoric and his affect constricted. Client's self-report '***Not too excited about things. I'm kind of bored most of the time, which leaves feeling agitated sometimes. I feel more antagonistic and angry.***" Multi-Service Progress Note dated 2/3/12.

"Client stressed that he often feels lonely and isolated, stressing '***there's not a lot there to hold my interest.***" Multi-Service Progress Note dated 2/7/12.

At his last meeting with client, the recovery specialist noted: "Client's mood was depressed and his affect constricted. Client self-reports '***feeling down.***' When informed that he would no longer be meeting recovery specialist each week – as nursing home would be taking

care of all his needs -, client remarked '***Well it's a blow because I won't be able to get to meeting [NA/AA meetings.]*** [Brackets in original.] ***Maybe something can be arranged so I can get there.***'" Multi-Service Progress Note dated 2/17/12.

On being notified of Mr. Benning's death, the Recovery Specialist noted: "Recovery Specialist offered details of client's psychiatric and medical functioning: . . . (2) isolated himself in bedroom whom he shared with three other residents; (3) expressed desire to leave nursing facility; (4) ongoing difficulty getting along with staff and residents; . . .." Multi-Service Progress Note dated 3/9/12.

Without a doubt, Mr. Benning did want to leave Deanwood. These were not the complaints of an individual who could not verbalize his desire to leave. Nothing in the notes explains why Mr. Benning could not be transitioned to the community to live independently with appropriate in-home supports to assist with his activities of daily living (bathing, dressing, toileting, eating, and mobility), instrumental activities of daily living (meal preparation, house cleaning, laundry, medication administration), and community mental health services.

MR. BENNING'S NEEDS SHOULD HAVE BEEN MET WITH APPROPRIATE COMMUNITY-BASED SERVICES

Mr. Benning's October 2010 admission records indicated that his primary diagnosis was "Adult Failure to Thrive."[26] His weight at the time he entered Deanwood was 112 pounds.[27] In addition, he had secondary diagnoses of "schizophrenia, hypotension, elderly abuse and neglect, and trauma to face with multiple [facial] fractures, malnutrition, anemia, DM II [type 2 diabetes], HIV/AIDS, dementia, dyspnea, PVC [premature ventricular contraction] ."[28] However, by the time Mr. Benning had been at the facility for little more than a year, records indicate that his health was significantly improved. At the time of his final Individual Treatment Plan, completed on January 16, 2012, Mr. Benning was independently ambulatory.[29] Moreover, he weighed 182 pounds, eliminating the failure to thrive diagnosis with which he was admitted.[30] When he died, Mr. Benning weighed 184.5 pounds.[31] A physical completed a month before his death found him "well developed" and "well nourished."[32] He had achieved significant weight gain and improved physical health.[33]

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[26] Deanwood Social Services Department Initial Assessment Psychosocial History dated 10/15/10 at 1.

[27] Resident Summary dated 10/15/10 at 3.

[28] Physician's Order dated 1/25/12 at 1, 3.

[29] Elopement Risk Assessment Tool at 1.

[30] Deanwood Weight Records dated 3/1/12.

[31] Deanwood Weight Records dated 3/1/12.

[32] Deanwood Physician History & Physical/Progress Note dated 2/12/12.

[33] Mr. Benning had been appointed a guardian; however, the court records indicate that the guardian had little involvement in Mr. Benning's care. The guardian failed to file a required annual report and was ordered to do so by the court. Except for the report of his death, only one report was filed with the court in December 2011. The statement in the report concerning his physical health noted that it had improved: "He received a new set of dentures so improving nutritional well being."[33] The report noted he "[g]oes to AA once per week, Fit for Life recreational therapy, Bible Studies, and also participates in social activities provided by the facility eg. Halloween party."[33] The guardian checked "I believe the ward is: Content."

