



Slipping through the Safety Net: How Indiana's Disability Services System Failed One Client and Jeopardizes Others

Case Study and Recommendations

Equality Through Advocacy

The Protection and Advocacy System for the State of Indiana

4701 N Keystone Ave
Suite 222
Indianapolis IN 46205
IndianaDisabilityRights.org

Phone: 317.722.5555
Toll Free: 800.622.4845
Fax: 317.722.5564

Content Warning

This report contains potentially sensitive content, including detailed descriptions of: ableism; an eating disorder and the withholding of food; the neglect of a protected person, as well as bodily injuries he resultantly sustained; death and dying; and interactions with medical personnel and law enforcement. Should readers need to prepare themselves prior to engaging in this content, or choose to skip it for their well-being, they should be aware that the majority of sensitive content is within Sections III(b), Aaron's Story; III(c), Response to Aaron's Neglect and Death; and IV, System Failures. Readers should also be aware that pages 11-15 photographically depict an emaciated body with pressure sores, which may trigger those sensitive to eating disorders, neglect, blood, hospitalization, and death.

Acknowledgments

This report would not have been issued were it not for Indiana Disability Rights' (IDR) employees. In particular, Advocacy Specialist Natasha Henry reviewed records and conducted interviews that laid the foundation for this report. Staff Attorney Justin Schrock, Investigation Coordinator Tina Frayer, and Senior Attorney Nikki Gray oversaw the investigation, conducted legal research, and provided preliminary feedback regarding the report. Senior Attorney Emily Munson was responsible for drafting the report and revising it to its current status, as well as ensuring the accuracy of all legal citations. Executive Director Melissa Keyes and Legal Director Tom Crishon provided leadership, support, guidance, and multiple rounds of edits.

IDR also wishes to acknowledge those individuals who participated in interviews with IDR staff and who responded to IDR's request for a response on this report.

Finally, IDR recognizes Aaron, whose story is described in this report. Most assuredly, his contribution is the greatest. IDR sincerely hopes that, by communicating the reasons for Aaron's death, policymakers will undertake efforts to spare other Hoosiers with disabilities from the same end.

The suggested citation for the report is:

EMILY MUNSON AND NATASHA HENRY, INDIANA DISABILITY RIGHTS, SLIPPING THROUGH THE SAFETY NET: HOW INDIANA'S DISABILITY SERVICES SYSTEM FAILED ONE CLIENT AND JEOPARDIZES OTHERS (2021), available at: <https://www.in.gov/idr/reports-and-press>.

Executive Summary

Indiana Disability Rights (IDR) is a state agency that serves as the designated federal protection and advocacy system (P&A)¹ for individuals with disabilities in Indiana. In addition to providing technical assistance and legal services to individual clients, IDR has expansive access authority to monitor and investigate settings, whether public or private, where people with disabilities are served.² IDR monitors facilities operated by the State of Indiana, nursing homes, waiver homes, and other congregate settings. IDR also conducts investigations when it receives allegations of abuse or neglect, as well as when it is notified of suspicious deaths of individuals with developmental disabilities.³

This report shares IDR's investigatory findings regarding the death of a man named Aaron,⁴ who had cerebral palsy, blindness, bipolar disorder, and other disabilities. Aaron's legal guardian was his brother, Harvey.⁵ In 2018, Aaron and Harvey moved from Tennessee to Indiana. Upon arriving, Harvey applied for Aaron to participate in the Community Integration and Habilitation (CIH) Waiver, managed by the Bureau of Developmental Disabilities Services (BDDS). Aaron was approved, and his CIH Waiver services began in May 2019.

Although BDDS approved Aaron to receive five hours of residential services and four hours of community habilitation each day, and although his Person-Centered Individualized Care Plan stated that he required round-the-clock care, Harvey insisted that only he serve as Aaron's caregiver, and only for four days per week. Provider Help at Home hired Harvey to staff Aaron's case, despite his failed test scores regarding Aaron's needs and routine neglect in submitting documentation about Aaron's health. Help at Home staff also failed to visit Aaron on the single occasion they went to his home to complete an initial assessment.

Harvey sought assistance on August 13, 2019, when he contacted 911 after finding Aaron unresponsive. At the emergency room, doctors discovered that Aaron weighed just 71 pounds and had 11 pressure sores, at least one of which exposed bone. Hospital staff contacted law enforcement and Adult Protective Services. Help at Home notified the Bureau of Quality Improvement Services (BQIS), BDDS's sister sub-agency. Aaron passed away, due to septic shock, two days after admission to the hospital.

¹ This investigation and report were funded through the Protection and Advocacy for Individuals with Developmental Disabilities (PADD) Program. IDR receives funding from the U.S. Department of Health and Human Services' (HHS) Administration on Intellectual and Developmental Disabilities (AIDD) to implement the Developmental Disabilities Assistance and Bill of Rights of 2020. This report and its contents are those of IDR and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HHS, AIDD, or the U.S. Government.

² 42 U.S.C. § 15043(a)(2)(H); 45 C.F.R. § 1326.27(c).

³ 42 U.S.C. § 15043; 45 C.F.R. §§ 1326.25(a)(5) and 1326.27.

⁴ To protect his privacy, "Aaron" is a pseudonym. See 45 C.F.R. § 1326.28(c).

⁵ "Harvey" is also a pseudonym.

BQIS's investigation missed violations that were subsequently uncovered by IDR. BQIS required Help at Home to participate in a corrective action plan (CAP), which merely required the provider to update its staff training requirements and ensure that clients with preferred caregivers were receiving appropriate care and supervision. By year's end, BQIS closed the matter.

Meanwhile, law enforcement officials conducted a thorough investigation, and caught Harvey telling conflicting accounts of his actions prior to Aaron's death. Their investigation led the Prosecutor's Office to initially charge Harvey with felony neglect of a dependent resulting in death. However, prosecutorial discretion resulted in the charge being dropped. The Prosecutor's Office currently has no charges pending against Harvey or Help at Home.

Is there no justice for Aaron?

This report details IDR's investigatory findings pursuant to Aaron's death. It also discusses the following conclusions that IDR reached, as well as recommendations to address the same:

- ❖ DDRS must promulgate regulations specific to BDDS clients using preferred caregivers, to improve oversight and uncover safety concerns. IDR recommends that these regulations include:
 - Mandatory in-person monthly visits between the BDDS client and the provider employing the preferred caregiver.
 - A prohibition on guardians serving as a BDDS client's only paid direct service provider.
 - An explicit requirement that preferred caregivers must pass the same competency examinations as other paid staff.
 - An explicit requirement that preferred caregivers complete the same documentation as other paid staff.
 - Termination standards for preferred caregivers.

- ❖ DDRS must transform the CAP process to discipline and/or eliminate providers that commit egregious violations of BDDS client rights. IDR recommends that transformation include:
 - Appointing a single agency as responsible for identifying Medicaid provider errors and the action(s) needed to correct the errors.
 - The availability of a broad range of administrative tools, to ensure that provider sanctions are proportionally increased with the severity of the situation.
 - Increasing transparency in the process and empowering affected Medicaid beneficiaries to participate in the investigatory process.
 - Measures to assist Medicaid beneficiaries obtain justice.

- ❖ FSSA must address inflexibility between its Divisions and programs, such that unnecessary barriers and distinctions are eliminated and constituents, including those with multiple diagnoses, can receive needed services. IDR recommends that FSSA address inflexibility by:
 - Creating and implementing a universal Medicaid Waiver program that offers beneficiaries the complete range of services.
 - Creating an agency-wide, executive-level Ombudsman position.
 - Enhancing communication between Divisions and other government agencies, both at the state and federal level.

Table of Contents

Executive Summary	2
III. Factual Digest	7
a. Introduction to Services	7
b. Aaron’s Story	8
Figure 1	11
Figure 2	12
Figure 3	12
c. Response to Aaron’s Neglect and Death	13
Figure 4	13
Figure 5	14
Figure 6	15
IV. System Failures	15
a. Provider	16
i. Failed to Complete an Accurate Background Check on Preferred Caregiver	16
ii. Failed to Require Preferred Caregiver to Pass Competency Test	17
iii. Failed to Ensure Client Received Appropriate Medical Care	17
iv. Failed to Supervise Environment and Service Provision	18
v. Failed to Address Preferred Caregiver’s Documentation Noncompliance	18
b. Division of Disability and Rehabilitative Services	20
i. Failed to Ensure Necessary Authorized Services Were Received	20
ii. Failed to Identify Patent Deficiencies during Death Investigation	20
iii. Failed to Address Critical Issues through Implementation of the Provider-Driven Corrective Action Plan Process	22
iv. Failed to Enforce Program Regulations and Policies	23
c. County Prosecutor’s Office	24
i. Failed to Prosecute Charges against Preferred Caregiver	24
ii. Failed to Bring Any Charges against Provider	25
V. Recommendations	25
a. Promulgate Regulations for the Preferred Caregiver Program	25
b. Transform the Corrective Action Plan Process	29

c. Address Inter-Divisional and Inter-Disability Inflexibility	31
Appendix A – Glossary	34
Appendix B – Scope of Investigation	36
Appendix C – Response from Help at Home	38
Appendix D – Response from the Bureau of Developmental Disabilities Services	39
Appendix E – Response from the Prosecutor’s Office	40

III. Factual Digest

a. Introduction to Services

The Family and Social Services Administration (FSSA) is Indiana's agency charged with administering services to vulnerable populations, including people with disabilities. Of FSSA's six sub-agencies, the Division of Disability and Rehabilitative Services (DDRS) primarily serves individuals with developmental disabilities.⁶ DDRS serves Hoosiers of various ages through subdivisions that include First Steps, the Bureau of Rehabilitation Services, and the Bureau of Developmental Disabilities Services (BDDS).

