



**DISABILITIES RIGHTS CENTER, Inc.**

**Investigation of the Death of J.H., a Client of the NH Health  
and Human Services and Area Agency System**

Prepared by the Disabilities Rights Center

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The DRC is the designated federal protection and advocacy system for New Hampshire and is a member of the National Disabilities Rights Network.

# AN INVESTIGATION INTO DEATH OF JH

## Executive Summary

JH, a 26-year-old woman with developmental disabilities, lived with her mother and father at 36 Main Street, Apt. 3, Pittsfield, N.H. JH required 24-hour supervision and assistance with all activities of daily living, including personal hygiene. JH was able to walk without assistance and used a combination of some vocalization and simple sign language signs for communication. On June 8, 2009 at approximately 5:20 a.m., JH suffered an untimely death when the family's apartment caught fire and burned to the ground. The cause of the death was identified as "smoke inhalation under accidental circumstances." JH was found lying on her left side in a fetal position at the foot of the bed in the master bedroom wedged between the bed and wall, directly under a window. An overturned dresser was on top of her head. JH's father also died in the fire.

JH's mother was her He-M 521-certified provider under the State He-M 521 program regulations. Under this program, JH was able to live with her family who was certified to receive Medicaid funding. In return, the home and provider (in this case, JH's mother) were required to meet minimum residential or combined day and residential standards upon initial and then annual inspection by the area agency, Community Bridges. Part of these regulations, He-M 521.07, required Community Bridges to visit JH at home a least quarterly to determine and document whether her services, among other things, met her individual "environmental and personal safety needs". The term "environmental safety" is not defined in the regulations, nor does Community Bridges or the Bureau of Elderly & Adult Services (BEAS) have a specific definition for this term. JH received 30 hours a week of 1 to 1 residential and day services through Lutheran Social Services with service coordination provided by Community Bridges in

accordance with He-M 503. These services were funded through Medicaid provided by NH DHHS.

Over the years, there had been numerous concerns and “incident reports” completed with regard to JH’s personal care and/or care of the home. Between 2005 and 2009, there were 35 such incident reports prepared primarily by JH’s direct care provider, Zeke Bara. The reports indicated that JH often had urine and/or body smells, as well as poor toe nail care and the residence was often in disarray, cluttered and dirty. There were also concerns about medication management. These concerns became so strong that in September of 2007, Lutheran Social Services had some serious concerns about the care being provided to JH by her parents and in November of 2007, both Community Bridges and Lutheran Social Services discussed the possible need for additional supports to the family with the goal being to maintain JH in the home, if possible. By April of 2008 when things had not improved, several employees of Lutheran Social Services made a formal, although anonymous, complaint to BEAS regarding JH’s hygiene as well as the condition of JH’s home. Jennifer Cook, the service coordinator supervisor from Community Bridges, also called BEAS to report potential family neglect.

The BEAS investigator, after meeting with JH, her parents, the staff at Lutheran Social Services, JH’s primary care physician, and reviewing the available records, determined that the complaint was unfounded. At no time, however, did the investigator enter JH’s residence or speak with JH’s direct care staff, Zeke Bara. Due to regulation He-E 704.10, which requires that records of unfounded cases, including the original report, be completely expunged after six months, the records of this investigation are no longer available. Based on her recollection, however, the investigator believed that the complaint was solely focused on JH’s hygiene and did not include the condition of the residence. The overall evidence, however, indicates that the

investigator was made aware not only of JH's personal hygiene issues, but the housing conditions and other incidents that may have occurred in the home. Additionally, the investigator never considered whether there might be evacuation issues for JH in the event of an emergency, nor is this something that is routinely checked.

After receiving the BEAS determination, Lutheran Social Services continued to have concerns about JH's hygiene and living situation, but were resigned to the fact that "in reality nothing was going to change." There is no indication that at any time before, during, or after the investigation, either Community Bridges or Lutheran Social Services discussed, explored or pursued petitioning for a change of guardianship, seeking a co-guardian or an outside advocate for JH. Nor was JH's ability or her parent's ability to safely evacuate the premises considered or discussed by any agency. All of this despite Community Bridges' obligation to "promote the health and safety" of JH as its client and to affirmatively "safeguard her rights." He-M 505.03 (d)(4) & (w)(5).

On February 9, 2009, the family notified Community Bridges that they were being evicted from their apartment. In March, 2009, it was reported that the family had given up on finding a new apartment because the family had no money for a security deposit. On April 30, 2009, Community Bridges conducted an annual He-M 521 Certification Review of the family's home as required. There was no comment on the condition of the home, nor was there any check on JH's or her family's ability to evacuate in the event of an emergency. In fact, the certification was renewed for another year.

On June 2, 2009, JH's mother reported that the family's phone had been turned off and inquired of Community Bridges whether there was funding to help them pay bills. Although internal records indicate that Community Bridges decided it was unable to help with funding,

there is no indication that the family ever received any response to its request, including information about the possibility of other funding sources.

On June 5, 2009, a team meeting was held to discuss JH's services and budget. The focus was on reducing JH's services for budget reasons. During this meeting, JH's father asked if he could **appeal** the decision to cut his daughter's budget and the response from Community Bridges was that he could, but he "couldn't get blood from a turnip".

Three days later, on June 8, 2009, JH's mother left the apartment around 4:50 a.m. to go to work at Home Depot. She arrived at work at 5:15 a.m. At about 5:45 a.m., she received a phone call from her son informing her of the fire.

According to the State Fire Marshall's report, JH's brother, who then lived next door, had been awoken by his father banging on his apartment door at about 5:10 a.m. saying the apartment was on fire. Both he and his father returned to the apartment where fire and smoke were visible at that time. JH's brother asked his father where JH was and then told his father that he had to get JH out of the apartment. JH's brother reported seeing flames coming from the refrigerator. He saw his father re-enter the apartment, turn right and disappear into the living room area. JH's brother was then forced back down the building stairs and out onto the street because of the intense heat and smoke.

JH's father was later found in the living room face down. JH was located lying on her left side in a fetal position at the foot of the bed in the master bedroom wedged between the bed and wall, directly under the window. An overturned dresser was on top of her head.

The Disabilities Rights Center ("DRC"), after conducting an investigation<sup>1</sup> into JH's and her father's deaths as a result of a fire occurring in their apartment, found that there were steps or

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<sup>1</sup> The investigation was conducted by Cindy Robertson, Esq., a senior staff attorney with the Disabilities Rights Center with supervision by Richard Cohen, Esq., DRC's Executive Director and former director of the Division of

actions that should have been taken by the Department of Health and Human Services/Bureau of Developmental Services (DHHS/BDS), BEAS, Community Bridges, and Lutheran Social Services, which may have prevented or reduced the risk of these deaths. DRC is New Hampshire's designated Protection and Advocacy system for individuals with disabilities, and pursuant to federal law, has the authority to conduct investigations of allegations of abuse and neglect committed against individuals with disabilities.

The investigation, which is fully described in the accompanying report, finds that Community Bridges should have conducted an assessment of JH's safety and other related needs across all environments particularly in relation to residential fire safety. Failure to do such a safety assessment relative to fire safety violated its professional and legal responsibility to JH.

Further, the investigation finds that there are no specific requirements under either the supporting state regulations or the internal policies of BDS and the Area Agency which require a fire safety evacuation plan be in place and practiced in He-M 521 homes. In this case, the investigation revealed, among other things, that although the specific governing regulations require the Area Agency to make quarterly home inspections and check for such things as "personal and environmental safety," what exactly should be checked is not prescribed by DHHS/BDS, but is left for each individual area agency to determine and, as such, varies from agency to agency. The Area Agency involved with JH, Community Bridges, does not identify specifically what needs to be checked when such inspections are conducted including safe evacuation. The vague language of the regulations, in particular the He-M 521 and 503 do not give sufficient instruction to area agencies to conduct safety inspections or require, request or

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Investigations of the Mass. Department of Mental Retardation, and author of "Best Practices in Abuse and Neglect Reporting and Investigation", a chapter in Bradley, V.J. & Kimmich, M.H. (2003) *Quality Enhancement in Development Disabilities*. Baltimore: Brookes Publishing.

promote evacuation plans or drills in He-M 521 certified homes, unlike other residential certifications.

## **RECOMMENDATIONS**

DRC recommends the following:

1. DHHS should revise He-M 521 to establish a clear definition for “personal and environmental safety” to include a provision providing for an individual’s safe and speedy evacuation from a premises in emergency situations. Clarifying provisions should be added to certification and recertification sections of the regulations and He-M 521.07 regarding service coordination contacts, and, as necessary and appropriate, encourage, promote or require other fire safety measures. Relevant sections of He-M 1001.06 and He-M 525.06 (l) (4-7) should be looked to for guidance.
2. DHHS should develop a uniform checklist to be used by the area agencies so that the clarified requirements of He-M 521 are consistently met. The checklist should include not only the definition of “personal and environmental safety,” but should include a check that the individual is able to safely evacuate the premises in an emergency situation and such other checks needed to ensure that the existing and new requirements are met.
3. There should be a home safety risk assessment conducted and offered to all individuals living in their own homes who are receiving services from the State.
4. The personal profile section (He-M 503.02(t)(3)(a)(6) and (3)(f) and relevant sections of the service agreement section (He-M 503.11) should be revised to more clearly specify that a needs assessment include a residential evacuation capacity of the individual and an evacuation plan that is appropriate and practiced and other measures that will reduce undue risk to fire and other dangerous or catastrophic events. Such a needs assessment and safety plan or measures should be incorporated into the individual’s ISP.
5. Documentation of the regular checks of evacuation drills should be kept in each client’s file.
6. DHHS should modify its retention policy with regard to investigation files of cases that are unfounded to require that all documents in investigation files in these cases be retained for five years at a minimum.
7. DHHS/BEAS should develop clear rules and/or protocols specifying the process and criteria when a BEAS or other DHHS investigator may or should enter and/or inspect a home (with

or without permission) as part of their investigative or protective service responsibilities and what to inspect or observe. The latter should include a checklist or guidelines on standard items to look for, such as, fire or life safety issues, the existence of an evacuation plan for a vulnerable adult, etc. DHHS should receive input from the State Fire Marshall's office, BDS and the Quality Council.