The District provides significant services to individuals living in the community so that they can live in their own homes and avoid institutional settings. The Medicaid Waiver for People who are Elderly and/or have Physical Disabilities ("EPD Waiver") enables individuals with physical disabilities to receive case management services, and up to 16 hours of daily personal case aide services, personal emergency response system services, respite services, homemaker services, chore aide services, and more.[34]

Moreover, D.C. Medicaid pays for home nurse visits as well as up to 8 hours of daily personal care aide services to "provide necessary hands-on personal care assistance with activities of daily living that assist a beneficiary to safely reside in the home." D.C. MUN. REGS. tit. 29 § 5000.

It is likely that through the EPD Waiver or Medicaid alone, all of Mr. Benning's needs could have been met in a community setting. Certainly, as discussed *infra*, he had the right to have his choice to live in the community respected and every legally-mandated step taken to make it a reality.

THE REQUIREMENTS OF LAW

Federal Law

The Americans with Disabilities Act (ADA) and the Rehabilitation Act of 1973 prohibit discrimination based on disability. 42 U.S.C. § 12132; 29 U.S.C. § 794(a). In *Olmstead v. L.C. ex rel. Zimring*, 527 U.S. 581, 597 (1999), the Supreme Court held that unnecessary confinement in an institution is a form of discrimination prohibited by the ADA. As the Supreme Court explained, "[u]njustified isolation of persons with disabilities" amounts to discrimination because "institutional placement . . . perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life" and "severely diminishes everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment." Id. at 599. The Court in *Olmstead* ruled that State and local governments must provide services and supports to people with disabilities in the most integrated settings appropriate to their needs and pursuant to their choice of community-based alternatives instead of institutional placement.

The U.S. Department of Justice has said in its Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and *Olmstead v. L.C.*:

> a public entity may violate the ADA's integration mandate when it:
> (1) directly or indirectly operates facilities and or/programs that segregate individuals with disabilities;

[34] D.C. MUN. REGS. tit. 29 § 4200, et seq. A good description of EPD Medicaid Waiver criteria and services are in the EPD Waiver Handbook pages 10-14: http://www.dccouncil.us/files/user_uploads/budget_responses/Attachment_1_to_Q66_DHCF_Response_FY12_-_handbook.pdf

> (2) finances the segregation of individuals with disabilities in private facilities; and/or
> (3) through its planning, service system design, funding choices, or service implementation practices, promotes or relies upon the segregation of individuals with disabilities in private facilities or programs.[35]

Thus, a governmental entity violates the ADA where it (1) segregates individuals with disabilities into private nursing facilities, such as Deanwood, even though they desire to live in the community, and (2) fails to make community service options available. Failure to take steps to transition individuals with disabilities who want to move back to the community and whose needs can be met by existing community-based services constitutes disability-based discrimination and violates federal law.[36]

In addition to broad anti-discrimination laws, the federal government has mandated requirements specifically for nursing facilities, including those in the Nursing Home Reform Amendments ("NHRA"). This law requires a Pre-Admission Screening and Resident Review ("PASRR") for all individuals with intellectual disabilities and/or mental illness who are being admitted to or reside in nursing facilities.

Congress' purposes in enacting the NHRA included ending the inappropriate admission of individuals with mental illness and/or intellectual disabilities to nursing facilities. The statute requires states to identify those individuals who do not require a nursing facility level of care and those whose needs could be met in an appropriate community setting. 42 U.S.C. § 1396r (b)(3)(F)(i) & (ii). To achieve this goal, the law requires that each person must be screened according to specific criteria, prior to admission to a nursing facility. For individuals with mental and intellectual disabilities, the PASRR evaluation must consider both the need for nursing facility level of care and the need for specialized services. 42 C.F.R. § 483.128. With respect to the first factor, if a determination is made that an individual does not require the level of services provided by a nursing facility, that individual cannot be admitted and must be referred to an alternative setting or service. 42 C.F.R. § 483.130(m)(2).