BDDS's mandate is to provide services that enable clients with developmental disabilities to live as independently as possible within their home communities. In furtherance of that goal, BDDS administers two home and community-based Medicaid Waivers: the Family Supports Waiver (FSW) and the Community Integration and Habilitation (CIH) Waiver. As of July 2021, cost of FSW services cannot exceed the maximum limit of \$19,614 per client per year.⁷ The CIH Waiver, which serves individuals with greater support needs than the FSW, has no annual spending limit; instead, clients are provided with an individualized budget determined by algorithm. FSW and CIH Waiver services include, but are not limited to: case management,

⁶ Indiana defines "developmental disability" as a "severe, chronic disability" that meets the following criteria:

- (1) Is attributable to:
 - (A) intellectual disability, cerebral palsy, epilepsy, or autism; or
 - (B) any other condition (other than a sole diagnosis of mental illness) found to be closely related to intellectual disability, because this condition results in similar impairment of general intellectual functioning or adaptive behavior or requires treatment or services similar to those required for a person with an intellectual disability.
- (2) Is manifested before the individual is twenty-two (22) years of age.
- (3) Is likely to continue indefinitely.
- (4) Results in substantial functional limitations in at least three (3) of the following areas of major life activities:
 - (A) Self-care.
 - (B) Understanding and use of language.
 - (C) Learning.
 - (D) Mobility.
 - (E) Self-direction.
 - (F) Capacity for independent living.
 - (G) Economic self-sufficiency.

Ind. Code § 12-7-2-61(a). This definition differs from the federal definition of "developmental disability." See Ind. Code § 12-7-2-61(b); see also 42 U.S.C. § 15002(8).

⁷ The previous annual limit was \$17,300. BDDS Director Cathy Robinson, *Memorandum to BDDS Stakeholders* (Jun. 28, 2021).

community-based habilitation, residential habilitation and support, prevocational services, speech therapy, and transportation.

BDDS clients, in conjunction with their support team,⁸ develop a Person-Centered Individualized Support Plan (PCISP) describing their individual needs and goals. A client-chosen facilitator leads the support team in outlining the seven required sections of a PCISP.⁹ The PCISP is updated at least annually, but also upon any relevant change to the client's condition or circumstances. Clients then select services and providers to meet goals established by the PCISP.

BDDS requires providers to report instances of abuse, neglect, or exploitation of clients, whether actual, suspected, or alleged, as well as client deaths, to BDDS within 24 hours. Investigations of abuse, neglect, or exploitation are conducted by the Bureau of Quality Improvement Services (BQIS) and, if applicable, external investigations may also be conducted by entities including Child Protective Services, Adult Protective Services (APS), and/or Indiana Disability Rights (IDR). Death reports are reviewed by the BQIS Mortality Review Committee, of which IDR is a member.

Should a BQIS investigation reveal wrongdoing by a provider, BDDS will require the provider to comply with a corrective action plan (CAP). Instances of abuse, neglect, and exploitation may be resolved through the CAP process. However, if a CAP is insufficient or insufficiently implemented, BDDS may pursue sanctions against an errant provider.

b. Aaron's Story

"Aaron"¹⁰ was friendly and easy-going with a sense of humor. He enjoyed going out into the community and enjoyed listening to country music. Aaron was also diagnosed with multiple disabilities including cerebral palsy, chronic kidney disease, blindness, bipolar disorder, and mitral valve disorder. For much of his life, Aaron was cared for by his mother, who also served as his guardian. Upon her death, Aaron's brother, Harvey¹¹, was appointed as Aaron's guardian and representative payee for Social Security benefits.

In July 2017, Harvey and Aaron moved to Tennessee so Harvey could be closer to his boyfriend, whom he had met online. Unable to secure housing, Harvey, Aaron, and

⁸ As appropriate, and as chosen by the BDDS client, the support team includes: "(1) The individual. (2) His or her legal guardian, as appropriate. (3) Close family members/advocates. (4) The provider providing case management services to the individual. (5) Providers providing services to the individual. (6) A BDDS service coordinator. (7) Others identified by the individual as being important in his or her life." 460 Ind. Admin. Code § 7-4-3(a).

⁹ The mandatory PCISP sections are: personal and demographic information; diagnosis; emergency contacts; outcomes; statement of agreement; participants in developing the PCISP; and meeting issues and requirements. 460 Ind. Admin. Code § 7-5-1. An eighth PCISP section, which pertains to financial resources, is optional. *Id.*

¹⁰ To protect the privacy of the subject of this report, IDR has assigned "Aaron" as his pseudonym. See 45 C.F.R. § 1326.28(c).

¹¹ IDR has assigned "Harvey" as the pseudonym for Aaron's brother.

Harvey's boyfriend all lived in Harvey's car. Because Aaron lacked Tennessee health insurance, Harvey never took him to see a doctor nor attempted to acquire Aaron's prescription medications. The trio survived on benefits from the Supplemental Nutrition Assistance Program, also known as "food stamps," and used Aaron's Social Security money to take showers at nearby truck stops and occasionally spend the night at a hotel.

While in Tennessee, APS and local authorities removed Aaron from Harvey's care when Harvey was arrested for domestic assault. Three witnesses reported seeing Harvey hit Aaron in the head and face. Aaron was placed in a nursing home at that time. However, the charges against Harvey were dropped the following month, and Harvey signed Aaron out of the nursing home.

In August 2018, Harvey and Aaron returned to Indiana with Harvey's boyfriend. They rented a mobile home with another man, Harvey's ex-boyfriend. In the mobile home, Aaron slept in a small room with a water heater, an air mattress, his wheelchair, a radio, a fan, and a small table used for dining. Once settled, Harvey applied for Aaron to participate in BDDS services through the CIH Waiver.

Aaron had a physical examination in April 2019, a mandatory step in the CIH Waiver eligibility process. The nurse practitioner conducting the exam was concerned that Aaron was markedly underweight. She ordered bloodwork and had Aaron scheduled for a follow-up appointment in July 2019.

Aaron's CIH Waiver services began in May 2019. Harvey selected Help at Home as Aaron's service provider and sought employment through this agency to serve as Aaron's paid caregiver through the state's preferred caregiver program.^{12, 13} As part of the hiring process, Help at Home was required to conduct a criminal background report on Harvey. However, Help at Home staff failed to notice that an incorrect spelling of Harvey's name was used for the inquiry. Further, because only a limited criminal history

¹² Help at Home, LLC, is a home care company with 159 branch offices in 13 states, including Indiana. See Help at Home, *Care to Live Your Life*, available at: <http://www.helpathome.com> (last accessed: Feb. 9, 2021). The company offers the following services to Indiana clients: homemaking; attendant care; home health; skilled nursing; habilitation; community-integrated living arrangements; home-based day programming; one-on-one supervision; behavioral support; respite care; and participant assistance and care. *Id.* Help at Home's nation-wide staff of more than 30,000 caregivers includes "certified nursing assistants and licensed nurses and social workers, as well as in-home and community-based companion caregivers for those who have intellectual or developmental disabilities." *Id.*

¹³ BDDS does not explicitly market nor recognize a formal "preferred caregiver" program, although its regulations and practices informally permit its occurrence. A preferred caregiver, as the phrase is commonly understood, is one that a Waiver participant or their guardian independently locates. This caregiver then applies for a job with an existing Waiver provider and, once hired, is assigned (often exclusively) to the Waiver participant's case. Currently, a Waiver participant's guardian may identify and hire themselves as the participant's preferred caregiver, creating a clear conflict of interest. Moreover, like many preferred caregivers, Harvey was neither certified nor licensed in a health care or social service field.

search was conducted, Help at Home did not receive notice of the criminal charges filed against Harvey – which involved Aaron – in Tennessee.

As a new employee, Harvey received mandatory training from Help at Home about appropriately caring for Aaron. A portion of this training was individualized, focusing on Aaron's specific health conditions and related high risk plans. When training was complete, Harvey took a competency test. His responses revealed that Harvey failed to correctly identify five of Aaron's high risk plans, including plans for skin integrity, kidney disease, and the service categories Aaron was to receive. Despite these errors, Help at Home's supervisory staff recorded a 100% score on Harvey's competency test. Subsequently, he was approved as Aaron's paid caregiver.

At the end of May 2019, Aaron's support team¹⁴ met at his home to discuss his needs and current status. Although support team members traveled to his mobile home, Help at Home staff did not meet Aaron or even see him; Aaron remained in his room for the entire meeting. Help at Home staff never returned to Aaron's home again during his time with the agency. Although BDDS and Help at Home both require monthly home visits, Harvey declined them.

Help at Home and Harvey began providing paid services to Aaron in early June 2019. Although Aaron's PCISP stated that Aaron required 24-hour care, and although BDDS had approved five hours of residential services and four hours of community habilitation services each day, Harvey only worked as Aaron's paid caregiver four days per week. Aaron had no other staff and was never provided with assistance accessing his community.

From the start, Help at Home failed to ensure that Harvey documented Aaron's care. For example, despite Aaron's high risk plan for medication administration, and BDDS's documentation requirements for medication administration, Harvey never documented whether Aaron's prescribed medications were administered as directed. Instead, Help at Home contacted Harvey, who responded with a verbal report. The same method was used to document Aaron's daily skin assessment and bowel movements.

Relatedly, Help at Home failed to maintain documentation of accurate medication changes. Aaron's medication administration high risk plan was written in May 2019 but included medications that had not been prescribed or taken since 2017. Although Help at Home supervisory staff verified Aaron's current prescription medications in July 2019, his outdated high risk plan was never amended.

Harvey did not take Aaron to his July 2019 follow-up appointment with the nurse practitioner. Although the appointment was missed, Harvey never attempted to reschedule it.

¹⁴ Aaron's support team included only Harvey, Aaron's Connections case manager, and Help at Home supervisory staff.