8. DHHS should undertake a more systematic effort including thorough training to disseminate information about staff's and other mandatory reporter's obligation to file abuse, neglect and exploitation reports with BEAS and within the Area Agency/BDS system under He-M 202. To help counter the reluctance to report, the training and disseminations should include notice that the failure to report would be subject to disciplinary action. Area Agency and State level quality assurance reviews should include a methodology to determine whether agencies and individuals are meeting their mandatory reporting obligations.
9. Training should be provided to BEAS staff, Community Bridges and other Area Agencies and providers and relevant staff about (a) the powers of the probate court and how to access those powers; (b) the obligation of service coordinators and relevant staff to access general and DHHS resources to address eviction issues, obtain alternative housing and related issues facing clients and/or their families on a protective basis, and how to access those resources; and (c) the need and process for referring or seeking outside advocates or counsel or independent service coordinators for individuals.
10. It is recommended that DHHS and Community Bridges take appropriate personnel action against employees who did not adequately fulfill their responsibilities in regard to JH and in this matter generally, as more fully outlined in Findings 25, 26, and 27.
  11. All recommended changes to He-M 503 should also be made to He-M 522.

## **FULL REPORT OF INVESTIGATION OF JH**

### **I. Report and Incident Triggering Investigation**

On June 8, 2009 at approximately 5:20 a.m. JH suffered an untimely death when the apartment in which she lived with her parents caught fire and burned to the ground. The cause of death was identified as “smoke inhalation under accidental circumstances”.

JH was found lying on her left side in a fetal position at the foot of the bed in the master bedroom wedged between the bed and wall, directly under a window. An overturned dresser was on top of her head. JH’s father also died in the fire. He was found face down in the living room of the apartment.

The State Fire Marshall determined that the fire started in the kitchen/cooking area, but the heat source or item ignited was undetermined.

Some time after the fire, the DRC received an anonymous letter alleging that JH’s death may have been prevented. As a result of this letter, an investigation into JH’s death was initiated.

### **II. Question Presented**

Whether there were steps or actions that should have been taken by any government agency, officials, individuals or entities licensed, designated, certified or funded by government agencies that may have prevented or reduced the risk of JH dying as a result of the June 8, 2009 fire?

### **III. Methodology**

DRC staff reviewed numerous records during the course of this investigation including:

1. All records held by Community Bridges
2. All records held by Lutheran Social Services
3. All records held by DHHS (Bureau of Developmental Services)
4. Investigation record of NH State Fire Marshall
5. Town of Pittsfield Housing Standards Agency records
6. Town of Pittsfield Housing Authority records

7. Town of Pittsfield Housing Standards Ordinance
8. Autopsy report and documentation of the Office of the Chief Medical Examiner
9. Town of Pittsfield Welfare Department

In addition, DRC staff interviewed:

1. Lorrie Ripley, NH BEAS investigator
2. Reporter of Incident
3. Jennifer Cook, Community Bridges
4. Ken Nielsen, Esq., Office of Client and Legal Services, DHHS

#### **IV. Background**

JH was a 26-year-old (DOB: 5/22/83) woman with developmental disabilities who lived with her biological mother and father at 36 Main Street, Apt. 3 in Pittsfield, N.H. Her mother was JH's legal guardian having been appointed on September 14, 2001, several months after JH turned 18. The family lived in a three-bedroom apartment that the family rented from Frank Volpe<sup>2</sup>. It is unknown for how long the family had resided at this location, but it is evident from the records that they had been living there as far back as September of 2001. JH required 24-hour supervision and assistance with all activities of daily living, including personal hygiene. She used a combination of some vocalization and simple sign language signs to communicate with her family and direct support staff. She was able to walk without assistance.

JH's mother was her 521-certified provider under the State He-M 521 program regulations. Under that program, a client of the DHHS/Area Agency service system lives with her family who is certified to receive Medicaid funding. In return, the home and provider (in this case, JH's mother) must initially and then upon annual inspection by the Area Agency, meet minimum residential or combined day and residential standards. These standards are described in more detail under Section V and VI below.

JH received \$623.00 per month in SSI benefits. Her mother was her representative payee for these funds. JH received community services through Lutheran Social Services with service coordination provided by Community Bridges in accordance with He-M 503. Community

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<sup>2</sup> It is unclear who the exact entity was that owned the apartment building. At various times, the documents identify Frank Volpe, Frank and Clara Volpe, or Frank Volpe, Trustee of the Frank Volpe Revocable Trust as owners.

Bridges, utilizing Medicaid funding provided by NH DHHS, funded Lutheran Social Services to provide community services to JH.

At the time of her death, JH was enrolled in a day program provided by Lutheran Social Services receiving 30 hours per week of 1 to 1 residential and day services through the He-M 521 waiver. Her day program was both community and residentially based with Lutheran Social Services providing transportation to and from her home, to her volunteer jobs, and out in the community. Only two hours of JH's time each week was provided within the home by JH's support staff. The rest of JH's service hours, 28 hours per week, were provided in the community, with all supports being provided on weekdays.

As an individual served by Community Bridges, JH had a service agreement (formerly called an Individual Service Plan hereinafter sometimes referred to as an "ISP"). Her last annual individual service plan meeting was held on March 17, 2009 at Lutheran Social Services. The Plan from that meeting stated that "although JH is not an active member of her team meetings, she lets those around her know whether she enjoys something or not, or whether she would like to leave".

Zeke Bara, JH's direct support staff, reported that JH was involved in many community-based activities and attended the YMCA daily. He described her as an "extremely active young woman who has lots of energy" and who enjoyed her day program thoroughly being eager to start each day with support staff with a smile on her face.

## **V. Review of Evidence**

### **A. Concerns over Hygiene, Personal Care and Sanitary Conditions of the Home; 2005 – April, 2008**

Over the years there had been numerous concerns noted and "incident reports" completed with regard to JH's personal care and/or the care of the home. While these concerns were not explicitly characterized as creating a fire safety risk, they were examined as part of this investigation because of the possible overlapping nature of sanitary and fire safety violations and the obligations each impose on government officials or their surrogates.

At the March 17, 2009 ISP meeting, (three months before JH died), the team believed JH desired to attain several goals including learning safety skills and gaining more independence with her self-care routine. According to JH's ISP and witness statements, "safety issues"

included things such as JH not speaking to strangers, not running into the street, etc. It did not include home evacuation or fire safety. Hygiene and foot care had been concerns over the years and there had been numerous meetings held to discuss these concerns. Staff had been working with JH to learn sign language so she could inform those working with her when she needed to use the bathroom, but the team agreed that it would take very intensive support and consistent encouragement to get JH to where she could be independent with her personal hygiene routine and continence.

In recent history, specifically from June of 2005 until April of 2009, there had been 35 incident reports related to JH's personal care and/or care of the home. The majority of these reports reflect that when JH was dropped off to her provider, Zeke Bara, she had urine and/or body smells. There were also a few reports related to poor toe nail care.

Additionally, it was noted that the residence itself was often in disarray and there were six cats living in the apartment along with five people at one time. A note of September 4, 2007 indicates that Lutheran Social Services had some "serious concerns" about the care being provided to JH by her parents because of the noted hygiene problems. In fact, JH received support in Zeke's own home each day. He changed JH out of the clothing her parents clothed her in because of their filthy condition. At the end of each day, Zeke would then take JH back to his home to have her change back into her dirty clothing before going home.

In November of 2007, Community Bridges and Lutheran Social Services discussed the possible need for additional supports to the family with the goal being to maintain JH in the home, if possible. Although there are no meeting minutes for 2007,<sup>3</sup> concerns remained by some of the Lutheran Social Services staff about JH's living conditions. In March of 2008, the question of "how long does this go on before someone does something for JH" was asked at a team meeting in which the staff worker was "very disheartened to know she has to live the way she does."<sup>4</sup>

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<sup>3</sup> A letter from Patricia Luoma, Program Director for Lutheran Social Services, indicates that the meeting notes which were produced were for internal purposes only and were not written for dissemination to JH's ISP team members or her family. There are no internal team meeting notes for 2007.

<sup>4</sup> E-mail dated 3/15/08 from Suzanne Pfister to Mary Jane Nichols (cc'd: Jennifer Cook; Patricia Luoma). Community Bridges' notes indicate that the focus of the meeting was to strategize about supports for the family to improve JH's hygiene. (p. 63 of Community Bridges' records).

**B. BEAS Investigation and Related Matters; April 2008 through February 2009**

About a month later, in April of 2008, about 14 months before JH's death, several employees of Lutheran Social Services made a formal, although anonymous, complaint to the State Bureau of Elderly and Adult Services (BEAS) regarding JH's hygiene, as well as the condition of the family home. Reportedly the complaint included the following:

- That JH's home was "filthy" and constantly smelled of cat urine/feces with cat urine/feces observed on the floor;
- The bathroom was "falling apart";
- JH was always dirty (hands, clothes) and smelled like a "horse stall";
- JH's diaper was always soiled, her genital area was red with a rash and she often had food in her teeth;
- JH's toenails would often be several inches too long or cut to bleeding;
- Concerns about JH's medication administration, and specifically –
  - It was usually "short" at the end of the month and there was concern that her brother was stealing it to sell on the street.<sup>5</sup>
  - That JH's mother would give JH her breakfast and morning medication before leaving for work at 5:00 a.m. with the result that JH was hungry by the time she got to Zeke's home at 9:00 a.m. and her meds would wear off soon thereafter.

There is also documentation that on April 2, 2008 Jennifer Cook, the service coordinator supervisor from Community Bridges, also called BEAS to report potential family neglect<sup>6</sup>; and on April 25, 2008 Ms. Cook spoke with the BEAS investigator, Lorrie Ripley, and, upon Ms. Ripley's request, provided background information. Jennifer Cook noted in the Community Bridges records that "Lorrie was already aware of this information (medical status – rash, toenails), that JH has been running out of ADHD medication and that Community Bridges and

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<sup>5</sup> Although JH's mother denied this allegation, it was evident to her day staff that JH had not taken her "meds" on some days.

<sup>6</sup> See Community Bridges Progress Notes dated 4/2/08 (p. 63 of documents).

Lutheran Social Services have employed various strategies to provide support to JH's mother. Lorrie will be conducting a home visit and will meet with the parents".

It should be noted, however, that when Ms. Cook was interviewed by this investigator, she portrayed a different picture minimizing and at times stating that there were no problems about the home itself or concerns about JH's hygiene, and when they arose, they were addressed by JH's mother as needed. She even stated that "incontinence was a part of who JH was" and it was dealt with as needed. Ms. Cook also denied that JH's personal hygiene and the condition of the home had become such an issue that no one knew what to do. She also denied that it was ever discussed that more supports were needed for the family in these areas. In fact she stated that "the team didn't feel more services were needed." Despite the documentation of her conversations with Ms. Ripley,<sup>7</sup> when interviewed by this investigator, Ms. Cook indicated that she had no recollection of speaking with Ms. Ripley or the specific details of the complaint.

