

Child Protection Accountability Commission

Training Committee

**DE-ESCALATION OF LIFE SUPPORT
WORKGROUP**

FINAL REPORT

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The Honorable Peter B. Jones – Judge

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Preface

On behalf of the De-Escalation of Life Support Workgroup, formed under the Training Committee, we respectfully submit our report to the Child Protection Accountability Commission (CPAC). We believe with the submission of this report our Workgroup has fulfilled the charge given us by CPAC to create a multidisciplinary response and protocol for handling de-escalation of care cases when the Department of Services for Children, Youth, and their Families (DSCYF) holds custody of the child.

We wish to thank the individuals who served as Workgroup members. Every member provided critical input to the discussion of the important and difficult issues surrounding de-escalating care for a child. The meetings have been well attended, and Workgroup meeting discussions have been candid, respectful, and productive.

Respectfully submitted,
Mark H. Hudson
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Workgroup Purpose

In 2015, the medical, legal, and child protection communities were faced with the case of *DSCYF v. Hunt*, wherein a child, Adam Hunt¹, suffered serious physical injury at the hands of his parents and ultimately died when his life-sustaining medical treatments were de-escalated following a legal battle over that issue. From the time Adam entered into the custody of DSCYF until his passing, and even thereafter, his case presented new and unique challenges to the Division of Family Services (DFS), all legal counsel involved, the courts, and Adam's medical providers. These challenges highlighted the need to improve practices and procedures in cases such as Adam's where there are competing needs for a quick resolution and fairness to the parties. During the proceedings in the Supreme Court related to the appeal, counsel were encouraged by the Court to develop procedures for future handling of these cases. Accordingly, CPAC mandated the development of a multidisciplinary protocol for removal of life support cases. The task was given to CPAC's Training Committee, which created the De-Escalation of Life Support Workgroup and charged it with creating a multidisciplinary response and protocol for de-escalation of care cases when DSCYF holds custody of the child.

In order to fulfill its charge, the Workgroup co-chairs recruited members from the medical profession, the judiciary, DFS, and the legal community, including legal counsel for several hospitals, counsel for parents, counsel for DFS, and counsel for children in DSCYF custody. Many individual Workgroup members were directly involved in the *DSCYF v. Hunt* case and were able to provide valuable insight into what worked well and what required improvement in that case. All Workgroup members discussed anticipated challenges in future de-escalation cases and recommendations they had for improving outcomes in future cases.

Over the course of examining the scenario where a child in the custody of DSCYF is recommended to have life-sustaining medical treatments de-escalated, the Workgroup identified three main areas wherein policies can be implemented to facilitate the efficient disposition of these cases while ensuring fairness to all parties. Those three areas are as follows:

1. Initial communication/investigation in early stages of the case
2. Court action
3. Implementation of Order and aftermath

The Workgroup has created a protocol detailing multidisciplinary best practices to be considered at every stage of a case falling within this Workgroup's purview.

¹ This is the pseudonym given to the child during the course of the appeal to the Delaware Supreme Court.

Overview of the *Hunt Case*

On May 23, 2015, emergency personnel were called to the home of the minor child, Adam Hunt, where he was found to be unconscious, unresponsive, and his face and lips were blue. Adam was transported to Beebe Hospital in Lewes, Delaware and subsequently transferred to Nemours/A.I. duPont Hospital for Children in Wilmington, Delaware due to his serious condition. At A.I. duPont, doctors determined that Adam was malnourished, had multiple fractures, chronic bilateral subdural hematomas, destruction of brain tissue, and splitting of the layers of the retina in his left eye. Adam was also struggling with seizures and respiratory failure. Adam's injuries were suspected to have been caused by unexplained abusive trauma and Adam's parents were the primary suspects.

On May 28, 2015, DSCYF filed an emergency petition for custody of Adam. Shortly after the commencement of the dependency/neglect custody proceedings, on June 26, 2015, Adam's Child Attorney from the Office of the Child Advocate (OCA) filed an emergency motion with the Family Court requesting that the Court enter an order instructing Adam's treating physicians to de-escalate medical intervention and place a "Do Not Re-Intubate" order and a "Do Not Resuscitate" order, along with an order for comfort measures, in his medical chart.

The Child Attorney's motion was opposed by Adam's parents and a hearing was held on June 30, 2015 to decide the motion. On July 6, 2015, the Family Court, unable to find a risk of immediate and irreparable harm, denied the request for priority and emergency relief. The Court noted that Adam had not yet been adjudicated dependent, neglected, or abused in his parent's care. The Court further granted the parents' request that an independent medical evaluation be performed on Adam.

On July 23 and July 28, 2015, the Family Court conducted an adjudicatory hearing for the parents. In an order dated August 11, 2015, the Family Court found Adam to have been abused and neglected by his parents.

By the time the Family Court held a teleconference on August 10, 2015, the parties, working in collaboration with one another, had failed to secure an independent doctor to perform a medical evaluation on Adam, despite diligent efforts. On August 13, 2015, the Court granted the motion to de-escalate Adam's medical interventions.

The parents both requested certification of an interlocutory appeal from the Family Court's August 13, 2015 order. The Family Court certified the interlocutory appeal and the parents appealed to the Delaware Supreme Court on an expedited basis.