On August 13, 2019, Aaron was found unresponsive by Harvey and transported to the emergency room (ER) by ambulance. During the ride, he was determined to be in asystole cardiac arrest. He was given two rounds of epinephrine and intubated. Upon his arrival, first responders and ER staff immediately notified APS and local law enforcement of Aaron's condition.

Aaron weighed only 71 pounds (Figure 1) and had 11 pressure sores (Figures 2 and 3), including at least one that exposed bone. His presentation unambiguously revealed that Harvey failed to follow his high risk plans, particularly those for constipation, kidney disease, and skin integrity. These plans required Harvey to contact Help at Home supervisory staff immediately in the event that Aaron showed signs or symptoms of skin breakdown or weakness, refused to eat two consecutive meals, or had minimal bowel movements for three days.

Aaron was admitted to the hospital and transferred to its Intensive Care Unit. He remained unresponsive and his organs were failing. Two days later, on August 15, 2019, Aaron passed away due to septic shock.

Figure 1

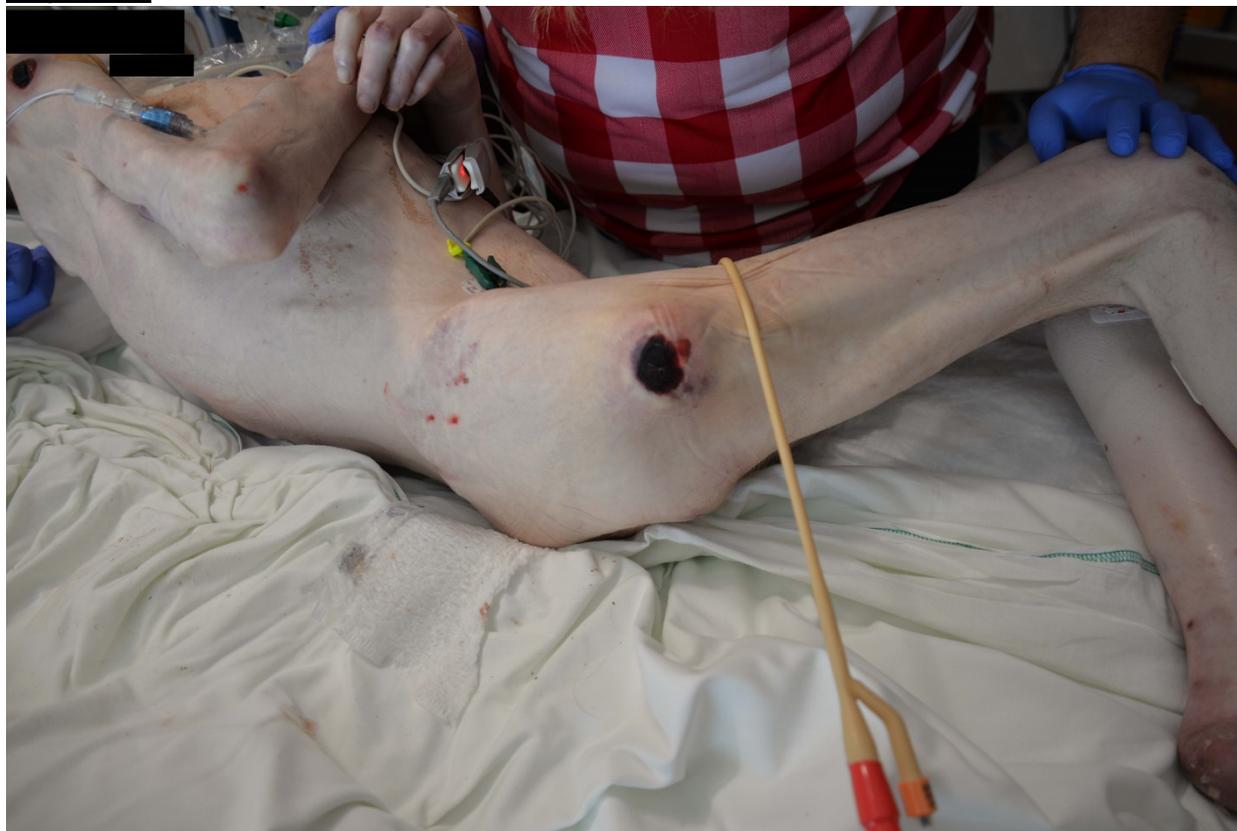


Figure 1: Aaron's emaciated, 71-pound body with pressure wounds on his shoulder and hip.

Figure 2



Figure 2: Two severe pressure sores on Aaron's shoulder.

Figure 3



Figure 3: Hospital staff measures the pressure sore on Aaron's knee.

c. Response to Aaron's Neglect and Death

Due to the severity of Aaron's condition, investigations were initiated by BQIS and law enforcement. BQIS's investigation concluded that: both Help at Home and Harvey neglected to provide Aaron with proper care; Help at Home failed to train Harvey properly; and Help at Home violated the regulatory Code of Ethics, betraying the values of honesty, integrity, and fairness when its supervisory staff documented daily records on Harvey's behalf, despite having never met – or even observed – Aaron.

During interviews with BQIS, Help at Home staff admitted to never meeting Aaron, even though staff visited his mobile home (Figure 4) in May 2019. Nevertheless, in the incident report it filed upon Aaron's hospitalization, Help at Home falsely claimed staff had observed Aaron during the May visit and had no concerns regarding his health. As the BQIS investigator failed to identify this inconsistency, Help at Home faced no corrective action for this statement.

Figure 4



Figure 4: Aaron's dark and crowded living room would have been difficult to navigate in his wheelchair.

Instead, BQIS approved a CAP written by Help at Home staff, which simply agreed to update staff training requirements and to ensure that all clients enrolled in the preferred caregiver program were receiving proper care and supervision. Help at Home completed these actions in December 2019 and BQIS acknowledged that the CAP was successfully completed. The State of Indiana imposed no disciplinary action, nor other sanctions, in response to the neglect leading to Aaron's death.

The thorough investigation conducted by the Richmond Police Department divulged that Aaron had been living in the mobile home's utility room on a bare and bloodied air mattress (Figures 5 and 6). Aaron lost the ability to walk independently five days before his hospitalization and refused all food at least three days before his hospitalization. Neither Harvey, nor any of the other men living in the mobile home took any action to obtain the medical care that Aaron obviously needed.

Figure 5



Figure 5: Aaron's small room is filled by his mattress, wheelchair, tray table, and a water heater.

Figure 6



Figure 6: Aaron's blood-stained mattress fills more than half of his bedroom.

Harvey initially reported that he had been giving Aaron nutritional supplement drinks after he began refusing food, but later admitted to police that the drinks were purchased the night before Aaron was hospitalized. Additionally, Harvey claimed to have been treating Aaron's pressure sores when they developed in July 2019. However, in a police interview Harvey's husband stated that the antibiotic and bandages for Aaron's pressure sores were purchased just days before Aaron was hospitalized.

The police investigation prompted the Wayne County Prosecutor's Office to charge Harvey with felony neglect of a dependent resulting in death. However, those charges were soon dismissed. No additional charges, including any against Help at Home staff, have been filed in response to Aaron's death.

IV. System Failures

This section of the report discusses the ways in which Aaron was failed by every part of the system that was designated to protect him. He was failed by: Help at Home, the agency providing his care; DDRS, the state agency funding his care; and his county

prosecutor's office, which failed to seek justice for Aaron's death.¹⁵ Importantly, the systemic failures enumerated by IDR are provided in chronological order; the order in which these failures are presented should not be interpreted hierarchically.

a. Provider

i. Failed to Complete an Accurate Background Check on Preferred Caregiver

The Bureau of Developmental Disabilities Services (BDDS) requires providers, such as Help at Home, to conduct a limited background check for each individual involved in the management, administration, or provision of services. See 460 Ind. Admin. Code § 6-10-5. Individuals cannot serve as BDDS-funded staff if they have been convicted, in Indiana, of: a sex crime; exploitation of an endangered adult; the failure to report battery, neglect, abuse, or exploitation; theft in the previous 10 years; murder; voluntary manslaughter; involuntary manslaughter; felony battery; or a felony offense related to a controlled substance. 460 Ind. Admin. Code § 6-10-5(b). In addition, if an individual will be involved in the management, administration, or provision of services, BDDS requires their employing provider to obtain a criminal history check from any county in which the individual resided in the previous three years. 460 Ind. Admin. Code § 6-10-5(c). Finally, providers must also ensure that no employees directly serving BDDS clients have been reported to the state nurse aide registry. 460 Ind. Admin. Code § 6-10-5(d).

Although Help at Home attempted to conduct a statewide background check on Harvey, his surname was incorrectly entered into the system. Due to this inaccuracy, Help at Home was unaware that Harvey was convicted of grand theft in 2003 and served three years of probation. Had Help at Home been diligent in correctly entering Harvey's name into the background check system, his conviction would not have precluded, but may have negatively influenced, his employment by Help at Home.

Indiana Disability Rights (IDR) found no indication that Help at Home conducted an out-of-state background check on Harvey, despite his recent move to Richmond from Tennessee. Had Help at Home conducted a criminal background check on Harvey in his previous domicile, as required by 460 Ind. Admin. Code § 6-10-5(c), it may have revealed Harvey's 2017 domestic violence arrest, made after Harvey was witnessed striking Aaron. Because BDDS prohibits employment based solely on convictions, rather than arrests, the domestic violence Aaron allegedly suffered at Harvey's hands would not have expressly precluded Help at Home from hiring Harvey to provide Aaron

¹⁵ In Appendix D, DDRS suggests that the case management system also failed Aaron. IDR agrees. Yet, because case management requirements are promulgated and monitored by DDRS, it is the agency ultimately responsible for reforming Indiana's case management system. Nonetheless, IDR appreciates DDRS's explicit recognition of failed case management in regard to Aaron, as well as its invitation to IDR to collaborate in improving case management in Indiana.

with care; however, Help at Home might have determined that hiring Harvey to care for Aaron would have been inappropriate, given that Aaron was allegedly Harvey's victim.

ii. Failed to Require Preferred Caregiver to Pass Competency Test

BDDS requires providers to train their employees to competently protect individual rights, including protecting clients from abuse, neglect, and exploitation. 460 Ind. Admin. Code § 6-14-4(a). Providers must also instruct their employees to appropriately document client progress toward achieving individual outcomes and objectives. 460 Ind. Admin. Code § 6-14-4(b). Additional training must be provided to staff directly caring for clients, including instruction on administering medication and first-aid, practicing infection control, and using universal precautions. 460 Ind. Admin. Code § 6-14-4(c). All such training must be complete before employees serve BDDS clients. 460 Ind. Admin. Code § 6-14-4(d).