It is found, however, that indeed Ms. Cook did generally have and conveyed the same concerns to BEAS that Lutheran Social Services staff communicated to BEAS. This is based on both the documentation cited above and the numerous incident reports, as well as other record entries in the Community Bridges records. It should also be noted that if Ms. Cook's more recent characterization of the conditions as minimal or unimportant reflect her views, additional concerns are raised about whether at least this supervisory staff person has an adequate level of caring, concern, professionalism, and/or candor.

There was no report of any type of abuse, however, physical or otherwise. In fact, it seems undisputed that JH loved her parents and they loved her and JH would often hug her mother upon returning home.

In May of 2008, Lutheran Social Services continued to report that supports were needed to assist the family with JH's hygiene care, but it was decided to wait until the BEAS investigation was complete, expecting the State to find the complaint substantiated.<sup>8</sup> In June of 2008, however, the investigation of the complaint was completed and deemed to be "unfounded".<sup>9</sup>

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<sup>7</sup> Id. See also Community Bridges Progress Note entry for 4/25/08 (page 63).

<sup>8</sup> See e-mails from Patricia Luoma to Jennifer Cook (cc: Suzanne Pfister and Mary Jane Nichols) dated May 7, 2008 and May 8, 2008.

<sup>9</sup> Letter dated June 26, 2008 from Lorrie Ripley to Roy Gerstenberger, ED, Community Bridges. The State of NH DHHS' policy is to keep investigation records for only six months if a complaint is determined to be "unfounded".

Due to regulation He-E 704.10 which requires that records of unfounded cases, including the original report, be completely expunged after six months, the records of this investigation are no longer available. This issue is discussed and addressed in the Findings below. Because the records were no longer available, the BEAS investigator, Lorrie Ripley, was interviewed. She stated that the Bureau received a complaint specifically charging neglect against JH's mother and father as a result of JH's poor hygiene. Based on her recollection (without the benefit of any records) she indicated that there was no specific formal complaint as to the condition of the residence. While that may have been her recollection, the overall evidence indicates that Ms. Ripley was made aware of not only personal hygiene issues, but the housing conditions, and other incidents that may have occurred in the home. As described above, this includes accounts from Lutheran Social Services staff about what was in the formal complaint to include bathroom issues, cat urine and feces in the apartment, medication issues, the crowded nature of the apartment, and that JH's brother, a convicted felon was living in the apartment. This finding is also based on the records of Community Bridges stating what Jennifer Cook conveyed to Ms. Ripley and Ms. Ripley's own statement recorded in Community Bridges' records when talking with Jennifer Cook, that she was planning to make a home visit as part of the investigation of the complaint.<sup>10</sup>

After meeting with JH, both of her parents, the staff at Lutheran Social Services, speaking with JH's primary care physician and reviewing the available records, Ms. Ripley determined that the complaint<sup>11</sup> was unfounded. At no time did Ms. Ripley enter the residence or speak with JH's direct care staff, Zeke Bara. She stated that she felt she could make her final determination of the specific allegation in the complaint based on the information she had obtained. She explained that she felt she had no jurisdiction to enter the home without permission since the parents were not paid providers.<sup>12</sup>

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As such, the investigation records were not available for this writer to review. (See letter dated July 7, 2009 from Atty. Ken Nielsen to DRC).

<sup>10</sup> Community Bridges Progress Note dated 4/25/08. Telephone Contact sheet dated 5/12/08 from Lorrie Ripley to Suzanne Pfister (Lutheran Social Services).

<sup>11</sup> Again, the "complaint" being investigated by Ms. Ripley pertained only to JH's hygiene.

<sup>12</sup> Although Ms. Ripley reported that she visited JH's residence on several occasions, she never found anyone at home, nor did she specifically ask permission to visit the home when she interviewed JH's parents. Again, she stated that she did not feel this was necessary given the basis for the complaint. It was also noted that the parents

Additionally, it was Ms. Ripley's feeling that the information she received concerning the condition of the apartment did not rise to the level of constituting a danger to JH's safety. If it had, she would have immediately taken some action.<sup>13</sup> Further, when questioned specifically, Ms. Ripley stated that she never considered whether there might be evacuation issues for JH in the event of an emergency, nor was this something that is routinely checked. Finally, although familiar with the procedure for seeking an alternative guardian, Ms. Ripley was not aware that anyone at either Lutheran Social Services or Community Bridges had ever taken steps in this direction. In essence, Ms. Ripley felt that Lutheran Social Services really did not know what to do with the family, therefore, she informally suggested Lutheran be creative in working with Community Bridges to see if the hygiene issues could be addressed in JH's ISP<sup>14</sup>

After receiving the BEAS determination, Lutheran Social Services continued to have concerns about JH's hygiene and living situation, but were resigned to the fact that "in reality, nothing was going to change".<sup>15</sup> It was believed that Zeke (her day program staff) was providing the best services possible for her.<sup>16</sup> Consistent with her ISP, JH's staff was implementing her residential goals in her home two days each week for an hour each day, plus 15 minutes on another day. The remaining time of programming was being done in the community.<sup>17</sup>

There is no indication that after, during, or anytime before the investigation Community Bridges or Lutheran Social Services discussed, explored, or pursued petitioning for a change of guardianship, seeking a co-guardian, or an outside advocate for JH.

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had made it clear over the years that they did not want anyone in their home and they had either actually terminated JH's services at one time, or threatened to do so because of too much intervention.

<sup>13</sup> Ms. Ripley stated that she could seek a court order if necessary, although she has never had to do this.

<sup>14</sup> Interview with Ms. Ripley. Telephone contact note dated 5/30/08 between Ms. Ripley and Susanne Pfister (LSS).

<sup>15</sup> Lutheran Social Services staff felt like it was only responsible for implementing JH's day program and Community Bridges was responsible for everything else. As such, it felt limited in what it could do to help improve JH's situation.

<sup>16</sup> E-mail from Suzanne Pfister to Mary Jane Nichols (cc'd: Patricia Luoma) dated 10/15/08.

<sup>17</sup> Ms. Cook could not recall there being any adverse reaction to the Department's finding of "unfounded". She stated several times that "it was what it was". She also could not recall the team doing anything in particular after the determination.

### **C. Eviction Notice, Extended He-M 521 Certification and Subsequent Improvement in Housing and Hygiene Conditions**

On February 9, 2009, JH's parents notified Community Bridges that they were being evicted from their apartment.<sup>18</sup> It was noted that in March of 2009, JH was living with her mother, father, brother, baby nephew and six cats. At an ISP meeting held on March 17, 2009, JH's mother reported that she had given up on finding a new apartment because the family had no funds for a security deposit.<sup>19</sup> Community Bridges records indicate that on June 2, 2009, JH's mother reported that the family's phone had been turned off and inquired of Community Bridges whether there was funding to help them pay bills. There is a notation that a staff person called back, but did not leave a message in case it was an incorrect phone number.<sup>20</sup> An e-mail from Mary Jane Nichols to Jennifer Cook dated this same day indicates that Community Bridges' response was that it was not able to help with funding as it did not have money for anything other than services that were within the pre-existing budget. Several other possible sources of funding, however, were identified, but there is nothing in the records which indicates that this information was passed along to JH's parents. As discussed below, several days later, on June 5, 2009, a team meeting on JH's services and budget was held. The records from the meeting do not indicate any discussion of the rent/security deposit request or imminent eviction date; rather the meeting was focused on reducing services to JH for budget reasons.<sup>21</sup>

It was also noted at the March 17, 2009 ISP meeting that "going to the laundry mat" was going to be added as a goal for JH because the family did not have a washer or dryer.<sup>22</sup> (sic).

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<sup>18</sup> Community Bridges Progress Note dated 2/9/09 (page 66).

<sup>19</sup> Meeting minutes dated 3/17/09.

<sup>20</sup> Community Bridges Progress Notes dated late May/early June, 2009 (exact dates on records cut off from copies).

<sup>21</sup> The only other place this issue shows up is in a telephone contact sheet dated 6/10/09 (two days after the fire) in which Anne Potozak of Community Bridges inquired of Suzanne Pfister as to what she knew about the Johnsons being evicted and owing money. Ms. Pfister indicated that the owed amount was \$1800 and that the family had asked both Lutheran Social Services and Community Bridges for money, but the only funds provided were respite funds contained in JH's budget.

<sup>22</sup> Apparently JH's family had a washer and dryer in their apartment, but as of 12/4/08, the landlord had made them get rid of them due to the noise. "Going to the laundry mat" had previously been a goal in JH's ISP on 6/27/08. The records indicate that there was some dispute between Community Bridges and Lutheran Social Services about how best to implement this goal – whether at home or in the community. It is unclear how this was resolved given the conflicting information received.

On April 30, 2009, Community Bridges conducted an annual He-M 521 Certification Review of the family's home as required. As a result of this favorable review, the certification was extended to May 1, 2010.<sup>23</sup> The certification notes that the "service provider documentation is well-organized and thorough. Family is satisfied with services. JH has started a new goal to increase independence, participation/responsibilities and to support her family's efforts to maintain her hygiene." There are six additional comments provided under the "comments" section:

1. Reviewer and service coordinator will check with Community Bridges business office re: attendance. 25 hrs/wk is being provided over three days/wk. This needs to be modified in the ISP to change from 20 hrs/wk to 25 hrs/wk, OR provide 20 hrs/wk over two days/wk, not 3?
2. JH struggles with hygiene/family benefits from agency reminders
3. Certification book/documentation is well organized.
4. Physical scheduled for 6/09.

There is no comment about the condition of the home. This may be because by May 1, 2009 Lutheran Social Services was repeatedly noting that JH was clean and her hygiene had improved. In fact, it was noted by Community Bridges in May that JH's personal care appeared to be improving and her "day program was going good". Zeke even noted that JH had been dropped off at his house "squeaky clean" which was a first.<sup>24</sup> It has been reported that the family was constantly reminded that JH could be removed from them if things did not improve. It is believed that it was in response to these concerns that JH's hygiene improved at this time.

#### **D. Funding and Service Cuts Proposed June 2009**

As noted above, on June 5, 2009, a meeting was held to discuss funding cuts to JH's program because the amount of money allocated to JH was reduced. It was proposed at that time that JH be provided 30 hours a week of 1 to 2 instead of 1 to 1 day services, with no respite being provided by Lutheran Social Services. It was noted that the respite funds for FY09 had

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<sup>23</sup> He-M 521.07 requires that the area agency service coordinator (in this case Mary Jane Nichols) visit the individual at home at least quarterly to determine and document whether services "meet the individual's *environmental and personal safety needs*". "Environmental safety" is not defined in the regulations, nor does Community Bridges or BEAS have a specific definition for this term. Ms. Cook stated that she believed this addressed such things as "basic necessities, personal living space, smoke detectors," etc. At no time, however, was JH's ability or her parents' ability to safely evacuate the premises considered or discussed.