The second element of the PASRR evaluation process determines if an individual requires specialized services. For individuals with mental illness, the evaluation must include a comprehensive drug history, psychosocial evaluation, comprehensive psychiatric evaluation and a functional assessment of the individual's ability to engage in activities of daily living. 42 C.F.R. § 483.134. Significantly, this assessment must determine whether the level of support needed by the individual can be provided in an alternative community setting. 42 C.F.R. §

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[35] Available *at* http://www.ada.gov/olmstead/q&a_olmstead.htm (June 22, 2011) at Question 2.

[36] University Legal Services (ULS), AARP Foundation Litigation, and Arent Fox LLP are plaintiffs' class counsel in Thorpe v. D.C., a class action lawsuit against the District of Columbia under Title II of the Americans with Disabilities Act (ADA). In Thorpe v. D.C., ULS represents D.C. residents in nursing facilities seeking assistance from the District of Columbia to facilitate their access to the long-term care services they need in order to live in the community. To access the most recent Complaint and pleadings filed in the Thorpe case, see Case No. 1:10-cv-02250 available through https://ecf.dcd.uscourts.gov/cgi-bin/login.pl, or contact University Legal Services, 202-547-0198.

483.134(b)(iv)(5). If the alternative community setting, or even an alternative institutional setting, can better address the individual's needs, the individual should not be admitted to a nursing facility. 42 C.F.R. § 483.132(a)(1) & (4).

If the individual has a diagnosis of mental illness, the law requires a mandatory second level PASRR review. The state's mental health authority is responsible for reviewing whether an individual requires a nursing facility level of care, and this decision must be based on an independent physical and mental evalution performed by an entity other than the State mental health authority. 42 U.S.C. §§ 1396r(e)(7)(B)(i); 42 CFR 483.106(d)(1). Furthermore, this second level evaluation of the need for nursing level care cannot be done by the nursing facility because the evaluation must be independent – something the nursing facility, with its financial incentive, is not. Very specific steps are required in the evaluation process and detailed notice is to be provided to the individual following the assessment. 42 CFR § 483.128(i), (j).

Furthermore, individuals in the nursing facility must be reassessed if there is a significant change in the individual's condition.[37] If a later PASRR assessment determines that a nursing facility resident with mental illness or intellectual disability no longer needs the level of services provided by a nursing facility, the state must arrange for the discharge of the resident, unless the individual has been institutionalized for longer than thirty months. 42 C.F.R. § 483.130(m), § 483.132; 42 U.S.C. §§ 1396r(e)(7)(C)(ii)(I), (ii)(II), (iii)(I), & (iii)(II). In short, the PASRR review process is designed to screen out of nursing facilities people who exclusively need mental health services and ensure that those who are able to live in the community, do so.

CMS regulations permit a state to create categorical exceptions, allowing the state's mental health department to bi-pass the second leval PASRR review if a determination is made that the individuals fits into a certain category. One of those permitted categories listed in 42 CFR 483.130(d) is:

> (3) Severe physical illness such as coma, ventilator dependence, functioning at a brain stem level, or diagnoses such as chronic obstructive pulmonary disease, Parkinsons disease, Huntington's disease, amyotrophic lateral sclerosis, and congestive heart failure which result in a level of impairment so severe that the individual could not be expected to benefit from specialized services.

Because categorical exceptions to the PASRR process can limit the individual's opportunity for a second level independent review of the appropriateness of the institutional setting, such exceptions should rarely, if ever, be used -- expecially given the fact that most, if not all, individuals with the diagnoses listed (chronic obstructive pulmonary disease, Parkinsons disease, Huntington's disease, amyotrophic lateral sclerosis, and congestive heart failure) are able to live in the community with appropriate supports and services. Certainly, a state must have very significant oversight of this decision-making process if it permits such an exception to the review process.

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[37] 42 U.S.C. § 1396r(e)(7)(B)(iii).