Relatedly, and importantly, candidates seeking to provide direct services to BDDS clients must demonstrate certain competencies before working with BDDS clients. Direct service providers must have adequate communication skills to complete forms and reports, as well as the ability to meet the service needs established in a client's Person-Centered Individualized Support Plan (PCISP). See 460 Ind. Admin. Code § 6-14-5. Documentation of these continued competencies must be maintained by the provider. 460 Ind. Admin. Code § 6-14-3; see also BDDS Policy Number 460 0228 027.

Help at Home administered a written competency test to Harvey after he was trained. During that test, Harvey failed to correctly identify five of Aaron's nine high risk plans. Harvey also failed to identify the specific services that Aaron was to receive. Despite his inability to demonstrate required competency in critical client-specific subjects, Help at Home gave Harvey a perfect score and approved him to serve Aaron.

iii. Failed to Ensure Client Received Appropriate Medical Care

BDDS requires its clients' health care to be coordinated by a provider. See 460 Ind. Admin. Code § 6-25-1. Aaron's PCISP identified Help at Home as the provider responsible for his health care coordination. Therefore, Help at Home was responsible for ensuring that Aaron attended annual physical, dental, and vision examinations, routine examinations and screenings, and referrals to specialists. 460 Ind. Admin. Code § 6-25-2. Help at Home was also obligated to document the administration of medication to Aaron, refusals to take medication, and any changes in Aaron's status. See 460 Ind. Admin. Code §§ 6-25-3(4) and 6-25-4.

Within 21 days of being offered a Waiver slot by BDDS, an individual (or their guardian, if applicable) must have a physician confirm, in writing, the diagnosis that makes them eligible for the Waiver. See Division of Disability and Rehabilitative Services, *Home and Community-Based Services Waivers: Provider Reference Module*, available at: https://www.in.gov/medicaid/files/ddrs_hcbs_waivers.pdf (Dec. 19, 2019). In essence,

this policy requires that a physical examination be performed before Waiver services begin.

Harvey took Aaron to his physical appointment in April 2019. Aaron had not been seen by a physician, nor taken any of his prescribed medications, in over a year. As such, the nurse practitioner conducting Aaron's 2019 physical noted several concerns, including weight loss, constipation, and medication noncompliance. A follow-up appointment was scheduled for July 2019. However, no one brought Aaron to this follow-up appointment, nor did Aaron receive medical care again until his final hospitalization. Help at Home took no additional action to ensure that Aaron had access to this follow-up medical care.

iv. Failed to Supervise Environment and Service Provision

BDDS mandates that, every 90 days, clients' environments be assessed by providers, to ensure that they are in good repair and free from accumulated garbage and infestation. 460 Ind. Admin. Code § 6-29-2(a) and (b). These assessments must be documented. 460 Ind. Admin. Code § 6-29-2(b)(2). Additionally, Help at Home's internal policy requires supervisory staff to visit clients' homes every 30 days.

While Aaron sought services through Help at Home, his support team, which included Help at Home supervisory staff, met at Aaron's home to discuss his needs. Records demonstrate that Help at Home staff did not meet with – or even see – Aaron during that meeting. Yet, Help at Home falsely claimed that its staff observed Aaron in May 2019, and had no concerns about his condition, in the incident report filed upon Aaron's death in August 2019.

Help at Home staff did not visit Aaron's home again while he was alive. During Aaron's hospitalization, Help at Home supervisory staff asked Harvey, as Aaron's guardian, to sign a form declining home visits. Harvey agreed, and his signature was backdated to May 2019.

It is also notable that, per his PCISP, Aaron required 24-hour supervision and assistance with activities of daily living. Aaron's service plan called for between eight and nine hours of paid service coverage each day. However, Harvey worked as Aaron's sole caregiver, and he worked only four days per week. There is no indication that Help at Home took efforts to secure additional staff to cover Aaron's remaining service hours. Therefore, Aaron rarely accessed the community.

v. Failed to Address Preferred Caregiver's Documentation Noncompliance

As noted in Section IV(a)(ii), BDDS requires direct service providers to competently and timely complete particular documentation regarding BDDS clients. *See also* 460 Ind. Admin. Code § 6-14-5. Nonetheless, Harvey consistently failed to submit Aaron's daily medication administration records, skin assessment checklists, and bowel tracking forms. Rather than retrain or discipline Harvey for his negligence, Help at Home

supervisory staff completed the forms based upon Harvey's verbal reports.¹⁶ Harvey and Help at Home's abdication of responsibility meant that Aaron's needs were undiscovered until it was too late.

Moreover, BDDS requires providers to complete incident reports within 24 hours when, for example, a BDDS client experiences inadequate medical or staff support or a medication error. 460 Ind. Admin. Code § 6-9-5(a)(12)-(14) and (b). Medication errors include the failure to administer prescribed medications. 460 Ind. Admin. Code § 6-9-5(a)(12)(B). When Aaron was hospitalized, Harvey acknowledged that he did not obtain Aaron's prescribed medications. Inadequate staff support includes the failure to obtain adequate staff, such that the BDDS client is at risk of significant harm or injury. 460 Ind. Admin. Code § 6-9-5(a)(13). Aaron was isolated in his home, despite being approved for services designed to allow him to engage in his community. Inadequate medical support includes the failure to obtain necessary medical services, routine medical services, and timely medication administration. 460 Ind. Admin. Code § 6-9-5(a)(14). Aaron had an appointment with a medical professional only once in 2019 and had not received prior medical care since 2017. Aaron was also denied prescribed medications.

Help at Home further failed to ensure that Aaron's high risk plans were accurate and up to date. For example, Aaron's high risk plan for medication administration, created in 2019, included medications that Aaron had not been prescribed since 2017. Records reflect that Aaron's prescriptions were reviewed by Harvey and Help at Home in July 2019, but Aaron's relevant plan was not subsequently updated. Aaron's high risk plans for skin integrity, kidney disease, and constipation required Harvey to contact Help at Home supervisory staff immediately if Aaron displayed skin breakdown, failed to eat to subsequent meals, or expelled minimal stool for three days. When Aaron was admitted to the hospital in August 2019, he had 11 pressure sores, was malnourished, and had lost significant weight. Help at Home should have submitted an incident report to BDDS for each incidence of Aaron's refusal to eat, significant weight loss, as well as for each pressure sore. Yet no incident reports were ever submitted while Aaron was receiving Waiver services.

¹⁶ Absent a disability-related need for reasonable accommodation, perhaps, it is important that the direct service provider complete daily tracking forms independently. First, updating the tracking forms should prompt the provider to check the BDDS client's critical risk factors each day. These daily updates also permit the provider to contemporaneously determine whether the client's risk factors are in a state of decline, stasis, or improvement. They also indicate when a problem began or ended. Because verbal reports do not require the direct service provider to proactively consider the client's risk factors, the direct service provider may simply tell their employer that there were no problems at the end of the week, month, or other timeframe. Verbal reporting relies on the direct service provider's fallible memory. Second, verbal reporting introduces a third party into the tracking activity, who can provide the direct service provider with someone to blame in the event that tracking and reporting is determined to be inaccurate. It would be difficult for an investigator to determine which individual is responsible for incorrect or missing tracking forms if the responsibility is shared.

b. Division of Disability and Rehabilitative Services

i. Failed to Ensure Necessary Authorized Services Were Received

The Division of Disability and Rehabilitative Services (DDRS) oversees BDDS. Ind. Code § 12-9-1-3. BDDS is responsible for monitoring provider compliance with its regulations at least annually and upon receiving information indicative of noncompliance. 460 Ind. Admin. Code § 6-7-2(a). Its monitoring actions may include records reviews, site inspections, interviews, and follow-up inspections. 460 Ind. Admin. Code § 6-7-2(b). However, these tools were insufficient to ensure that Aaron received the services that BDDS had deemed necessary and authorized.

Aaron's PCISP indicates that he required 24-hour supervision and assistance with activities of daily living. As such, BDDS authorized more than eight hours of paid care each day, in the form of residential and community rehabilitation supports. However, Harvey served as Aaron's only staff member, and Harvey only worked four days per week. Even on those days Harvey worked, Aaron rarely accessed his community, remaining at home instead. There is no indication that Help at Home attempted, either independently or at BDDS's prompting, to secure additional staff coverage for Aaron.

Given BDDS's practice of assessing compliance on an annual basis, and given that Aaron died less than six months after becoming a Waiver participant, BDDS was oblivious to the insufficiency of his care. Although BDDS can also address provider compliance upon the receipt of a report or complaint, such concerns are typically raised by guardians or other staff members. Here, Harvey was Aaron's guardian and sole staff member. Aaron's isolation and limited contact with anyone outside of the mobile home reduced the likelihood that BDDS would be notified of provider noncompliance.

ii. Failed to Identify Patent Deficiencies during Death Investigation

As described in the previous section, BDDS has authority to inspect care settings, interview providers, review provider records, and make follow-up inquiries and visits when provider noncompliance is suspected. 460 Ind. Admin. Code § 6-7-2(b). Investigations are conducted through DDRS Bureau of Quality Improvement Services (BQIS).^{17, 18} See Ind. Code § 12-9-1-3; see *also* BQIS Policy Number 460 0221 005.