<sup>24</sup> E-mail dated 5/13/09 from Suzanne Pfister to Patricia Luoma (cc'd: Mary Jane Nichols; Jennifer Cook).

been used up by the end of May. It was proposed that these cuts would take effect on July 1, 2009. Because it was felt that providing 1 to 2 services would not meet JH's needs, other changes were considered including moving the mileage line item, providing respite through Medicaid, limiting eating out to once a week and bringing a bag lunch. The minutes from this meeting indicate that JH's father, asked if he could appeal the decision to cut JH's program.<sup>25</sup> He was referred to the ISP documents for the appeal process. He was also told by Jennifer Cook that although he could appeal, he "couldn't get blood from a turnip" in terms of funding.<sup>26</sup>

On this same date, Patricia Luoma, Lutheran Social Services, requested a specific budget amount that would be available so she could begin working on the proposed budget and service design. It was anticipated that Zeke's hours were going to be cut. However, no specific budget or programming changes had been actually implemented by the time of JH's death, three days later.

#### **E. Events of June 8, 2009 Fire, JH's Death and Cause**

At 3:45 a.m. on Monday, June 8, 2009, JH's mother, got up, woke JH up, fixed her a cold breakfast and had her dressed by 4:30 a.m. JH's mother left JH in the master bedroom with her father. JH's mother then left the apartment around 4:50 a.m. to go to work at Home Depot. She made sure, as she generally did every work day, that the door was locked and the lights turned off. No cooking devices had been used to make breakfast and no one in the apartment smoked. JH's brother had moved out of the apartment about a month before because of physical threats from drug dealers. JH's mother arrived at work at 5:15 a.m. At about 5:45 a.m., she received a phone call from JH's brother informing her of the fire.<sup>27</sup>

According to the State Fire Marshall's report, JH's brother, who then lived next door, had been awoken by his father banging on his apartment door at about 5:10 a.m. saying the apartment was on fire. Both JH's brother and father returned to the apartment where fire and smoke were visible at that time. JH's brother asked his father where JH was and then told his father he had to "get her out of there." JH's brother reported seeing flames coming from the refrigerator. He saw his father re-enter the apartment, turn right and disappear into the living room area. JH's

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<sup>25</sup> Ms. Cook stated that, in fact, no firm decisions had been made about JH's services only that the team was trying to reconfigure her services to meet her needs.

<sup>26</sup> See handwritten notes of Patricia Luoma (Lutheran Social Services) from 6/5/09 meeting.

<sup>27</sup> Information provided from the State Fire Marshall's report.

brother was then forced back down the building stairs and out onto the street because of the intense heat and smoke.

As previously noted, JH's father was later found in the living room face down, and JH was located lying on her left side in a fetal position at the foot of the bed in the master bedroom wedged between the bed and wall, directly under the window. An overturned dresser was on top of her head.

It was determined by the State Fire Marshall that the fire had started in the kitchen/cooking area, but the heat source or item ignited was undetermined.

The medical examiner was notified at 7:20 a.m. The autopsy report on JH indicates that when the fire broke out, JH was asleep with her father. Both the medical examiner and the State Fire Marshall indicated that it was difficult to evaluate the condition of the apartment prior to the fire because of the extensive damage. The cause of death is identified as "smoke inhalation under accidental circumstances".

A review of the Pittsfield Building Inspector records shows no citations of the apartment at the time of the last inspection on December 18, 2008, approximately six months before the fire.<sup>28</sup>

## **VI. Applicable or Relevant Law and Standards**

The statutes, regulations and standards applicable to the facts of this investigation are:

- RSA 161-F 42-57, the State's Adult Protective Services Act, and the regulations promulgated pursuant to this Act; and
- RSA 171-A, the State's Services of the Developmentally Disabled Act, and the regulations promulgated pursuant to this Act.

The specific provisions under the above-cited statutes and regulations are set forth in Appendix A, attached. The findings and recommendations below are based on these laws and regulations.

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<sup>28</sup> The Town of Pittsfield Housing Standard Ordinance governs the quality of rental dwelling units and is designed to protect the "health, morals, safety and general welfare of the citizens of the Town". The Pittsfield Housing Standards Board, which manages the Housing Standards Agency, has the Town Fire Chief as a standing member. The ordinance mandates that all rental units be inspected biennially for fire safety. The ordinance states that the "minimum conditions and standards for fire safety" are included in the inspection and that "the owner of premises shall provide and maintain such fire safety facilities and equipment in compliance with the Life Safety Code and State Fire Code". In addition to a certain number of egresses, each rental unit is inspected for smoke detectors and fire extinguishers.

## VII. FINDINGS

The findings below address or relate to the overarching question examined in this investigation - whether there were steps or actions that should have been taken by any government agencies, officials or individuals or entities licensed, certified, designated, or funded by government agencies that may have prevented or reduced the risk of JH dying as a result of the June 8, 2009 fire. Section VIII presents some additional findings that emerged as a result of the investigation.

### **Community Bridges and DHHS Responsibilities in Regard to Assessing for Fire Safety**

1. It should first be noted that while staff at Lutheran Social Services, Community Bridges, and BEAS were aware of poor living conditions in the home, there is no clear evidence that those conditions caused the fire. For example, the State Fire Marshall's report does not comment on the conditions of the home prior to the fire because of the extent of the damage, but simply concludes that JH died from smoke inhalation. Without some evidence to the contrary, it cannot be concluded that the poor living conditions caused the fire and JH's and her father's death. However, as noted below, there were steps or actions which could have been taken by Lutheran Social Services, Community Bridges and BEAS and that were required by the circumstances and/or legal requirements that very likely would have reduced the risk of the fire or JH's and her father's death.

2. Based on the purpose and fundamental requirements of RSA 171-A (to include social and other services within the limits of modern knowledge to protect and promote health, safety, independence, etc.) and specific regulatory requirements as well as federal guidelines,<sup>29</sup> Community Bridges should have conducted an assessment of JH's safety and other related needs across all environments and services and developed/implemented plans and actions to address them to include consideration of the risk of fire in JH's residential environment. The specific regulatory requirements requiring a safety assessment include:

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<sup>29</sup> CMS has developed a "quality framework" for guiding states in establishing quality assurance standards. See United States Dep't of Health and Human Services, "Summary of Results: National Quality Inventory Survey of HCBS Waiver Programs" (Jan. 2004). Participant safeguards include "housing and environment" providing that the "safety and security of the participant's living arrangement is assessed, risk factors are identified and modification are offered to promote independence and safety in the home". (Id, Focus Area IV:C (Working Draft), at p. 27).

- a. He-M 503.11(f)(1)(a) & (b); and see also He-M 503.08(b)(3)(4).
- b. He-M 521 (b)(3)
- c. He-M 521.05
- d. He-M 525.06(l)(4)
- e. CMS HCBS Quality Framework

3. As required by these regulations, Community Bridges, as part of the service planning process for JH and the He-521 certification process and pursuant to its He-M 505 responsibility as Area Agency, should have assessed JH's safety and risk in relation to residential fire safety. The only risk or safety issues the service plan addressed concerned JH speaking to strangers and not running into the street. Given the basic and widely accepted need for an evacuation plan accompanied by practice drills, it would be expected that such a risk/safety assessment would have called for such a plan and drills. This standard and basic requirement is now commonly recommended in all homes with or without state involvement, and with or without a vulnerable person in the home. Where JH was receiving services from the state, including some home support, the home was certified by the state, and given the circumstances of JH's situation, a safety assessment with at least an evacuation plan with a requirement of drills, a minimal and no cost imposition by the state, should have been proposed to the family and/or been in place. The need for such an assessment and steps were particularly obvious and warranted here. First, JH had a diagnosis of pervasive developmental disability, with cognitive impairment. She required 24/7 supervision for all physical, medical and safety precautions. She was unable to take care of herself including dressing, personal hygiene, bathing, toileting, food preparation and oral care. She was also non-verbal except for a few sign language signs. Second, both parents worked, and JH's father was limited in his capacity. Third, an evacuation plan and drills had not been developed or practiced by the family on its own. Fourth, housing conditions were generally poor and at best cluttered. The apartment was hardly an optimal facility in terms of fire prevention.<sup>30</sup> Fifth, the apartment was located on the second floor, accessible only by an exterior stairway.<sup>31</sup>

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<sup>30</sup> While national standards call for all families to have an evacuation plan and to practice it, the fact that conditions were poor or suboptimal made the need for an evacuation plan even more compelling. JH lived in an older wooden structure without a sprinkler system. While there was no requirement that families install sprinklers or modify their home with all fire retardant material, these are factors that should be taken into account when assessing what can be done to reduce the risk of fire, injury or death in case one does occur. As discussed in Finding 8, recent fires and

4. Community Bridges' failure to do a safety assessment relative to fire safety violated its professional and legal responsibility to JH. Given what happened during the fire, had there been an evacuation plan in place which had been rehearsed, the risk of this fire resulting in JH's and her father's death would have been reduced and the deaths likely prevented. As noted above, JH's father, after observing the fire, apparently in panic, ran out of the second floor apartment, leaving JH in the bedroom, and went across the street to seek help from his son. By the time both had come back into the apartment, it was too late to save JH. Had there been a rehearsed fire evacuation plan, it is likely that JH's father would have acted differently and removed JH initially and promptly.

5. DHHS shares in some of the responsibility here as well. While the circumstances clearly cried out for an evacuation plan, both the He-M 503 regulations and He-M 521 regulations are wanting in specificity in requiring that safety needs and assessments encompass, include, or promote an evacuation plan and drills when an individual is receiving state services and/or is living in a He-M 521 certified home. He-M 503.11 requires an assessment of safety needs in developing a service agreement, but does not speak specifically about the need for conducting such assessments across all environments or in the residential environment. He-M 521 regulations require the service coordinator in his/her quarterly reviews to make sure the services the person receives "meet the individual's environmental and personal safety needs" (HeM 521.07). Other similarly broad or vague language that may be said to cover this area may be found in He-M 521.10 under the revocation section. That provision broadly states that grounds for revocation of He-M 521 certification may include that "any provider or staff working directly with individuals [having] an illness or behavior that, as evidenced by the documentation obtained and the observations made by the department, would endanger the well-being of the individuals." These vague, cryptic or under inclusive provisions do not give

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catastrophes in and out of state should also have increased Community Bridges' sensitivity and consciousness about the need to assess for fire safety.