The District has created specific procedural protections for individuals with mental illness which must be completed or the individual cannot be admitted to a nursing facility. DMH published "DMH Guidelines on Nursing Facility Referrals and Required Reviews," Policy 511.3 dated October 28, 2008 -- recently revised.[38] According to this policy as written in 2008, the initial screening for nursing home level of care was to be done by the "referring clinician at the provider level."[39] However, "if a consumer is found to have a primary or secondary diagnosis of mental illness, a referral **must** be forwarded to the DMH Mental Health Authority for a PASRR Level II screening."[40] The regulations stated that the DMH Chief Clinical Officer shall:

> (7a) **Review** and **evaluate** referrals of all individuals with mental illness who are deemed as appropriate candidates for a nursing facility.
>
> (7b) **Determine** if the nursing facility is the least restrictive alternative where the individual will receive proper medical care, psychiatric care, and assistance with activities of daily living as required.[41]

The "provider" was required to complete the initial screening and provide the individual with notice.[42] The policy also stated that the "responsible CSA shall request DMH to discharge/disenroll consumers from the rolls of DMH: upon placement of a consumer in the nursing facility . . .."[43]

In addition to the PASRR determination, the federal government requires a nursing facility to conduct a comprehensive assessment of its residents not less than once a year, in addition to a quarterly assessment whereby information is gathered by a survey known as the Minimum Data Set ("MDS"). 42 CFR 483.20. The comprehensive assessment must include the individual's expressed interest in community-based alternatives and an assessment of the individual's discharge potential. 42 CRF 483.20(b)(xvi). Moreover, the assessment must include direct observation and communication with the resident . . .." Id. at 483.20(b)(xviii).

Requirements of District of Columbia Guidelines

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[38]The policy was rewritten and changes became effective on May 22, 2013.

[39] Policy 511.3 dated 10/28/08 at 1. The updated policy states that the screening is conducted "by hospitals, nursing facilities or DMH CSA providers . . .." Policy 511.3 dated 5/22/13 at 2.

[40] Id. (emphasis added).

[41] Policy 511.3 dated 10/28/08 at 2 (emphasis in original).

[42] Id. at 3-4.

[43] Id. at 6. The current policy requires the provider to: "Request DMH to discharge/disenroll consumers from its services after 90 days of placement in the NF, depending on the stability of the consumer during transition, complexity of the case, and/or completion of the transition plan goals. The CSA shall consult with the PASRR Coordinator and the NF in this regard prior to discharge or disenrollment. The Director of Care Coordination in consult with the PASRR Coordinator must approve the discharge/disenrollment." DMH Policy 511.3B dated 5/22/13 at 7.

The District government established the level of need that people must meet in order to obtain long-term care services either in nursing facilities or in the community.[44] In order to qualify for D.C. Medicaid funding for long-term care services, individuals must show they need assistance with at least two activities of daily living ("ADLs") (e.g., bathing, dressing, toileting, mobility, eating). Depending on the level of ADL assistance needed, the criteria allow individuals to show they also need assistance with their instrumental activities of daily living (e.g., meal preparation, grocery shopping, laundry, housekeeping).[45] The District's level-of-need determination qualifies individuals with disabilities to receive long-term care services either in nursing facilities or in the community under the Medicaid Waiver Program for People Who are Elderly and/or have Physical Disabilities ("EPD Waiver"). The District's contractor, Delmarva Foundation, reviews each long-term care applicant's level of need and determines whether to authorize their admission to a nursing facility or, alternatively, to provide access to long-term care services in the community.

Requirements of the District's Mental Health Law

District law provides certain rights to individuals with mental disabilities. It requires that all providers of mental health services provide the services to the consumers "in the least restrictive, most integrated setting appropriate to their needs. Mental Health Consumers' Rights Protection Act, D.C. Code § 7-1231.04(d). DMH and the providers must "at all times, treat consumers with consideration and respect for the consumer's dignity, autonomy, and privacy." Id. at § 7-1231.04(a). Moreover, consumers "have the right to meaningful participation in the development of their service plans." D.C. Code § 7-1231.05(a). DMH and the providers are "responsible for ensuring that a consumer's service plan is implemented." D.C. Code § 7-1231.05.