¹⁷ The Indiana Administrative Code contains no mention of BQIS, and its responsibilities, as provided in the Indiana Code, are vague. When IDR requested a copy of DDRS's CAP process, it received a February 21, 2011, policy that references complaints received under supported living services programs, including the Developmental Disabilities Waiver, Support Services Waiver, and Autism Waiver, each of which no longer exists. See BQIS Policy Number 460 0221 005.

¹⁸ For several years, BQIS has contracted with private companies to complete investigations. However, because BQIS is ultimately responsible for the work of these contractors, this Report does not distinguish between BQIS and its contractors, and instead refers simply to BQIS.

Upon receiving a complaint, BQIS will first classify it as urgent, critical, or non-critical.¹⁹ BQIS Policy Number 460 0221 005. As an “urgent or direct serious adverse effect on the health, rights or welfare of an [i]ndividual,” investigations involving death meet the criteria for urgent investigations. *Id.*

In conducting an investigation, BQIS may use photographs; conduct one-on-one interviews with provider staff; interview the client who was allegedly harmed; review policies, employee files, employee timekeeping records, documentation regarding the delivery of services, incident reports, and other provider documentation; and make announced or unannounced visits. *Id.* The investigator must share a summary of his or her investigation findings with the provider. *Id.* The provider is to receive the summary five days after the completion of fact-finding for urgent investigations, within 30 days of the completion of fact-finding for critical investigations, and within 60 days of the completion of fact-finding for non-critical investigations.

BQIS opened an investigation of Aaron’s death on August 19, 2019. Following the investigation, BQIS issued a summary that substantiated Aaron’s neglect by Help at Home and Harvey and concluded that Help at Home failed to properly train and supervise Harvey as a paid caregiver. BQIS additionally determined that Help at Home failed to operate with honesty, integrity, and fairness when it completed required daily documentation on Harvey’s behalf based upon his verbal reports.

Nonetheless, BQIS investigators failed to uncover additional concerns that were discovered during the course of Indiana Disability Rights’ investigation. For example, during interviews with BQIS, Help at Home staff admitted to having never met Aaron. Yet, in the incident report that it filed after Aaron’s hospitalization, Help at Home falsely claimed its staff had observed Aaron in May 2019 and noted no concerns. BQIS did not uncover this inconsistency, so DDRS took no further action regarding Help at Home’s falsification of records.

¹⁹ Urgent investigations involve “an immediate or direct serious adverse effect on the health, rights or welfare” of a BDDS client. BQIS Policy Number 460 0221 005. Critical investigations involve “an indirect threat” to a BDDS client’s “health, rights or welfare.” *Id.* Non-critical investigations include any threat not classified as urgent or critical. *Id.*

iii. Failed to Address Critical Issues through Implementation of the Provider-Driven Corrective Action Plan Process²⁰

After the provider reviews a BQIS investigation summary raising concerns, the provider must draft a corrective action plan (CAP) and file it with BQIS by a determined date.²¹ *Id.* If BQIS deems the CAP unacceptable, or if the provider fails to timely submit a CAP, the provider receives another opportunity to submit an appropriate CAP. *Id.* Once BQIS is satisfied that a CAP has been implemented, it prepares and issues a final investigative report to the provider; the BDDS client; the BDDS Director; the BQIS Director and Field Director of Quality Assurance; and, if the complaint was substantiated, to the Office of Medicaid Policy and Planning (OMPP). *Id.* Should BQIS be unable to validate the implementation of a CAP, the provider is given another opportunity to comply. Only after twice failing to demonstrate CAP implementation may BQIS recommend referring a provider to the Sanctions Committee.²² *Id.*

Here, Help at Home proposed a CAP in which it agreed to: (1) update training requirements for staff and (2) stop allowing staff and guardians of BDDS clients to decline monthly home visits. BQIS deemed this CAP acceptable and validated its implementation in December 2019.

Because Help at Home was permitted to propose its own CAP, it was free to focus upon the rights violations, as well as the measures to address them, of its choosing. As noted, BQIS was unaware of Help at Home's post-dating of documentation and misleading investigatory attestations about home visits. It certainly was not in Help at Home's interest to self-disclose this activity. Therefore, the misrepresentations were never addressed in the approved CAP. Similarly, Help at Home's CAP never addressed

²⁰ In Appendix D, DDRS states that IDR incorrectly describes its corrective action process. However, in drafting this section of the report, IDR relied upon current statutes and regulations, as well as BQIS Policy Number 460 0221 005 which was provided by email from BQIS Director Jessica Harlan-York to IDR Legal Director Tom Crishon on or around July 1, 2020. A subsequent search of DDRS and BQIS's websites revealed no updated corrective action policies or activities, but for the contract with Liberty of Indiana, discussed in the next footnote.

In a follow-up meeting with IDR Executive Director Melissa Keyes, DDRS Director Kim Opsahl elaborated on DDRS' response (i.e., Appendix D) by stating that BQIS currently drafts CAPs. While this may be current practice, IDR's review of CAPs reveals a tendency to use of boilerplate language, which does not adequately individualize each need for improvement. Moreover, CAPs continue to show that BQIS does not use its authority to sanction providers, but instead it tends to rely upon retraining for even the most egregious rights violations.

²¹ IDR acknowledges that BQIS contracted with a new quality improvement services agency, Liberty of Indiana, which began delivering services on July 1, 2020. Jessica Harlan-York, Memorandum Re: Transition of quality contract to Liberty of Indiana, available at: <http://www.in.gov/fssa/ddrs/files/BQIS-provider-FAQ.pdf> (June 30, 2020). Liberty of Indiana likely amended quality assurance policies and procedures when it assumed its contractual role for BQIS, and the company may continue amending policies and procedures as it acclimates with the agency. Nevertheless, as noted in the previous footnote, these policies and procedures have not been promulgated into regulations or otherwise made public.

²² Director Harlan-York's email communication with Director Crishon confirmed that no Sanctions Committee has existed during her tenure. However, she acknowledged BQIS's statutory authority to sanction providers.

the provider's failure to obtain documentation from Harvey regarding medication administration and reports relevant to Aaron's risk plans. See Sections IV(a)(iii) and (v), *supra*.

Even the concerns that Help at Home's CAP addressed are unlikely to be resolved through the CAP process, given the underwhelming methods employed to address them. For example, Help at Home agreed to address training. Yet BDDS training requirements for providers were already clearly present in existing regulations when Help at Home passed Harvey through those requirements. See Section IV(a)(ii), *supra*. Thus, Help at Home is not agreeing to do anything different in practice. In effect, Help at Home is merely agreeing to follow the rules it was already required to follow.

iv. Failed to Enforce Program Regulations and Policies

As noted in the previous section, BQIS grants providers multiple opportunities to draft and submit acceptable CAPs. See BQIS Policy Number 460 0221 005. Additionally, BQIS may notify the Medicaid Fraud Control Unit (MFCU) within the Attorney General's Office and the Social Security Administration's Office of the Inspector General of any fraudulent activity. *Id.* Notably, policy does not *require* BQIS to report any provider to the Sanctions Committee, MFCU, or Social Security Administration, even if fraud or other egregious behavior is discovered during an investigation. *Id.*

If provider noncompliance "seriously endangers the health or safety of an individual such that an emergency exists," state regulations permit BDDS to terminate the continued authorization of services through that provider and deny future requests for authorized services through the provider from new clients. 460 Ind. Admin. Code § 6-7-4(a). In circumstances where endangerment is not serious nor deemed an emergency, BDDS may cease authorizing services through the involved provider for clients affected by the noncompliant behavior and for clients not already receiving services through it, but only in the event that the provider fails to submit an acceptable CAP. 460 Ind. Admin. Code § 6-7-3(a). Finally, BDDS shall revoke the approval of a provider who has demonstrated repeated or continued noncompliance with program requirements, or who has seriously endangered an individual's health or safety due to noncompliance. 460 Ind. Admin. Code § 6-7-5.²³

OMPP, on the other hand, has a wider array of provider sanctions at its disposal. If an OMPP investigation determines that a provider has failed to comply with a Medicaid statute or regulation, it may: deny Medicaid payments to the provider during a specified period; reject a prospective provider's application for participation in Medicaid; terminate a provider from continued participation in Medicaid; assess a penalty, up to triple an amount legally owed to Medicaid, against a provider; assess interest against a provider; and/or exclude the provider from further participation in Medicaid for a period of time consistent with that set forth in 42 U.S.C. § 1320a-7 et seq. Ind. Code § 12-15-22-1. Yet

²³ It is unknown why BDDS did not revoke Help at Home's approval as a BDDS provider. Surely Aaron's death constituted "serious[] endanger[ment of] an individual's health or safety due to noncompliance."

there is no indication that DDRS referred Help at Home, a Medicaid provider, to OMPP for further investigation.

Although Help at Home's noncompliance directly contributed to Aaron's death, BDDS never suspended its authorization to provide services, let alone revoked its license to continue serving as a provider. It is also doubtful that BQIS referred Help at Home to the MFCU, as its investigation did not reveal the misrepresentations that were discovered by IDR. Instead of imposing these sanctions, which are relatively moderate in consideration of the circumstances, Help at Home's proposed CAP was accepted without critique. In the instant case, this act amounted to Help at Home merely amending internal policy, to come into compliance with regulations it was already obligated to follow and agreeing to do better in the future. No punitive action was taken against Help at Home for its flagrant noncompliance and neglect of Aaron, which unambiguously contributed to his death. Help at Home continues serving clients today.

c. County Prosecutor's Office

i. Failed to Prosecute Charges against Preferred Caregiver

Indiana recognizes neglect of a dependent as a criminal act. If an individual caring for a dependent "knowingly or intentionally: (1) places the dependent in a situation that endangers the dependent's life or health; (2) abandons or cruelly confines the dependent; (3) deprives the dependent of necessary support; or (4) deprives the dependent of education as required by law," that individual is guilty of a Level 6 felony. Ind. Code § 35-46-1-4(a). Should the individual commit one of the first three acts and cause the dependent to obtain a bodily injury, he or she should be found to have committed a Level 5 felony. Ind. Code § 35-46-1-4(b). If, rather than bodily injury, the neglectful act results in the death or catastrophic injury of a dependent under the age of 14 or a "dependent of any age who has a mental or physical disability," the individual committing it shall be found guilty of a Level 1 felony. Ind. Code § 35-46-1-4(b)(3).