<sup>31</sup> In making these and other findings, consideration was given to the balance between the right to individual autonomy vs. the authority and obligation of the state (and its surrogates) in its *parens patrie* and similar or derivative roles to protect the safety of especially our more vulnerable citizens. These balances are taken into account and struck in many of the above cited laws and regulations. See also RSA 161:F:42, the purpose clause to the Adult Protective Service Statute. Given the facts and factors of this situation during the months and years preceding the fire, the balance here between state intrusion vs. individual autonomy would certainly weigh in favor of conducting a residential safety assessment which very likely would have led to the minimal and no cost requirement of an evacuation plan and practice drills.

sufficiently explicit instruction to area agencies to conduct safety inspections or require, request, or promote evacuation plans or drills in He-M 521 certified homes.

6. By way of comparison, the Department has used more explicit language in He-M 1001.06 and 1001.07 and He-M 525 .06(1)(4) regulations which govern certification of clients living in enhanced family care of staffed model homes. Both sets of regulations have a number of provisions regarding fire safety. Amongst the core elements of these rules are extensive and explicit provisions on risk assessments, evacuation plans, drills, and training plans for residents in case of fire, or other natural or man-made disasters or catastrophes as well as the supports necessary to assure a safe and prompt evacuation in the case of such events. While the balance between individual autonomy and the state's interest in protecting vulnerable adults in He-M 521 homes may not require the same level of prescription, the need and justification for some of the protective provision of He-M 1001 and He-M 525 apply to vulnerable individuals living in He-M 521 certified homes. Indeed the evacuation plan and drills requirements are recommended national standards for all families and homes in the United States.<sup>32</sup> DHHS, in developing He-M 521, could have included some or all of the 1001 provisions regarding risk and life safety assessment and evacuation plans, but instead chose to utilize vague and cryptic passages requiring that the service coordinator make sure that services meet "environmental and safety needs" on a quarterly basis, leaving to each area agency how they would address these issues, according to Ken Nielsen, an attorney for the DHHS Office of Client and Legal Services.<sup>33</sup> This approach sets the stage for uneven and inconsistent policies and practices and is inconsistent with the State's (DHHS's) obligation as the supervisor and overseer of the service delivery system under RSA 171-A: 1 & 4.

7. Given the obligation as the single authorized Medicaid agency and its supervisory responsibility over the service delivery system, under RSA 171-A, DHHS should have been

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<sup>32</sup> United States Fire Administration, a division of FEMA, recommends that everyone should have a comprehensive fire protection plan that includes smoke alarms, residential sprinklers, and practicing a home fire escape plan. ([www.usfa.dhs.gov/media/press/2009releases/102809.shtm](http://www.usfa.dhs.gov/media/press/2009releases/102809.shtm)).

<sup>33</sup> Counsel for BDS, Ken Nielsen, confirmed that DHHS does not have any specific policies or guidance documents which an area agency must follow when conducting routine home checks pursuant to He-M 521 nor are the terms "personal and environmental safety" specifically defined in the regulations. It is DHHS' responsibility, however, to initially certify a home under He-M 521 upon the recommendation of the area agency. Attorney Nielsen stated that the Department essentially leaves it up to each individual area agency to define these terms as it sees fit. In this case, Community Bridges also had no specific definition or written checklist for its service coordinators to follow when determining if, in fact, a home met the He-M 521 criteria.

clearer and/or more prescriptive in its regulations in requiring, at the very least, evacuation plans and drills, and other less intrusive measures to help protect safety, rather than leave it to each area agency to decide. Clearer regulations in this regard would have likely reduced the risk of fire or at least JH's and her father's deaths.

8. Both with regard to DHHS and Community Bridges, there should be a heightened level of sensitivity and scrutiny in carrying out their respective roles in this area stemming from the publicity around and the policy changes that were made and disseminated relative to a fire in Tilton, a nearby community, two years earlier in which many of the circumstances were quite similar. There, two individuals with developmental disabilities and clients of an area agency died along with their enhanced family male provider who was also trying to save them. There has also been a heightened consciousness by the public and from government and service providers about risk assessments and evacuation plans for individuals with disabilities in other man-made or natural disasters or catastrophes because of Katrina, 9/11, and the New Hampshire floods. These factors make each agency's failure to fulfill their respective roles and responsibilities, even more disturbing.

### **Community Bridges' Responsibilities Regarding Housing Conditions and Issues**

9. As the evidence revealed, JH was subject to most, if not all, of the following conditions for at least four years, and little or no effective action was taken to address them until about a month before her death:

- The majority of the reports reflect that JH was dropped off to her provider, Esequiel "Zeke" Bara, with urine and/or body smells. There are also reports related to poor toe nail care.
- The residence itself was often in disarray and there were six cats living in the apartment along with five people at one time.
- JH's home was "filthy" and constantly smelled of cat urine/feces, with cat urine and feces observed on the floor;
- The bathroom was "falling apart".
- JH was always dirty (hands, clothes) and smelled like a "horse stall."

- Her diaper was always soiled, her genital area red with rash and she often had food in her teeth. In fact, a plan was formulated whereby Zeke Bara would change JH into clean clothes for the day, changing her back into her soiled clothing at the end of the day before returning her home.<sup>34</sup>
- Her toenails would often be several inches long or cut to bleeding; and
- Concerns about JH’s medication administration, and specifically:
  - That it was usually “short” at the end of the month possibly due to JH’s brother stealing it to sell on the street.<sup>35</sup>
  - The timing of administering JH’s medication in conjunction with meals, and specifically that JH’s mother would give JH her breakfast and morning medication before leaving for work at 5:00 a.m., with the result of JH being hungry by the time she got to Zeke’s home at 9:00 a.m. and her meds would wear off soon thereafter.

These conditions prompted one Lutheran Social Services staff person to state at a March 2008 meeting: “How long does this go on before someone does something for JH?”<sup>36</sup>

10. Up until May 2009, conditions remained deplorable and the few steps that were taken to improve conditions were inadequate, e.g., a laundromat goal, BEAS complaint.<sup>37</sup> The failure to adequately address these concerns over at least a four-year period, particularly by Community Bridges, violated its obligation under the above-quoted provisions of He-M 503, He-M 505, and He-M 521. Some of the actions that could have been considered or taken to

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<sup>34</sup> This condition violates basic standards of human decency, as reflected in regulations, e.g. human dignity. Most people would not tolerate this to occur to their child or elderly parent, or to a vulnerable loved one, disabled or not, for any period for a day or two, let alone for months and years on end.

<sup>35</sup> Although JH’s mother denied this allegation, it was evident to her day staff that JH had not taken her meds on some days.

<sup>36</sup> See e-mail dated 3/13/08 from Susanne Pfister to Mary Jane Nichols, cc: Jennifer Cook; Patricia Luoma.

<sup>37</sup> As pointed out below, filing a report of neglect with BEAS (which was done initially by Lutheran Social Services staff) did not let Community Bridges off the hook either while the complaint was pending (nearly a three-month period from April 2, 2008 to June 26, 2008) and certainly thereafter even though the case was unfounded.

address the conditions were decertifying the home as an He-M 521 residence, providing more supports in the home, removal of JH from the home,<sup>38</sup> petitioning for a new or co-guardian,<sup>39</sup> seeking Probate Court assistance with the matter, or obtaining or affirmatively referring the family to an outside advocate or independent service coordinator for JH. The latter options should not only have been considered desirable but necessary, where the major principals had conflicting interests, either from budgetary constraints, or relationships, e.g., mother being the guardian, provider, and payee. In failing to take these or other types of action over at least a four-year period, Community Bridges also violated He-M 505.03 which requires the agency to affirmatively “monitor and safeguard all of their clients’ rights,” including fundamental, personal, and treatment rights under He-M 310 and the service guarantees under He-M 508.08.

11. While one or more of the above-described actions that should have been taken in response to the personal hygiene, housing, and housing-related conditions may have prevented the fire and/or JH’s death, Community Bridges’ culpability in regard to the fire for its failures in these areas is not as direct as its failure to require or encourage fire safety measures such as an evacuation plan. Nevertheless, as described above, Community Bridges did violate its duty to JH in failing to address conditions over a lengthy period of time.

12. The record reveals that Community Bridges also failed to adequately respond to the fact that JH and her family was facing eviction for nonpayment of rent from their He-M 521 certified apartment. According to the evidence, the evacuation process began in February, 2009, and Community Bridges was aware of it at least as early as March, 2009 when JH’s mother

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<sup>38</sup> Again, however, this concern must be weighed against the client’s right to live where she chooses. He-M 521.05(a)(1)a. specifically provides that an individual’s service agreement must “meet the individual’s expressed interests, *preferences*, needs and *lifestyle*”. (emphasis added). Although JH was virtually non-verbal, she was able to communicate what she liked and didn’t like through some vocalization and simple signs. It is unclear whether anyone ever asked JH if she would prefer to live somewhere else. Given what has been described as a very loving relationship between JH and her parents, it is most probable that JH enjoyed and preferred to live with her family. Additionally, Ms. Cook stated not only that JH was not cognitively able to indicate if she preferred to live with her parents, but there was no need to even consider changing either her guardian or place of residence. In fact, Ms. Cook stated that such changes would not be the decision of Community Bridges, but of the State.

<sup>39</sup> The issue of “Guardianship/Decision-Making” is an item identified on the ISP. In 2006 it was noted under this section that JH’s “support team recommends that this arrangement not be changed at this time” referencing the fact the JH’s parents were her legal guardians. The last ISP dated 3/17/09 is silent on the subject other than to identify JH’s parents as her guardians. Given that this issue is identified on the ISP form, it must be assumed that if there was truly a concern, it would have been (or certainly could have been) discussed at the March 2009 team meeting and every previous meeting. It is unclear whether, in fact, either Lutheran Social Services or Community Bridges understood that they could have sought a change in guardianship. Whether or not they did understand this option was available, RSA 171:A:10 (A) and/or He-M 503.10(f)c clearly gives these agencies that authority.

reported at an ISP meeting that “she had given up on finding a new place because they have no funds for a security deposit”.<sup>40</sup> The record reveals Community Bridges’ only “action” was attempting to return a phone call from JH’s mother in May, 2009 requesting security deposit assistance for a new apartment, one month before the fire. When no one answered the phone, the staff person left no message indicating that the call was returned.

13. Oddly enough, the eviction issue and Community Bridges assisting the family with new housing did not come up at a meeting held a few days later, on June 5<sup>th</sup>, in which JH’s mother and father were present. According to the minutes, the principal subject of the meeting was Community Bridges notifying JH’s parents that JH’s services may be cut.

14. Community Bridges failed to take action or even respond to JH’s parents regarding their request for assistance for a security deposit and/or rent for a new apartment despite the fact that they were aware that this was a non-payment eviction case, the family was poor and in a precarious financial state. While it is difficult to assess how imminent the actual eviction was during the February through June time frame, the uncertainty about continued housing and the specter of JH, a Community Bridges’ client facing homelessness, should have prompted a decision and action on the part of Community Bridges under any one of a number of it’s responsibilities<sup>41</sup> to either: (1) help the family in remedying the nonpayment situation in their current housing; or (2) procure other housing.