Moreover, D.C. law has specific requirements for treatment. "Each person's mental health services and mental health supports are based on an Individual Recovery Plan ["IRP"] designed to promote recovery and develop social, community, and personal living skills, and to meet essential human needs, and includes the appropriate integrated, community-based outpatient services [including] housing . . .." D.C. Code § 7-1131.02(30). DMH regulations describe the person-centered process to be used in developing the IRP. Treatment goals are to be "based on the consumer's expressed needs and needs identified through Diagnostic/Assessment services, and referral information." D.C. MUN. REGS. tit. 22A § 3408.5. The IRP must "include a statement of the mutually desired overall long-term results of each intervention, intermediate steps to be taken to achieve" the goals. Id.

DEANWOOD, DMH, and GREEN DOOR VIOLATED MR. BENNING'S RIGHTS BECAUSE THEY FAILED TO FACILIATE HIS TRANSITION TO THE COMMUNITY

Mr. Benning did not want to live at Deanwood. He clearly stated his desire to leave; nevertheless, nothing in the record suggests that Deanwood, DMH, or the Green Door took any steps to end this discriminatory institutionalization.

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[44] See DHCF Transmittal #09-21 available at: http://dhcf.dc.gov/sites/default/files/dc/sites/dhcf/publication/attachments/DHCFTransmittal09-21.pdf

[45] See Form 1728 available at: http://dhcf.dc.gov/node/198872.[46] See *supra* at 8.

The District provides significant services to individuals living in the community so that they can live in their own homes and avoid institutional settings. As described above, available services provided through the Medicaid EPD Waiver include case management services, up to 16 hours of daily personal case aide services, personal emergency response system services, respite services, homemaker services, chore aide services, and more. D.C. Medicaid pays for up to 8 hours of daily personal care aide services to provide necessary hands-on personal care assistance with activities of daily living that assist a beneficiary to safely reside in the home.[46] Nothing in the records indicates that these services would not have been sufficient to enable Mr. Benning to live in the community. Certainly, the District, Deanwood and the Green Door should have taken steps to facilitate the transition process. Instead, the system failed him, and his rights were violated.

<u>The Initial PASRR was Flawed.</u>

One step that might have prevented Mr. Benning's institutionalization was the initial PASRR screening, but Deanwood's initial PASRR assessment was severely flawed. Even though he clearly had a mental health diagnosis -- in fact, he was being served by a DMH ACT team, Green Door, at the time he was assessed,[47] DMH did not do a secondary PASRR review. The District's PASRR form is only a short two-page check list with little to no room for written comments.[48] Mr. Benning's form was signed by his nursing facility case manager, and, despite noting that he was diagnosed with schizophrenia,[49] there is no evidence that the mandated second level review was done.

However, Part C of the District's PASRR assessment form includes several categorical exceptions to the second level PASRR review. The DMH form specifically states that "[i]f any questions are checked 'yes' there is no need for referral for Level II evaluation." The case manager checked "yes" to one of those questions: "Does the individual have a severe physical illness, which results in a level of impairment so severe that the individual cannot be expected to benefit from specialized services."[50] There is no explanation of how this determination was made, or how Mr. Benning's unspecified "physical illness" precluded him from benefiting from any mental health services. Nevertheless, according to the form, this "yes" answer meant no Level II DMH review was needed.

The nursing facility's characterization of Mr. Benning's "physical illness" relieved DMH of its obligation to do a secondary PASRR review. This instance illustrates starkly how the DMH form is seriously flawed and can result in unnecessary institutionalization. Though CMS has permitted categorical exceptions on a limited basis, see the discussion *supra* at 10, the CMS regulation illustrates the type of illness which it considers serious enough for an exception to the secondary PASRR review: coma, ventilator dependence, functioning at a brain stem level. It

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[46] See *supra* at 8.