The probable cause affidavit executed by the Richmond Police Department confirms that Aaron required 24-hour care, for which Harvey was responsible and compensated. The affidavit further indicates that Reid Hospital doctors contacted the police department because Aaron had not been receiving necessary care. The doctors diagnosed Aaron as severely malnourished, weighing in at only 70 pounds. Aaron was also diagnosed with cachexia, the medical term for wasting of the body due to chronic neglect. Although the probable cause affidavit clearly supports that criminal charges for neglect of a dependent, as both a Level 1 and 5 felony, be pursued against Harvey, the Wayne County Prosecutor's Office dismissed the charges soon after they were filed. The Prosecutor's Office does not appear to prioritize obtaining justice for Aaron.

ii. Failed to Bring Any Charges against Provider

In regard to the elements of the crime of neglect of a dependent, Indiana statute defines “dependent” as either “(1) an unemancipated person who is under eighteen (18) years of age; or (2) a person of any age who has a mental or physical disability.” Ind. Code § 35-46-1-1. As such, a dependent need not be a relative; any “person having the care of a dependent, whether assumed voluntarily or because of a legal obligation” can be criminally liable for neglect. See Ind. Code § 35-46-1-4(a).

By contracting with BDDS to provide support services, Help at Home accepted the legal obligation to care for BDDS clients, all of whom are individuals with mental and/or physical disabilities. Therefore, Help at Home also appears to be criminally liable for the neglect that led to Aaron’s death. However, despite the Richmond Police Department’s unambiguous probable cause affidavit, the Wayne County Prosecutor’s Office never filed charges against the provider.

V. Recommendations

Although it is too late to improve the system for Aaron’s benefit, similarly-situated individuals with disabilities remain at risk of suffering analogous outcomes. As IDR’s investigation reveals, Bureau of Developmental Disabilities Services (BDDS) clients who have a single individual serving in multiple oversight roles are particularly susceptible to eluding the checks and balances within Indiana’s current system. Here, Harvey was Aaron’s guardian, representative payee, and sole paid caregiver. This sweeping control over Aaron’s life, including authority to circumscribe access to Aaron, permitted Harvey to engage in neglectful behavior for months without attracting attention. Whereas a guardian might complain to a provider or BDDS upon witnessing dramatic weight loss of their ward, for example, Harvey was not going to complain about his own caregiving skills. Whereas a representative payee might question why a Social Security beneficiary is paying for showers at a truck stop and question the safety of their living situation, Harvey was not going to report himself for the misappropriation of Aaron’s benefits.

The entities that failed Aaron should provide him with a modicum of justice by learning from, and rectifying, their mistakes. IDR offers several recommendations to bolster systemic checks and balances. Specifically, IDR encourages the State to promulgate regulations for BDDS’s preferred caregiver program, transform the Corrective Action Plan process, and dissolve inter-Divisional and inter-diagnoses barriers within the Family and Social Services Administration (FSSA).

a. Promulgate Regulations for the Preferred Caregiver Program

Harvey selected himself as Aaron’s paid support staff through a process commonly referred to as the “preferred caregiver” program. As an individual receiving home and community-based services, Aaron needed to choose an agency, such as Help at Home,

to manage and provide his services.²⁴ As Aaron's guardian, Harvey had legal authority to make this choice for Aaron. Harvey also used the Division of Disability and Rehabilitative Services' (DDRS) distorted gesture toward self-direction to choose himself as Aaron's sole paid caregiver.

Traditionally, disability services providers directly hire staff and schedule them to fulfill client needs based upon availability, geography, and, occasionally, compatibility. Too often, this system fails to meet the needs of people with disabilities. Although they can complain about caregiver issues to their provider agency, consumers have little to no role in proactively identifying skilled and compatible caregivers, nor do they have any role in disciplining noncompliant or disrespectful caregivers. Demanding more autonomy in these important matters, individuals with disabilities began calling for self-directed care (also called consumer-directed care) services decades ago.

Across the country, various models of self-directed care programs exist. At one end of the spectrum, the government funding source directly deposits a monthly budget into the disabled individual's account, and the individual is responsible for selecting and purchasing all needed goods and services. At the other end of the spectrum, and adopted more prevalently, the government funding agency contracts with a fiscal intermediary to handle the administrative aspects of the individual's services, and the individual informs the fiscal intermediary who should be hired or fired. Notably, Indiana only permits individuals receiving care through its Aged & Disabled Waiver limited opportunities to receive self-directed services, through a single fiscal intermediary. Bureau of Developmental Disabilities Services (BDDS) clients currently have no self-directed service options.²⁵

In addition to the individuals receiving care, their family members are also harmed by the agency care system in Indiana. Given that the State allocates a significant percentage of its disability services budget to institutional settings, less funding is available for home and community-based services. As such, direct service providers and other caregivers earn low wages. Unable to attract sufficient quality candidates, provider agencies regularly have difficulty maintaining stable staffing to meet the needs of individuals with disabilities. Having to repeatedly retrain new caregivers, and having to provide care when agency-based caregivers do not show, makes it difficult for family

²⁴ As Aaron's legal guardian, with authority to make health care decisions on his behalf, Harvey hired Help at Home.

²⁵ Prior to the pandemic, DDRS was actively involved in redesigning the two Medicaid Waivers offered through BDDS. Although several new potential services were highlighted in a concept paper, DDRS proposed limiting Waiver participants to mere "elements of" self-directed services, stating that an infrastructure for self-direction "is not feasible on the timeline for waiver redesign." DDRS, *Indiana Waiver Redesign Concept Paper*, available at: https://www.in.gov/fssa/files/IndianaConceptPaper_FINAL.pdf (Jan. 2020). Since the pandemic, DDRS officials have been even less optimistic about the State's financial ability to engage in significant Waiver redesign efforts. 1102 Task Force Meeting (Sept. 2, 2020), recording available at: <https://www.in.gov/fssa/ddrs/5457.htm>.

members to maintain their own careers. Too often, family members state that meeting the needs of someone with a disability is their full-time job.

To placate impoverished familial caregivers and frustrated clients with disabilities, BDDS created the preferred caregiver program. It allows individuals with disabilities, or their guardians, to find workers to staff their services – including non-spouse family members – and get them hired by a provider agency. This is not self-directed care, as the provider agency retains responsibility for employee training and discipline, and charges significant overhead expenses for doing so. Neither does the program fully compensate family members for meeting the outstanding needs of individuals with disabilities, as individual family members are precluded from being paid for more than 40 hours of care per week. However, BDDS has consistently framed the preferred caregiver program as an empowering alternative to the traditional agency model.²⁶

Preferred caregivers do provide BDDS clients with one alternative, albeit a limited one. The difficulty, as it pertains to Aaron's situation, is that becoming a preferred caregiver also provides the guardians of clients with the opportunity to enrich themselves at the potential expense of their ward. This conflict of interest also jeopardizes the integrity of systemic checks and balances. Although BDDS receives complaints about individual caregivers and provider agencies from guardians and complaints about guardians from provider agencies, it is unlikely that any of these entities will file a complaint against itself for alleged misconduct. Further, reducing the number of individuals having contact with the BDDS client by allowing one individual to fill multiple roles reduces the client's opportunities to obtain assistance from oversight entities. Because the preferred caregiver program appeals to families, a sphere in which the government is reluctant to encroach, it contains limited controls to counteract self-dealing by unscrupulous guardians. In fact, other than the 40-hour-per-family-member weekly limit, the preferred caregiver program has no rules or policies differentiating it from the traditional agency model.

IDR understands that programmatic flexibility is a critical factor in services being able to meet the individualized needs of people with disabilities. However, IDR investigations have uncovered multiple instances of abuse and/or neglect within the preferred caregiver program. As such, IDR recommends that BDDS promulgate basic program regulations. These regulations should include:

- *Mandatory in-person monthly visits with the BDDS client.* Help at Home allowed Harvey to waive the industry-standard monthly in-home visit, which precluded its staff from witnessing Aaron's physical deterioration. BDDS should require monthly visits with clients participating in the preferred caregiver program.

²⁶ Most recently, DDRS proposed expanding the preferred caregiver model as an alternative to implementing a self-directed care option through its Waiver redesign process. See DDRS, *Indiana Waiver Redesign Concept Paper*, available at: https://www.in.gov/fssa/files/IndianaConceptPaper_FINAL.pdf (Jan. 2020).

Importantly, these need not all be home visits,²⁷ and should accommodate the client.