15. Had Community Bridges followed at least the second option in a timely manner, the family, including JH, may have been out of the home before the fatal fire on June 8th. While, again, Community Bridges could not have foreseen the June 8th fire, its failure to act in assisting to address the eviction situation is in conflict with its multiple obligations to address JH’s needs.

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<sup>40</sup> See ISP meeting notes dated 3/17/09

<sup>41</sup> See He-M 503.09; He-M 505.03. Although the major funding stream Area Agencies use for services and assistance to individual and families, the Medicaid waiver, does not provide funding for rent or security deposits, Area Agencies and its service coordinators are not precluded from using other sources of funding for such things. In fact, the obligation to assure an individual’s health and welfare and his/her rights are met is not based on available Medicaid funding . He-M 505.03(x) specifically authorizes and requires “**The area agency shall utilize all applicable federal, third party, and other public and private sources of funds to carry out its mission and responsibilities.**” Based on cases involving Community Bridges and other area agencies with which DRC has been involved over almost 30 years, it is clear that Area Agencies do, in fact, access either pure state dollars or private money on a one-time or continuous basis to assist in housing, dental work, vacations or other non-Medicaid governed items or make active referrals to towns for municipal assistance. All of these options were available in this matter.

### **Mandatory Reporting Responsibilities of Staff from Community Bridges and Lutheran Social Services**

16. It is found that Lutheran Social Services filed a report with BEAS in March 2008, frustrated by the lack of effective action by Community Bridges to address the lack of personal hygiene issues for JH and the housing conditions over at least a three-year period, and that this report covered both personal hygiene and housing conditions as recounted in Section V of this report.<sup>42</sup> It is also found, based on the written records that Jennifer Cook, Community Bridges service coordinator supervisor, piggy backed on the Lutheran staff report and conveyed similar information in April, 2008 to the BEAS investigator though she now claims that she never spoke with the BEAS investigator.

17. That Lutheran Social Services staff came forward and filed a report with BEAS was a positive development. However, given that reported conditions existed for years previous, and presumably staff suspected (or should have suspected) the conditions constituted neglect, it violated its mandatory reporting responsibility under both RSA 161-F:46 and He-M 202.06 which requires that suspected cases of abuse and neglect also be reported to the DHHS/BEAS and Area Agency, respectively. With regard to the reporting obligation to the area agency, it could be argued that Lutheran Social Services staff was continually or frequently doing just that through various communications and incident reports and it was the Area Agency who was not sufficiently responsive in addressing them or as treating them as complaints under He-M 202. We cannot resolve this question with any certainty. Based on the incident reports alone, however legally classified, Community Bridges should have acted. As noted above, staff from both agencies who had reason to suspect had an obligation to report in a timelier manner.

### **BEAS Investigative and Protective Services Responsibilities**

18. BEAS, and specifically the investigation of this matter, was deficient and inadequate based on legal requirements and/or minimally acceptable professional investigation/adult protective services practices. The investigator:

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<sup>42</sup> Although the written documents are no longer available, Ms. Riley stated that she had received information about the condition of the home and thus was aware of the situation.

- a. Failed to interview Zeke Bara, a key collateral contact, in accordance with He-E 704.07 (a).
- b. Unduly narrowed the investigation to personal hygiene issues, when information she received from both Lutheran Social service staff and Community Bridges initially and during the course of her investigation revealed poor housing conditions or issues that occurred in the home, such as problems with medication administration. Those facts and factors, coupled with JH's own cognitive and communication issues and vulnerability and the following legal requirements, should have prompted the investigator to assess residential issues, including fire and life safety.
  - The regulations required the investigator to obtain information about:
    - the "type of living arrangement," He-E 703.05(a)(2)
    - whether there were hazards present in the environment He-E 703.05(a)(10); and
  - During the interview of the victim:
    - Obtain information regarding **the alleged victim's safety, functioning, and environment;** He-E 704.05(b)(5) (Emphasis added.)

19. Related to the failure described in finding 18 is the investigator's failure to conduct an announced or unannounced home visit. Although the investigator reported attempting to make efforts to inspect the inside of the home, ultimately, she claimed that it was not necessary to conduct a home visit to make a finding on the complaint since it was narrowly focused on JH's personal hygiene. Because all the records of the report and the investigation are expunged pursuant to regulations within six months after the investigation, that source of information is not available. The wisdom of the expungement policy is discussed below. The next best sources of information, the recollection of persons who talked to the investigator and the relevant documentary information available, indicate that the issues complained of were broader and in some cases different than just individual hygiene issues (e.g. cat feces, bathroom disrepair, medication administration errors) and/or had their origin in the home, e.g. JH showing up for day activity in soiled diapers. One Community Bridges note indicated that the

investigator stated that she was going to conduct a “home visit.”<sup>43</sup> Those facts coupled with the fact that JH was not able to provide information herself and the legal requirements quoted above to determine environmental and safety conditions, should have required a home visit. The investigator’s other reason for not pursuing a home visit was that she felt she did not have authority because J’s parents were not paid caretakers. This justification has no basis in law or fact. RSA 161-F:53, which authorizes home visits, draws no distinction between paid and unpaid caregivers. In this matter, the investigator neither asked permission nor sought a court order. In sum, the failure to conduct a home visit was a dereliction of her responsibility.

20. While the combination of factors and requirements in this matter clearly warranted a home visit, the regulations issued by DHHS/BEAS should provide clearer guidance and prescription as to when a home visit should occur, and what to look for while conducting the visit. While the regulations call for an investigation and determination about environmental and safety conditions, it does not mandate or otherwise specify a procedure and criteria for a home visit, announced or unannounced. The lack of guidance and prescription in the regulation in this important area is a failure on the part of DHHS/BEAS to fulfill its responsibilities under federal and state law in protecting incapacitated adults suspected of abuse, neglect or exploitation. RSA 161-F:42 *et seq.*, 42 C.F.R. §441.302.21. If the investigator had performed the components of an investigation that she omitted, it cannot be known for certain whether there would have been a finding of neglect and/or this would have led to actions which would have prevented the fire or the fatalities, e.g. removal of guardianship, relocation to other housing. Even if a home visit had occurred, or one or more of these other investigation components were done, a determination whether there was an evacuation plan in place and practiced probably still would not have been made. Ms. Ripley stated that she never considered whether there might be evacuation issues for JH in the event of an emergency, nor is this something that is routinely checked. Therefore, more guidance and prescription is clearly needed from the DHHS/BEAS in the context of BEAS adult protective services’ role.

## **VIII. ADDITIONAL FINDINGS**

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<sup>43</sup> See Progress Note dated 4/25/08 by Jen Cook.

22. As noted in the findings, there were multiple failures to accept and discharge responsibilities by Community Bridges, Lutheran Social Services, DHHS, BEAS, and DHHS/BDS. A related dynamic is how each, at various points, failed to act in the hopes that one of the other agencies would act. Lutheran Social Services and Community Bridges staff were obligated to report what they believed was neglect to BEAS at least three to four years earlier than they did, as noted above. However that did not relieve Community Bridges from taking action to address conditions even while the report was pending. This they failed to do. Similarly, Ms. Ripley, rather than carry out all the elements required of this investigation, concluded the matter was unfounded and suggested to Lutheran Social Services to be creative in working with Community Bridges to see if the hygiene issues could be addressed through JH's ISP.

23. It is essential that each agency carry out its respective responsibilities in protecting the rights of persons who are vulnerable. This should not be interpreted to mean that, where appropriate, agencies should not work collaboratively when that is called for. However, it is not appropriate or consistent with each agency's respective responsibilities or the overall DHHS regulatory scheme for agencies to abdicate their responsibilities in the hopes that another agency will address the problem. In addition to clearer regulations, as discussed above, oversight and supervision from DHHS, and its Commissioner, is essential to ensure the respective Bureau's community surrogates, contractors, sub-contractors and personnel carry out their responsibilities in accordance with good practice, specific legal requirements and the overall regulatory scheme the law and DHHS has created.

24. As noted above, there are a number of requirements that are imposed on Area Agencies to ensure that the purposes of the law are carried out. Area Agencies obviously are not only prohibited from violating rights, but are under a duty to affirmatively "monitor and safeguard"<sup>44</sup> and "advocate"<sup>45</sup> each client's rights. This is particularly the case for service coordinators. These affirmative safeguarding and advocating responsibilities are needed due to the inherent vulnerability of many individuals with developmental disabilities and barriers they face to leading secure and quality lives. As was found above, Community Bridges and its service coordination staff failed in this role in multiple ways in failing to address poor housing

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<sup>44</sup> He-M 505.03

<sup>45</sup> He-M 503.09

conditions, JH's having to endure rashes and soiled diapers day after day, year after year, medication and eating issues, eviction, etc. While the evidence shows there were a number of ways, times, and opportunities Community Bridges and its service coordination staff could have assisted and assured JH's rights under RSA 171-A and regulations promulgated pursuant thereto, they failed to do so. Community Bridges' insensitivity to JH's needs and rights, its failure to carry out its basic responsibilities and understand its advocacy and safeguarding role are best illustrated by two incidents.

25. As noted above, on June 5, 2009, which turned out to be three days before the fatal fire, Community Bridges convened a meeting in which JH's mother and father were present to discuss possible cuts to JH's services reportedly because of funding cuts. As also previously noted, the record of the meeting reveals no discussion, decision or action regarding the family's request for rent or security deposit assistance to address the eviction they were facing on June 9th. While no firm decision was made at the meeting or apparently prior to her death regarding the proposed service cuts, at least two concerns were raised by the process and substance of the meeting. First, the budget cuts which would have diluted JH's day programming and activity were proposed based on funding considerations, not JH's needs. In fact, the reduction by all accounts was contrary to her needs. This violates the basic purpose of RSA 171-A and the specific requirements of the law. RSA 171-A: 1, He-M 503.09, He-M 503.11, and Area Agency responsibilities under He-M 505.03. Second, to add insult to injury, when JH's father asked whether he could appeal the reduction, he was told yes, but it would be like "getting blood from a turnip." Thus, rather than affirmatively apprise him of his rights and offer encouragement to challenge this possible action in accordance with its safeguarding and advocacy role, staff chilled his right to appeal by offering discouragement. This is even more disturbing considering the staff's awareness of this family's limited means and resourcefulness.