[47] See Green Door Treatment Plan dated 9/29/10.

[48] The current policy also is a similar two page check list form. DMH Policy 511.3B dated 5/22/13 at Exhibit 1.

[49] <u>Id.</u> "Does the client have a major mental illness? _xx__yes." See Pre-Admission Screen/Resident Review for Mental Illness and/or Mental Retardation (PASRR) dated 10/29/10 at 1.

[50] PASRR dated 10/29/10 at 2.

also lists diagnoses such as chronic obstructive pulmonary disease, Parkinsons disease, Huntington's disease, amyotrophic lateral sclerosis, and congestive heart failure. As discussed, individuals with these diagnoses are able to be active members of the community and benefit from mental health services, if needed. The CMS regulation includes the additional requirement that these diagnoses result in a level of impairment so severe that the individual could not be expected to benefit from specialized services.[51]

The DMH form, however, does not list the type of illness or diagnoses that are considered serious enough to permit this categorical exception to the level two PASRR review. In this instance, and in an unknown number of other instances, this exception may have been incorrectly checked, resulting in inappropriate institutionalization. This case illustrates how easily the form can lead to harmful results. Not only did Mr. Benning not have one of the serious diagnoses required by the CMS regulations, he was actually receiving the specialized DMH services that the nursing home claimed he could not benefit from. Though revised, the current DMH PASRR form continues to use this flawed language.[52]

As described above, the DMH review is critical not just to learn what specialized services may be needed for an individual but also to ensure that individuals with mental disabilities are not segregated in nursing facilities when in-home supports can be provided to meet their needs in the community. This review must not be perfunctory but must serve as a check on the ease with which society can violate the rights of individuals with disabilities.

Mr. Benning did not receive the review required by law. Certainly the DMH Chief Clinical Officer did not "(7a) **Review** and **evaluate** referrals" for Mr. Benning or "(7b) **Determine** if the nursing facility [was his] least restrictive alternative."[53] The secondary PASRR review may have resulted in Mr. Benning's return to the community where he might be living today.

<u>**No PASRR was Completed after Mr. Benning's Status Changed.**</u>

A second step that could have ended Mr. Benning's institutionalization was a supplemental PASRR review. The PASRR must be completed again if there is a change in the individual's status.[54] Mr. Benning entered the nursing facility with a primary diagnosis of "failure to thrive." He weighed 112 pounds.[55] When he died, Mr. Benning weighed 184.5 pounds.[56] A physical completed a month before his death found him "well developed" and "well

[51] CMS regulations should not permit this exception to reach so broadly. As described, many, if not all, individuals with the diagnoses listed are able to live in the community. A secondary PASRR review would help to ensure that these individuals do not remain in nursing homes **even if** their illness is such that they cannot benefit from mental health specialized services. Certainly, completion of the PASRR review does not relieve a state of its ADA, Rehabilitation Act, or <u>Olmstead</u> obligations to prevent discrimination through institutionalization; and thus, individuals within this CMS created categorical exception still have the right to live in the community with support -- whether or not a secondary PASRR review is completed.

[52] Policy 511.3 dated 5/22/13, Exhibit 1 at 2.

[53] Policy 511.3 dated 10/28/08 at 2.

[54] 42 U.S.C. § 1396r(e)(7)(B)(iii).

[55] Resident Summary dated 10/15/10 at 3.

[56] Deanwood Weight Records dated 3/1/12.

nourished."[57] His significant weight gain and improved physical health should certainly have triggered the change in status requirement to reassess Mr. Benning, resulting in another PASRR assessment to determine the appropriateness of his segregated living situation. At that time, the District government, its mental health provider Green Door, or its nursing facility licensed to provide Medicaid-funded services should have provided any transitional assistance needed to enable Mr. Benning to move back to the community. They did not.