- *A prohibition on guardians serving as a BDDS's client's sole paid direct service provider.* Arguably, Harvey signed Aaron up for the Waiver not to ensure that Aaron's needs were met, but rather to create a revenue stream for himself. As his guardian, Harvey had the ability to approve or deny services for Aaron. By denying the involvement of other direct service providers, who could have helped meet Aaron's needs, Harvey isolated Aaron.
- *Requiring preferred caregivers to pass the same competency examinations as other paid staff.* In Aaron's case, Help at Home may have assumed that Harvey already knew how to care for Aaron after serving as an unpaid caregiver for several years. However, this assumption is clearly false. BDDS compensates agency providers for training staff, so this training should occur and effectively teach direct service providers clients' individualized needs.
- *Requiring preferred caregivers to complete the same documentation as other paid staff.* Some individuals with disabilities do not require the level of oversight mandated by traditional agency care. For such individuals, at least one self-directed care option should exist. Those individuals receiving care through an agency may need assistance managing medications and environmental risks. For that reason, and because they are being paid, in part, to do so, preferred caregivers should be explicitly required to complete the same reporting and documentation standards as other paid caregivers.
- *Termination standards for preferred caregivers.* A provider agency may be concerned that imposing the same responsibilities on a preferred caregiver as are imposed on other direct service providers will displease the preferred caregiver and cause the BDDS client to hire a different provider agency. However, requiring provider agencies to fire noncompliant preferred caregivers, just as they are expected to fire noncompliant non-preferred caregivers, will both

²⁷ While this Report maintains that visits with BDDS clients are a critical component to ensure the health and safety of preferred caregiver program participants like Aaron, IDR does not advocate for mandatory monthly *home* visits for all clients with preferred caregivers. First and foremost, not every BDDS client has the same needs. For that reason, blanket requirements should generally be avoided. Second, home visits are inherently invasive and paternalistic. Home visits imply that the BDDS client needs a stranger to come into their home and make decisions about their lifestyle. If the provider and BDDS client have developed a good rapport, there is no reason why capable BDDS clients should be precluded from *personally* providing updates to their provider. Third, mandatory home visits actually deter community involvement and the promotion of independence. Because the majority of providers will not want to meet with BDDS clients after regular work hours, a monthly mandatory home visit requirement would interfere with BDDS clients who work or volunteer on a regular basis.

reduce the likelihood that transferring to a different provider agency will make a difference and that preferred caregivers will continue to be noncompliant.

IDR additionally recommends that BDDS share the text of proposed regulations with current BDDS clients, and particularly those who use the preferred caregivers. Although preferred caregivers and guardians of BDDS clients using the preferred caregivers are also stakeholders whose feedback should be solicited, BDDS must make an effort to obtain feedback directly from individuals the program is designed to serve. Finally, IDR recommends that BDDS also start a self-directed care program so clients seeking more direction over their services can exercise it, especially in the event that BDDS adds additional oversight to the preferred caregiver option.

b. Transform the Corrective Action Plan Process

Various Divisions and sub-agencies within FSSA have unique standards for licensing and disciplining providers. Compared to the Office of Medicaid Planning and Policy (OMPP), which has statutory authority to sanction providers through multiple methods,²⁸ DDRS has limited means to discipline providers that violate clients' rights or jeopardize their safety. Even when an investigation reveals that a provider has created an emergency, such that client health is seriously endangered, BDDS lacks authority to fine the provider. See 460 Ind. Admin. Code § 6-7-4(a). The constrained disciplinary power BDDS does possess has largely been abdicated; under its Corrective Action Plan (CAP) process, providers have the discretion to choose the means to rectify any issues identified by DDRS's Bureau of Quality Improvement Services (BQIS).

The CAP process lacks retributive elements. Most certainly, no fines are levied for noncompliance or other rights violations. Moreover, in drafting its own CAP, a provider can set its own timeframes for compliance and methods to address errors. No provider will draft a CAP against its interests; no CAP will include swift, costly, or any other type of action that significantly hurts the provider. Help at Home, for example, did not finish implementing its CAP until December 2019, four months after Aaron's death. Ironically, Aaron was a Help at Home client for approximately the same period of time. Thus, although the CAP process does not hurt the provider, it may harm the provider's clients.

Indeed, the CAP process also fails to deter provider wrongdoing. Medicaid provider agreements specify that providers must follow federal and state Medicaid laws. Failing to do so, for a BDDS provider, means only that the provider complete CAP paperwork and promise to do better next time. Although the CAP process may include amending internal practices and procedures, it produces a perverse incentive for new providers to refrain from spending money upfront to draft compliant policies. If DDRS identifies a deficiency within a provider's existing policies, BDDS assists the provider in obtaining

²⁸ OMPP may deny payment to a provider for a specified period of time; reject a provider's application to participate in Medicaid; terminate a provider agreement to participate in Medicaid; assess treble damages against providers; charge interest to a provider owing the Medicaid program money; and exclude a provider from participating in Medicaid for a specified period of time. Ind. Code § 12-15-22-1.

compliance through the taxpayer-funded CAP process. If the provider remains noncompliant, BDDS will continue to give it opportunities to try again.

FSSA should maintain a uniform process for addressing provider noncompliance and other concerns. Whether providers serve individuals with intellectual and developmental disabilities or individuals with other disabilities is immaterial; all FSSA clients should be treated with dignity, respect, and humanity, as well as be free from abuse and neglect by providers. All Medicaid providers, regardless of their clientele, should be subject to disciplinary consequences when they defy, or otherwise fail to act in compliance with, the law. This proposed sanctions process should include the following elements.

- *A single agency should be responsible for identifying Medicaid provider errors and action(s) needed to correct the errors.* Upon the conclusion of an investigation, a provider would no longer craft their own CAP. Instead, the agency would issue a notice to the provider, demanding discrete corrective action within a determined timeframe, including any sanctions assessed. If the provider disagrees, it may appeal to the Office of Administrative Law Proceedings.
- *A range of available administrative actions must be available.* Consistent with existing statute, FSSA should have authority to address provider wrongdoing, through a multitude of administrative tools. Sanctions should be imposed in parallel to the egregiousness of the situation. Administrative options should include:
 - Denying provider payments;
 - Rejecting a provider's application to participate in the Medicaid program;
 - Terminating a Medicaid provider agreement;
 - Assessing civil penalties;
 - Assessing interest; and
 - Expressly excluding a provider from participating in the Medicaid program for a future period of time.²⁹
- *Increased transparency is critical to empowering individuals with disabilities.* Under DDRS's current CAP process, BDDS clients are not always informed when their name is associated with a BQIS complaint. Sometimes a client will be informed and interviewed by investigators, but this practice is not universally

²⁹ IDR recognizes that this final sanction is extreme and should be used sparingly. IDR also recognizes that some may be concerned that the application of sanctions will diminish provider capacity, which is already limited in many areas of the state. Nonetheless, IDR maintains that the willful abuse and neglect of Hoosiers with disabilities must result in adverse consequences for the perpetrator(s). No one wants an abusive or neglectful caregiver. In those few cases where a provider is excluded from participating in Medicaid, provider capacity will technically be diminished. However, direct service providers that were not involved in the event prompting the provider's elimination are free to seek employment from other providers in the area or to create their own provider company. Thus, terminating abusive and neglectful providers is unlikely to adversely affect services in the region that the provider served.

applied. Any revised procedure must inform FSSA clients when their name has been included in a complaint, and such individuals should be given the opportunity to contribute to the investigation. Moreover, when the individual is the subject of an abuse, neglect, or exploitation complaint, they should be educated about the process, their role, and their right to participate. During this education process, FSSA clients should also be informed about their rights to pursue restitution or other appropriate remedies in civil court.

- *Medicaid beneficiaries should be aided in obtaining justice.* Although criminal wrongdoing must be addressed by the courts, prosecutorial discretion results in few convictions of those perpetuating crimes against people with disabilities. In Aaron's case, for example, the Prosecutor's Office dropped charges against Harvey and never brought charges against Help at Home. Thus, victims must seek justice through the civil court system, if at all. The General Assembly should enact a law whereby courts can assess punitive damages, to be paid to the plaintiff in a civil court case or his or her estate, if the investigating FSSA agency finds a defendant provider noncompliant.

c. Address Inter-Divisional and Inter-Disability Inflexibility

FSSA effectively siloes Hoosiers by disability status. If one is a Medicaid beneficiary, their benefits will be primarily administered by: the Division of Aging, if they are elderly and/or have a physical disability; the Division of Disability and Rehabilitative Services (DDRS), if they have an intellectual disability; the Division of Mental Health and Addiction (DMHA), if they have a mental illness; and the Office of Medicaid Policy and Planning (OMPP), if they do not identify, or qualify, as disabled under one of the preceding categories. Indeed, Indiana offers more than 35 Medicaid benefit plans, each offering different services to their respective beneficiaries.³⁰ Too frequently, this system forces individuals to make difficult decisions and forgo needed services.

As beneficiaries with multiple disabilities can attest, FSSA has difficulty meeting their needs within this siloed system. Consider Aaron, an individual with multiple disabilities; he could have benefited from DDRS services, due to his cerebral palsy and blindness diagnoses, as well as DMHA services, due to his bipolar disorder diagnosis. Harvey pursued DDRS's Community Integration and Habilitation (CIH) Waiver for Aaron, rather than, say, DMHA's Adult Mental Health Habilitation services program. Had Harvey and Help at Home provided quality care for Aaron, his physical needs would have been met, but he still would have had to forgo intensive mental health services available through DMHA but not DDRS. Individuals with dual diagnoses of a developmental disability and mental illness frequently have difficulty obtaining comprehensive Medicaid services, as

³⁰ FSSA, *Indiana Health Coverage Programs: Provider Reference Module – Member Eligibility and Benefit Coverage*, available at: http://www.in.gov/medicaid/files/member_eligibility_and_benefit_coverage.pdf (May 14, 2020).

well as finding providers in the community willing to qualify for, and participate in, serving them through multiple Medicaid programs.