26. The second incident also involved Jennifer Cook, a Community Bridges service coordinator supervisor. As noted, when interviewed by this investigator, Ms. Cook denied giving information to the BEAS investigator, despite the fact that the Community Bridges' records reflect that she did speak with the investigator about the same or similar issues raised by the Lutheran Social Services staff. As was also noted in speaking with this investigator, she minimized or denied the severity or chronic nature of the hygiene and housing problems and with regard to the fact that JH was incontinent and left in soiled diapers, her response was

*“incontinence was part of who JH was”* and it was dealt with as needed. Clearly, credibility and issues of sensitivity are raised by these statements.

27. Whether due to conflicts of interest, callousness, lack of sensitivity or training, or a combination, these two incidents and the other actions or omission by Community Bridges, demonstrate that staff involved in this agency, especially including the service coordinators and the service coordinator supervisor, acted in a manner to deprive JH of her rights to be free from neglect and harm, her right to dignity and other quality of life opportunities, and, as previously noted, increased her risk of exposure to dangerous situations, including fire, an event which ultimately came to pass and took her life.

28. He-E 704.10, which requires that all records including the original complaint of unfounded cases be expunged after 6 months of case closure, is contrary to professional public investigation standards and practice and principles of individual public investigator and agency accountability. It also increases the risk of harm to vulnerable adults in at least two ways: one, by incentivizing, especially in closed cases, unfounded results; and two, by eliminating any record of past conduct of an individual to be considered in future cases when an individual engages in future misconduct. Additionally, in subsequently founded cases, knowing patterns of behavior or other information in prior cases may be important in determining the scope and nature of protective services in the subsequent case. The accountability issue is clearly evident in this matter not only with regard to determining the quality and completeness of the investigation, but about what was reported, and whether the various principals in this case were properly discharging their role. Expungement of records allows people to reconstruct different accounts in follow up or secondary investigations. Particularly today, with cases re-opened years later due to advances in forensic evidence evaluation, the recognition of repressed memories, and the need to re-examine prior unfounded cases when new issues or conduct arises, retention of records outweighs any theoretical counterpoints of expunging records in unfounded cases. It is recommended that the records in unfounded cases be retained for at least five years, the same period as founded cases with additional restrictions to safeguard against inappropriate access.

## **IX. RECOMMENDATIONS**

DRC recommends the following:

1. DHHS should revise He-M 521 to establish a clear definition for “personal and environmental safety” to include a provision providing for an individual’s safe and speedy evacuation from a premises in emergency situations. Clarifying provisions should be added to certification and recertification sections of the regulations and He-M 521.07 regarding service coordination contacts, and, as necessary and appropriate, encourage, promote or require other fire safety measures. Relevant sections of He-M 1001.06 and He-M 525.06 (1) (4-7) should be looked to for guidance.
2. DHHS should develop a uniform checklist to be used by the area agencies so that the clarified requirements of He-M 521 are consistently met. The checklist should include not only the definition of “personal and environmental safety,” but should include a check that the individual is able to safely evacuate the premises in an emergency situation and such other checks needed to ensure that the existing and new requirements are met.
3. There should be a home safety risk assessment conducted and offered to all individuals living in their own homes who are receiving services from the State.
4. The personal profile section (He-M 503.02(t)(3)(a)(6) and (3)(f) and relevant sections of the service agreement section (He-M 503.11) should be revised to more clearly specify that a needs assessment include a residential evacuation capacity of the individual and an evacuation plan that is appropriate and practiced and other measures that will reduce undue risk to fire and other dangerous or catastrophic events. Such a needs assessment and safety plan or measures should be incorporated into the individual’s ISP.
5. Documentation of the regular checks of evacuation drills should be kept in each client’s file.
6. DHHS should modify its retention policy with regard to investigation files of cases that are unfounded to require that all documents in investigation files in these cases be retained for five years at a minimum.
7. DHHS/BEAS should develop clear rules and/or protocols specifying the process and criteria when a BEAS or other DHHS investigator may or should enter and/or inspect a home (with or without permission) as part of their investigative or protective service responsibilities and what to inspect or observe. The latter should include a checklist

or guidelines on standard items to look for, such as, fire or life safety issues, the existence of an evacuation plan for a vulnerable adult, etc. DHHS should receive input from the State Fire Marshall's office, BDS and the Quality Council.

8. DHHS should undertake a more systematic effort including thorough training to disseminate information about staff's and other mandatory reporter's obligation to file abuse, neglect and exploitation reports with BEAS and within the Area Agency/BDS system under He-M 202. To help counter the reluctance to report, the training and disseminations should include notice that the failure to report would be subject to disciplinary action. Area Agency and State level quality assurance reviews should include a methodology to determine whether agencies and individuals are meeting their mandatory reporting obligations.
9. Training should be provided to BEAS staff, Community Bridges and other Area Agencies and providers and relevant staff about (a) the powers of the probate court and how to access those powers; (b) the obligation of service coordinators and relevant staff to access general and DHHS resources to address eviction issues, obtain alternative housing and related issues facing clients and/or their families on a protective basis, and how to access those resources; and (c) the need and process for referring or seeking outside advocates or counsel or independent service coordinators for individuals.
10. It is recommended that DHHS and Community Bridges take appropriate personnel action against employees who did not adequately fulfill their responsibilities in regard to JH and in this matter generally, as more fully outlined in Findings 25, 26, and 27.
11. All recommended changes to He-M 503 should also be made to He-M 522.



**DISABILITIES RIGHTS CENTER, Inc.**

## Appendix A

## APPLICABLE STATUTES AND REGULATIONS

### Excerpts from RSA 161-F:42—57 The State's Adult Protective Services Act

RSA 161-F:43 IV defines "neglect" as "*an act or omission which results or could result in the deprivation of essential services necessary to maintain the minimum mental, emotional, or physical health and safety of an incapacitated adult*".

RSA 161-F:46 establishes the requirement that any person, including health care professionals, social workers and law enforcement officials, who suspect neglect of an incapacitated adult or that the incapacitated adult is living in *hazardous conditions* report that suspicion to the commissioner of the NH Department of Health and Human Services (DHHS) or his/her representative. (emphasis added.)

RSA 161-F:50 makes it a misdemeanor if a "*person knowingly fails to make any report required by RSA 161-F:46*".

RSA 161-F:51 states "*The commissioner or his or her authorized representative, upon the substantiation of a report of abuse, neglect, or exploitation of an incapacitated adult, shall provide, when necessary, protective services to such adults*".

RSA 161-F:53 Entry of Premises provides: "*If either an incapacitated adult reported or suspected of being abused, neglected, or exploited refuses, or a caretaker or caregiver refuses, to allow the representative of the department entrance to the premises for the purpose of investigating a report of abuse, neglect, or exploitation, the probate court, in the county where the adult is found, upon a finding of probable cause, may order an authorized representative of the commissioner, a police officer, or other authorized individual to enter said premises in furtherance of such investigation.*"

**Excerpts From He-E 703-704 Protective Reports (issued to RSA 161-F42-47)**

He-E 703.05 Obtaining Information From Reporter. The individual responsible for the intake of the report shall request the following information from the reporter, if known:

(a) Information on the alleged victim, including:

- (2) The type of living arrangement;**
- (4) Whether the alleged victim is thought to be in imminent danger;
- (5) Whether the alleged victim is injured, and if so, what treatment, if any, has been sought or provided;
- (6) A description of the incident or situation that prompted the report, and where the incident/situation occurred;
- (9) Whether measures have been taken to protect the alleged victim, and if so, what they are;**
- (10) Whether there are hazards present in the environment; and**

(c) Information on the alleged perpetrator, if any, including:

- (1) The name, age, gender, address, and telephone number;
- (2) The relationship of the alleged perpetrator to the alleged victim;
- (3) Whether the alleged perpetrator resides in the alleged victim's household;**

(Emphasis added.)

He-E 704.03 Investigation Responsibilities.

(a) During the course of the investigation, the investigator shall:

- (1) Interview the alleged victim;
- (2) As necessary, request emergency services to be approved by the supervisor in order to protect the alleged victim while the investigation is in progress;

- (3) Interview the alleged perpetrator, if any, unless the alleged perpetrator refuses;
- (4) Interview collateral contacts<sup>46</sup> as necessary;
- (5) Obtain and review relevant written reports, records, photographs, and any other necessary documentation in accordance with RSA 161-F:56;
- (6) Consult, as necessary, with other professionals who have expertise regarding the type of report or allegations being investigated;
- (7) Review all information collected during the investigation process;
- (8) Determine whether or not the allegation(s) is or are substantiated;
- (9) Determine whether or not the report is founded or unfounded;
- (10) Determine whether there is a need for protective services; and
- (11) Complete all required forms, summaries and letters in order to document the investigation and provide necessary notification(s).

He-E 704.05 Interviewing The Alleged Victim.

- (a) **The investigator shall interview the alleged victim in person, regardless of his or her mental or physical condition, even if the alleged victim cannot communicate verbally.**

He-E 704.06 Interviewing The Alleged Perpetrator.

- (a) The investigator shall request a face-to-face interview with the alleged perpetrator.
- (b) If the alleged perpetrator has a guardian appointed pursuant to RSA 464-A, the investigator shall contact the guardian to inform him/her of the need to interview the alleged perpetrator, except under the circumstances described in He-E 703.04 (g).
- (d) If the alleged perpetrator refuses to be interviewed or cannot be located, the investigator shall send a letter to the alleged perpetrator's last known address, requesting an interview.

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<sup>46</sup> He-E 701.14 "Collateral contacts" means individuals who have either witnessed or have information about the alleged victim's situation that could aid the investigator in determining the facts necessary to complete a protective investigation in accordance with RSA 161-F:42-57 and He-E 700.

He-E 704.09 Determining The Need For Protective Services. When the report is founded, the investigator shall determine that there is a need for protective services if any of the following is true:

- (a) The victim's health or safety is in jeopardy;
- (b) The victim's living arrangement is unsafe; or**
- (c) The victim has functional or cognitive limitations that prevent the necessary performance of personal care activities or household tasks.

He-E 704.10 Retention Of Protective Investigation Material.

- (a) For investigations that result in one of the dispositions described in He-E 704.04, material related to the investigation **shall be retained for 6 months** after the supervisor decided that an investigation could not be conducted or completed.
- (b) For investigations that resulted in an unfounded determination, material related to the investigation **shall be retained for 6 months** from the date that the supervisor reviewed the investigation material and approved the unfounded determination.

**EXCERPTS FROM RSA 171-A, THE STATE'S SERVICES FOR  
DEVELOPMENTALLY DISABLED ACT**

**RSA 171-A:13 Service Guarantees.** – Every developmentally disabled client has a right to adequate and humane habilitation and treatment including such psychological, medical, vocational, social, educational or rehabilitative services as his or her condition requires to bring about an improvement in condition within the limits of modern knowledge.