The Minimum Data Set and CMS' Annual Assessment were Flawed.

A third step, the regular, continuing assessments should have led to Mr. Benning's transition to the community. As described above, CMS requires nursing facilities like Deanwood to complete quarterly reassessments for each of its residents - an MDS survey which includes a reassessment of the resident's expressed interest in community alternatives and discharge potential, and at minimum, an annual comprehensive assessment of the individual's level of need.[58]

Mr. Benning's first MDS assessment indicated that there was not an active discharge plan in place for Mr. Benning and that there was no determination made by the care planning team regarding the feasibility of his transition to the community.[59] The last MDS assessment done before his death was completed on January 26, 2012. It states that there was no active discharge plan in place because "[d]ischarge to [the] community [was] determined to be not feasible."[60] Question 500 required Mr. Benning's response to the question: "Do you want to talk to someone about the possibility of returning to the community?"[61] It was simply not answered, even though Mr. Benning had been telling his Green Door case worker repeatedly that he desperately wanted to leave.[62] CMS requires the nursing facility to refer individuals who express an interest in community alternatives as part of the MDS survey to designated community representatives to discuss their options. No such referrals were made for Mr. Benning. Indeed, DMH and its community mental health provider not only failed to discuss his community options; they removed him from their mental health services rolls entirely.

The Annual Social Services Assessment was Flawed.

Other assessments should have resulted in action. The District's Department of Health performed a formal review of Mr. Benning's death, interviewing individuals about the events and making findings. DOH reviewed Mr. Benning's November 3, 2011 Annual Social Services Assessment and found: "There was no evidence that facility staff fully completed the 'Annual Social Services Assessment' form and there was no evidence that facility staff followed up with discharge planning after November 3, 2011."[63] In a DOH telephone interview, a Deanwood

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[57] Deanwood Physician History & Physical/Progress Note dated 2/12/12.

[58] 34 CFR § 483.20(b)(xvi).

[59] Resident Assessment and Care Screening dated 10/25/10 at 31.

[60] MDS (1-26-12) at 28.

[61] <u>Id.</u>

[62] See *supra* at pages –5 to 7.

[63] DOH Report at 12. See also Health Regulation & Licensing Administration Statement of Deficiencies dated 3/30/12 at 4. It is ULS' understanding from the records that DOH was not saying there was evidence of discharge planning **before** November 3, 2011, but because DOH's review included limited records, it did not make

employee "acknowledged that the Assessment was incomplete and there was no additional discharge planning. He/she also informed the writer that the Social Worker assigned to [Mr. Benning] was terminated from the facility on March 7, 2012."[64] Nevertheless, DOH concluded: "Based on observation, record review and interviews, this investigation was unable to substantiate a violation of Federal regulations and Local laws as it pertains to the isolated incident."[65]

Green Door's Treatment Planning was Flawed.

Inexplicably, Green Door failed to act upon Mr. Benning's expressed desire to live in the community even though the case worker noted it again and again. Nothing in the record indicates that Green Door took any steps to facilitate Mr. Benning's transition to the community. Nothing in Mr. Benning's Individual Recovery Plans drafted by Green Door describes steps needed to enable Mr. Benning to live independently in community housing.[66] District law clearly requires consumer-directed care. Mr. Benning's IRP should have been based on the "consumer's expressed needs,"[67] and he should have had "meaningful participation in the development of [his] service plans." D.C. Code § 7-1231.05(a).