Barriers between services and FSSA Divisions are not uniquely experienced by Aaron and those with multiple disabilities. Consider, for example, Shonda, an individual with severe cerebral palsy. She relies upon personal care attendants (PCAs) to assist with all activities of daily living (ADLs) through the Aged and Disabled (A & D) Waiver. Due to her effective quadriplegia, Shonda meets the skilled level of nursing care required to participate in the A & D Waiver. The A & D Waiver provides Shonda with services through high school. When she graduates, she decides she would like to pursue competitive, integrated employment. Shonda calls her home health care agency to ask if her PCAs can help transport her to and from the job. The agency's manager explains that transporting clients is a liability, but the PCAs could ride in a vehicle with Shonda. Shonda calls the Division of Aging, which offers the A & D Waiver, and learns that beneficiaries are not eligible for non-medical transportation services. Division staff suggest that Shonda give up the A & D Waiver and apply for the CIH Waiver. CIH Waiver providers do regularly transport their clients into the community. However, in order to qualify for the CIH Waiver, Shonda needs to prove there is no available, appropriate supported group living placement for her. In other words, Shonda may have to agree to live in a Waiver home with strangers just to get access into her community and maintain critical assistance with ADLs.

IDR maintains that Hoosiers with disabilities would be better served if FSSA dissolved its rigid inter-Divisional and inter-disability silos. Instead, FSSA should put more focus on the individual being served and their particular needs. To that end, IDR recommends the following actions.

- *Implementation of a universal Waiver.* FSSA should explore the feasibility of creating a Medicaid Waiver that offers eligible beneficiaries the complete range of services available under all Medicaid beneficiary programs. That is, individuals with multiple disabilities should be able to obtain access services needed to address each of their disabilities, regardless of which entity manages providers' licenses. Individuals like Aaron would have access to community integration and mental health services, while individuals like Shonda would maintain their PCA care and have access to non-medical transportation services.
- *Creation of a universal Ombudsman position within the FSSA Executive Team.* Although FSSA has a BDDS Ombudsman, hosts the Office of the Indiana Long-Term Care Ombudsman, and supports Mental Health America of Indiana to serve as the DMHA Ombudsman, these safeguards are insufficient. First, each existing Ombudsman has limited reach within his or her particular Division. Second, many Medicaid beneficiaries have no access to any Ombudsman; those served in programs outside the reach of FSSA's existing Ombudsmen, including individuals receiving home and community-based long-term care services

through the A & D Waiver, have no access to and ombudsman. Thus, FSSA should create a new executive-level ombudsman position, preferably filled by an individual with a significant disability, with authority to investigate and rectify client-raised service issues, regardless of Division.

- *Enhance communication among Divisions and other government agencies.* FSSA's Divisions must communicate critical information with one another and to outside agencies, as appropriate, while maintaining client confidentiality. It is unclear why, in Aaron's case, BQIS never communicated Harvey's misappropriation of Aaron's Social Security funds to the Social Security Administration. When there is probable cause to determine that abuse, neglect, or financial exploitation was perpetrated against a client, FSSA should not simply hold that information, but should instead share it with the proper authorities.

Appendix A – Glossary

Term	Definition
APS	Adult Protective Services (APS) is a program, in each state and territory, responsible for investigating reports of abuse, neglect, and/or exploitation against endangered adults.
BDDS	The Bureau of Developmental Disabilities Services (BDDS) is a subagency of DDRS that provides a variety services to eligible Hoosiers with intellectual and/or developmental disabilities.
BQIS	The Bureau of Quality Improvement Services (BQIS) is a subagency of DDRS, tasked with creating assurance systems to protect the health and safety of BDDS clients.
CAP	Generally, if BQIS substantiates that a provider has not complied with BDDS law and/or policy, it will ask that provider to draft and submit a Corrective Action Plan (CAP). The CAP includes remedial actions the provider must successfully implement before being deemed compliant once again.
CIH Waiver	The Community Integration and Habilitation (CIH) Waiver is one of two home and community-based service waivers offered through BDDS. Those participating in the CIH Waiver typically have greater service needs than those participating in the FSW.
DDRS	The Division of Disability and Rehabilitative Services (DDRS) is one of six FSSA divisions. DDRS has its own subagencies, including BDDS, BQIS, and the Bureau of Rehabilitation Services.
ER	The emergency room (ER) is the part of a hospital where patients receive immediate treatment.
FSSA	The Family and Social Services Administration (FSSA) was created in 1991 by the General Assembly to consolidate the State's human services

agencies. The FSSA Secretary is a member of the Indiana Governor's Cabinet.

FSW	The Family Supports Waiver (FSW) is one of two home and community-based service waivers offered through BDDS. In 2020, services obtained through the FSW cannot exceed an annual maximum of \$17,300 per participant.
Guardian	A guardian has legal authority to care for and protect the interests of a protected person, known as a ward. This authority is obtained after a judicial hearing, and may apply to personal decisions, financial decisions, or all decisions.
IDR	Indiana Disability Rights (IDR) was designated as the State's designated protection and advocacy system in 1977. IDR is governed by the Indiana Protection and Advocacy Services Commission, whose members are either appointed from within or by the Governor.
MFCU	The Medicaid Fraud Control Unit (MFCU) is part of Indiana's Office of the Attorney General. Its staff investigates fraud by Medicaid providers, misuse of Medicaid recipients' funds, and abuse and neglect in facilities that accept Medicaid reimbursement.
OMPP	The Office of Medicaid Policy and Planning (OMPP) is one of six FSSA divisions. OMPP is the State's administrative authority for Medicaid matters, including home and community-based services delivered through Medicaid Waivers.
PCISP	An Individualized Support Plan is a written document that establishes the supports and services an individual BDDS client requires to meet their goals. If developed using a person-centered planning process, the document is a Person-Centered Individualized Support Plan (PCISP).
Support Team	Each BDDS client has a support team, comprised of themselves, their legal representative (if applicable), their providers, their case manager, and others they wish to include. The support team helps the BDDS client develop and implement their PCISP.

Appendix B – Scope of Investigation

IDR's investigation included interviews with:

- Help at Home branch management.
- A local investigator for Adult Protective Services.
- Officers from the Richmond Police Department.

IDR's investigation also included the thorough review of the following documents:

- Incident reports regarding Aaron that were filed with BDDS by Help at Home.
- Incident report from the Richmond Police Department.
- Report from the Richmond Fire Department.
- Report from Emergency Medical Services.
- Help at Home's internal investigatory reports regarding Aaron's case.
- Timeline of events developed by Help at Home.
- Help at Home's records regarding Aaron's care, including:
 - Daily narrative reports.
 - Medication administration records.
 - Skin check forms.
 - High risk plans.
 - Service agreement forms.
- Help at Home's relevant personnel records, including:
 - Harvey's personnel records.
 - Harvey's training records.
 - Aaron's staffing calendar.
- Aaron's PCISP.
- BQIS's investigation report summary.
- Help at Home's Corrective Action Plan and supporting documentation, provided by BQIS.
- A Notice of Action from BDDS and BQIS to Help at Home.
- Harvey's criminal history report.
- Records generated during the Richmond Police Department's investigation, including:
 - Supplemental case report.
 - Subpoenas for Help at Home.
 - White sheet.
 - Affidavit from Harvey.
 - Recordings of police interviews with Harvey, Harvey's husband, and other parties that knew Aaron.
 - Photographs of Aaron and his home.

- Aaron's hospital records.
- Aaron's death certificate.
- Aaron's autopsy report.

Appendix C – Response from Help at Home

On June 11, 2021, IDR sent a copy of this report to Help at Home President and General Counsel Joel Davis, and invited him to provide comments by June 25, 2021. As of mid-July, IDR has received no reply from Help at Home.

Appendix D – Response from the Bureau of Developmental Disabilities Services

Eric Holcomb, Governor
State of Indiana



Division of Disability and Rehabilitative Services
402 W. WASHINGTON STREET, P.O. BOX 7083
INDIANAPOLIS, IN 46207-7083
1-800-545-7763

June 25, 2021

Sent via electronic mail

Indiana Disability Rights
4701 N. Keystone Ave., Suite 222
Indianapolis, Indiana 46205

Attn: Melissa Keyes, Executive Director
mkeyes@indianadisabilityrights.org

Emily Munson, Senior Attorney
Emunson1@indianadisabilityrights.org

Re: Response to June 10, 2021 IDR Opportunity to Respond to Investigatory Report

Dear Ms. Keyes and Ms. Munson:

The Division of Disability and Rehabilitative Services (DDRS) is in receipt of Indiana Disability Rights' correspondence from June 10, 2021, regarding an opportunity to respond to a working draft of an investigatory report. We appreciate IDR's efforts to provide information, feedback, and recommendations.

DDRS believes that there are opportunities for building on the current systems and supports to enhance checks and balances for individuals in home and community-based services. Although IDR's recommendations focus only on DDRS, we believe these opportunities apply across all systems affecting these services. Current DDRS efforts to enhance our community monitoring activities include focusing on training and technical assistance, development of a quality onsite provider review process with a focus on individual outcomes, a system consolidation project, rule and regulation review, and case management innovation.

However, the draft report contains inaccurate information and misconceptions about Bureau of Developmental Disabilities Services and Bureau of Quality Improvement Services processes and programs, particularly as it relates to the allegation that DDRS administers or promotes a "preferred caregiver program," the inaccurate description of our current corrective action plan process, and the omission of any discussion about the role of the case manager as it relates to systems intended to provide oversight and protections for individuals in home and community based services.

We understand this report is a working draft. DDRS anticipates that any final report and recommendations from IDR would reflect accurate information. We believe this information should be corrected for the final report to ensure it accurately reflects the various processes and factors highlighted in the draft and to support our shared desire to collaborate and partner in the future.

Thank you again for the opportunity to respond to your working draft. If you would like to discuss any of the items identified above, we are happy to schedule a time for further discussion.

Sincerely,

Kimberly A. Opsahl
Director, Division of Disability and Rehabilitative Services

Appendix E – Response from the Prosecutor’s Office

On June 11, 2021, IDR sent a copy of this report to Michael Shipman, the Wayne County Prosecutor, and invited him to provide comments by June 25, 2021. As of mid-July, IDR has received no reply from the Office of the Wayne County Prosecuting Attorney.