Excerpts from RSA 171-A State Services for Developmentally Disabled Act

**“171-A:1 Purpose and Policy.** – The purpose of this chapter is to enable the Department of Health and Human Services to establish, maintain, implement and coordinate a comprehensive service delivery system for developmentally disabled persons. The policy of this state is that persons with developmental disabilities and their families be provided services that emphasize community living and programs to support individuals and families, beginning with early intervention, and that such services and programs shall be based on the following:

- I. Participation of people with developmental disabilities and their families in decisions concerning necessary, desirable, and appropriate services, recognizing that they are best able to determine their own needs.
- II. Services that offer comprehensive, responsive, and flexible support as individual and **family needs evolve over time**.
- III. Individual and family services based on full participation in the community, sharing ordinary places, developing meaningful relationships, and learning things that are useful, as well as **enhancing the social and economic status of persons served**.
- IV. Services that are relevant to the individual's age, abilities, and life goals, including support for gainful employment that maximizes the individual's potential for self-sufficiency and independence.
- V. Services based on individual choice, satisfaction, **safety**, and positive outcomes.
- VII.** Services provided by competent, appropriately trained and compensated staff.”

(Emphasis added.)

**171-A:4 State Service Delivery System.** – The department shall maintain a state service delivery system for the care, habilitation, rehabilitation, treatment and training of developmentally disabled persons. Such service delivery system shall be under the supervision of the commissioner.

**171-A:13 Service Guarantees.** – Every developmentally disabled client has a right to adequate and humane habilitation and treatment including such psychological, medical, vocational, social, educational or rehabilitative services as his condition requires to bring about an improvement in condition within the limits of modern knowledge.

**171-A:18 Area Agency Responsibilities and Operations.**

- I. The commissioner may designate by rules adopted pursuant to RSA 541-A for each area one area agency which shall be responsible for administering area-wide programs and services for developmentally disabled persons. Each area agency so designated shall be the primary recipient of funds that may be dispensed by the

commissioner for use in establishing, operating or administering such programs and services. The programs and services for which an area agency is responsible include, but are not limited to, diagnosis and evaluation, service coordination, community living arrangements, employment and day services, and programs designed to enhance personal and social competence.

## **EXCERPTS FROM REGULATIONS ISSUED PURSUANT TO RSA 171-A**

Excerpts from He-M 503 Eligibility and the Process of Providing Services

### He-M 503.02 Definitions

- (t) “Personal profile” means a narrative description that includes:
- (1) A personal statement from the individual and those who know him or her best that summarizes the individual’s strengths and capacities, communication and learning style, challenges, **needs**, interests, and any health concerns, as well as the individual’s hopes and dreams;
  - (2) A personal history covering significant life events, relationships, living arrangements, health, and use of assistive technology, and **results of evaluations which contribute to an understanding of the person’s needs;**
  - (3) A review of the past year that:
    - a. Summarizes the individual’s:
      4. Challenging issues or behavior;
      - 6. Safety considerations during the year;**
    - b. Addresses the previous year’s goals with level of success and, if applicable, identifies any obstacles encountered;
    - c. Identifies the individual’s goals for the coming year;
    - d. Identifies the type and amount of services the individual receives and the support services provided under each service category;
    - e. Identifies the individual’s health needs;
    - f. Identifies the individual’s safety needs;**
    - g. Identifies any follow-up action needed on concerns and the persons responsible for the follow-up; and
    - h. Includes a statement of the individual’s and guardian’s satisfaction with services;

(Emphasis added.)

He-M 503.08 Service Guarantees on Services for Which Funds Are Available

- (b) All services shall be designed to:
- (1) Promote the individual's personal development and quality of life in a manner that is **determined by the individual**;
  - (2) Meet the individual's needs in **personal care**, employment, adult education and leisure activities;
  - (3) Promote the individual's **health and safety**;
  - (4) Promote the individual's right to freedom from abuse, **neglect** and exploitation.
- (Emphasis added).

He-M 503.09 Service Coordination

- (b) The service coordinator shall:
- (1) **Advocate on behalf of individuals for services to be provided in accordance with He-M 503.08 (b)**;
  - (2) Coordinate the service planning process in accordance with He-M 503.08, He-M 503.10, and He-M 503.11;
  - (3) Describe to the individual or guardian service provision options such as self-directed services;
  - (4) Monitor and document services provided to the individual;
  - (5) Ensure continuity and quality of services provided;
  - (6) Ensure that service documentation is maintained pursuant to He-M 503.11 (b)(7), (f)(1), and (i)(2)-(3);
  - (7) **Determine and implement necessary action and document resolution when goals are not being addressed, support services are not being provided in accordance with the service agreement, or when health or safety issues have arisen**;

(Emphasis added.)

He-M 503.11 Service Agreements

- (f) Within 10 business days following a service planning meeting pursuant to (c) above, the service coordinator shall:

- (1) Prepare a written expanded service agreement that:
  - a. Includes the following:
    1. **A personal profile;** and
    2. A list of those who participated in the service planning agreement meeting; and

(Emphasis added.)

### **Excerpts from He-M 505 Establishment and Operation of Area Agencies**

#### He-M 505.03 Role and Responsibility of the Area Agency

- (a) The primary responsibility of the area agency shall be to plan, establish, and maintain a comprehensive service delivery system for individuals who are residing in the area. The area agency shall plan and provide these services according to rules promulgated by the commissioner.
- (b) Pursuant to RSA 171-A:18, I, the area agency shall be the primary recipient of funds provided by the bureau for use in establishing, operating, and administering supports and services and coordinating these with existing generic services on behalf of individuals in the area. The area agency may receive funds from sources other than the bureau to assist it in carrying out its responsibilities.
- (c) When possible, the area agency **shall utilize generic, integrated services, rather than establish separate services for people with developmental disabilities.**
- (d) Services provided by, or arranged through, an area agency shall:
  - (3) Meet the individual's needs in **personal care**, employment and leisure activities;
  - (4) **Protect the individual's right to freedom from abuse, neglect and exploitation;**
  - (5) **Promote the individual's health and safety;**
- (w) The area agency shall be responsible for assuring that appropriate services are provided in accordance with RSA 171-A and the regulations promulgated there under, including the following:
  - (5) Monitoring and **safeguarding of rights; and**

- (x) **The area agency shall utilize all applicable federal, third party, and other public and private sources of funds to carry out its mission and responsibilities**

(Emphasis added.)

Excerpts from He-M 521 Certification of Residential Services, Combined Residential and Day Services, or Self-Directed Day Services Provided In The Family Home

He-M 521.05 Administrative Requirements.

- (a) Once a family expresses interest regarding He-M 521 services, but before services are provided under He-M 521, the area agency shall:
  - (1) Ensure that the proposed service arrangement:
    - a. Meets the individual's expressed interests, preferences, needs and lifestyle;
    - b. Is consistent with the goals and services identified in the individual's service agreement; and
    - c. Meets the individual's environmental and personal safety needs; and
- (c) When services are being provided under He-M 521, the area agency shall:
  - (1) Have, at a minimum, quarterly contacts with the family to provide information and support to ensure that services are provided in accordance with the service agreement and He-M 521; and
  - (2) Ensure that the service arrangement is in compliance with He-M 506.03, He-M506.05 (a)-(c), and He-M 521.06.

He-M 521.06 Medication Administration. **When an individual living with his or her family is in need of medication administration, such administration shall:**

- (a) **Comply with He-M 1201 when administered by area agency or subcontract agency staff, or home providers;**
- (b) Comply with Nur 404 when a nurse identified in Nur 404.03 delegates the task of medication administration to providers who are neither family members nor under contract with an area agency or subcontract agency, except in situations where the individuals are living with their families and receiving respite arranged by the family; or

- (c) When **performed by family members paid under He-M 521**, include discussion between the area agency or subcontract agency and the family about any concerns the family might have regarding medication administration.

He-M 521.07 Quality Assessment. An area agency shall monitor services provided pursuant to He-M 521 as follows:

- (a) On at least a monthly basis, the service coordinator shall visit or have verbal contact with the individual or persons responsible for services to review progress on achieving the goals in the service agreement, inquire about other service needs, and document such visit or contact;
- (b) The service coordinator or a designated area agency staff shall visit the individual at home and contact the guardian, if any, at least quarterly, or more frequently if so specified in the individual's service agreement, to determine and document whether services:
  - (1) Match the interests, needs, preferences and lifestyle of the individual;
  - (2) Meet with the individual's satisfaction;
  - (3) Meet the individual's environmental and personal safety needs; and**
  - (4) Meet the terms of the service agreement; and

He-M 521.10 Denial and Revocation of Certification.

- (a) In the event of the denial or revocation of certification of services pursuant to (c) below, the individual's service coordinator shall assist him or her to continue receiving alternative services that meet his or her needs.
- (b) The bureau shall deny an application for certification or revoke certification of services, following written notice pursuant to (d) below and provide an opportunity for a hearing pursuant to He-C 200, due to:
  - (1) Failure of a staff member, provider, subcontract agency, or area agency to comply with He-M 521 or any other applicable rule adopted by the department;
  - (4) The staff, provider, subcontract agency, or area agency preventing or interfering with any review or investigation by the department;
  - (5) The staff, provider, subcontract agency, or area agency failing to provide required documents to the department;
  - (6) Any reported abuse, neglect, or exploitation of an individual by a provider, staff member, or person living in an individual's residence, if:
    - d. Such abuse, neglect, or exploitation is reported on the state registry of abuse, neglect, and exploitation in accordance with RSA 161:F-49;

- b. Such person(s) continues to have contact with the individual; and
  - c. Such finding has not been overturned on appeal, been annulled, or received a waiver pursuant to He-M 521.14;
- (c) If the department determines that services meet any of the criteria for denial or revocation listed in (b)(1)-(10) above, the department shall deny or revoke the certification of the services.

Excerpts from He-M 310 Rights of Persons Receiving Developmental Services In The Community

He-M 310.04 Fundamental Rights.

- (a) Any person receiving services for a developmental disability or acquired brain disorder shall be entitled to any legal right to which all citizens are entitled regardless of that person's admission to the developmental services system, except as provided by RSA 171-B.
  - (5) The right to legal remedies including the right to petition for and receive the benefits of a *writ of habeas corpus* and to seek any other remedy provided by law.

He-M 310.05 Personal Rights.

- (a) Persons who are applicants for services or individuals who are receiving services from provider agencies shall be treated with dignity and respect at all times.
- (b) Individuals shall be free from abuse, neglect, and exploitation including, at a minimum, the following:
  - i. Freedom from any emotional, physical, or sexual abuse or neglect;