Mr. Benning had a right to receive mental health services "in the least restrictive, most integrated setting appropriate to [his] needs" and to have his wishes respected. Mental Health Consumers' Rights Protection Act, D.C. Code § 7-1231.04. Green Door's failure to act on Mr. Benning's expressed desire or taking any steps to meet his need to leave the segregated setting of the nursing facility violated this District law as well as federal law. Mr. Benning consistently stated that he wanted to leave the nursing facility, yet neither the staff nor his IRP addressed his desire for transition assistance, thereby violating the District's requirement that his IRP be "designed to promote recovery and develop social, community, and personal living skills, and to meet essential human needs, and includes the appropriate integrated, community-based outpatient services [including] housing . . .." D.C. Code § 7-1131.02(30). Instead of working towards community integration, Green Door closed Mr. Benning's case because the "nursing home would be taking care of all his needs."[68]

CONCLUSION

Mr. Benning wanted to leave the nursing facility. His condition when he entered Deanwood was significantly different from his condition at the time he ultimately died. Though he entered weighing 112 pounds, he had gained significant weight and expressed repeatedly his

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findings about discharge planning before that date. The Report also found that the "staff failed to ensure that window stoppers were maintained to provide a safe and supportive environment for 11 of the 72 resident rooms." DOH Report at 12.

[64] HRLA Statement of Deficiencies and Plan of Correction at 4. As a part of its Plan of Correction, Deanwood agreed to conduct a "facility audit of the resident Annual Social Services Assessments to ensure full completion of all sections of form."

[65] DOH Report at 11.

[66] Individual Recovery Plan (signed 1/10/12) pages 1 to 6.

[67] D.C. MUN. REGS. tit. 22A § 3408.5.

[68] Green Door Multi-Service Progress Note date 2/17/12.

desire to leave. The system failed him. Though federal law requires the District and its providers to assess and reassess the potential of individual residents in nursing facilities to transition to the community -- and even greater review requirements exist for individuals with mental or intellectual disabilities -- these safeguards did not work. Mr. Benning clearly should have received a secondary PASRR review by the District's Department of Mental Health -- both to ensure that he was in the least restrictive environment and to ensure he was receiving appropriate mental health services. This review should have occurred when he first entered Deanwood and again when his status changed. Moreover, the quarterly assessments, the MDS, and the justification for Mr. Benning's level of need to stay in the nursing facility should have alerted Deanwood to his desire to leave. Finally, Green Door knew for a fact that he longed to leave Deanwood, yet Green Door did not take steps to begin planning for his transition.

Though the actual reason for Mr. Benning's death may not have been a direct result of his desperation to get out of Deanwood, there is no doubt the he did not want to be there. The District and its providers continually ignored his voice and violated his rights.

RECOMMENDATIONS

1. Deanwood must develop and implement practices to ensure that all of its residents are informed about community-based alternatives and must actively provide transition assistance to those who express their choice to leave the nursing facility. Deanwood should reassess all of its residents to determine if the residents wish to explore the option of living in the community. Staff must develop transition plans with the residents and provide assistance with applications and linkages to community-based services. If any resident has a mental health diagnosis, Deanwood must refer him or her immediately to DMH for a secondary PASRR review. Finally, all Deanwood staff should be trained (1) to take affirmative steps to honor residents' desire for transition assistance as required under Title II of the ADA and (2) to respect and act on the expressed preferences of individuals with mental or intellectual disabilities.

2. DMH and DOH must revise the PASRR form to comply with federal law, and most importantly, train hospital and nursing facility staffs on how to properly assess people prior to admission and periodically during their institutional stay. The District must review the PASRR forms at all nursing facilities that house D.C. residents. If any individual with a mental disability did not have a secondary DMH review because the form indicates that the individual with mental illness has a "physical illness" so severe that the individual cannot be expected to benefit from specialized services, a DMH Level II PASRR review must be done. DMH and DOH must regularly review a random sampling of PASRRs from all nursing facilities that house D.C. residents to ensure they are in compliance with federal law.

3. DMH must train and require all CSAs, including Green Door, (1) to inform people about community-based alternatives, (2) to link those who prefer these alternatives to community living options, (3) to draft appropriate treatment plans, and (4) to take all steps needed to facilitate community transition. This must occur prior to admission to

and during the stay in nursing facilities. DMH must maximize all resources, including DMH housing options, to allow for living in the community.