After a conference between the Justices and counsel for all parties, on September 4, 2015, the Delaware Supreme Court remanded the matter to Family Court so that an independent medical evaluation could be conducted. The Supreme Court based the remand, in part, on the Family Court having previously ordered that an independent medical evaluation be performed. With its remand to the Family Court, the Supreme Court directed the Family Court to afford whatever doctor performed the independent evaluation certain immunities and also to protect the doctor from testifying or being deposed.

On September 9, 2015, a pediatric neurologist submitted a report to Family Court detailing conclusions from his independent medical evaluation of Adam which supported de-escalating medical interventions. On September 10, 2015, the Family Court advised the Supreme Court, via Letter Order, that the report did not change the Family Court's decision on de-escalation.

Oral argument, *en banc*, was held before the Supreme Court on September 15, 2015, and on September 16, 2015, the Supreme Court issued its opinion affirming the Family Court's decision.

The Family Court's order on de-escalation of medical interventions was implemented three days after the Supreme Court's opinion was issued, and Adam passed away shortly thereafter.

Challenges Inherent in De-Escalation of Life Support Cases

PARENTAL DECISION MAKING

Even when a child is in the custody of DSCYF, the parents retain the right to make certain medical decisions for their child which are set forth in 13 *Del.C.* § 2521(2). Although the right to make decisions regarding de-escalation of life-sustaining medical treatment for a child in DSCYF custody is not specifically retained by the parents or taken away from the parents by statute, the limited practice in Delaware has been for the Family Court to review any request to de-escalate life-sustaining medical treatment before it is implemented. Because of the immense consequences of a request to de-escalate life-sustaining medical treatment for a child in DSCYF custody, this Workgroup agrees that it is best practice for the Family Court to review these requests regardless of the parties' positions. The rationale is that ending the life of a child is a serious and permanent decision, and when the state has custody of a child for any reason, the Court should review such a decision first in furtherance of its duty of *parens patriae*, to ensure the decision is in the best interest of the child.

If a parent is not suspected to have caused the life-threatening injuries to the child at issue in DSCYF custody, then generally, medical providers are comfortable following the parent's decision so long as the parent is involved in the child's treatment and is cooperative. Parental cooperation can be defined as a willingness to sit down with doctors and be educated on all medical options. Or, stated differently, parental cooperation is active participation in an informed consent conversation. Moreover, the parent should make decisions that are in the child's best interest and that are reasonable within the family's context of values and beliefs. If a cooperative parent who is not suspected of causing the injuries opposes de-escalation of medical treatment, it is the position of the Workgroup that, generally, DSCYF and the Child Attorney will not intervene and the Family Court will not review that decision.

When the parents are suspected of having caused the life-threatening injuries to the child, or suspected of negligently failing to protect the child from same, the dynamic shifts. In such a situation, a parent's decision to oppose the de-escalation of life-sustaining medical treatment may be driven by his or her own self-interest as opposed to the child's best interest. Sustaining the child's life contrary to medical advice could be the parent's effort to avoid more serious criminal charges. Furthermore, once the Family Court has made an adjudicatory finding that the child was abused in the parent's care, that parent's right to speak for the child may be diminished, or even lost entirely. In such a situation, the decision whether or not to de-escalate care should not be left to the child's alleged abuser. This practice is in line with the policy statement from the American Academy of Pediatrics (AAP) that provides guidance on forgoing life-sustaining medical treatment in cases of suspected abuse or neglect.² The policy statement affirms that there may be a conflict of interest when a decision to forgo life-sustaining medical treatment risks changing the legal charge faced by a parent, and recommends the appointment of a guardian ad litem for medical decision making in such cases.³

² Weise, K. L., Okun, A. L., Carter, B. S., & Christian, C. W. (2017). Guidance on Forgoing Life-Sustaining Medical Treatment. *Pediatrics*, 140(3). doi:10.1542/peds.2017-1905.

³ *Id.*

TIMING

When a child enters DSCYF custody, the parents and the child are afforded various procedural protections designed to ensure that the fundamental rights surrounding the familial relationship are not abridged. The legal process through which these procedural protections are implemented, by necessity, requires time so that the parents, the child, and DFS can all be adequately prepared either to defend against the state intrusion into the family's life or, for DFS and perhaps the child, to justify the necessity of state intervention. The rules and laws governing such state-initiated child welfare proceedings are well established in the State of Delaware.

In contrast, when a child is received and treated by a hospital for life-threatening physical injuries, particularly neurological injuries, treatment decisions for the child must be made quickly. Generally, within two weeks of the child's injuries, the child's medical team will know if they will be making a recommendation to de-escalate or limit care. Because of the child's suffering and the likelihood that, with the passage of time, changes will need to be made to the child's treatment (without impacting the child's prognosis), the medical community suggests that a decision on de-escalation of care should be made within one to two weeks of the recommendation.

The timing of the legal proceedings and the child's medical treatment are at odds. The Workgroup repeatedly discussed that while the legal players involved might view a child's case as moving blindingly fast, the medical team might view it as moving painfully slow. These two conflicting timelines will never align, but through the cooperation of counsel and the medical team, with flexibility by the Family Court, the legal process can be expedited as much as possible so as to minimize the delay in making medical decisions in the best interest of the child, as outlined in the attached protocol.

COMMUNICATION AND COORDINATION

Communication is a crucial component to the efficient and appropriate handling of any case concerning the de-escalation of medical treatment for a minor in the custody of DSCYF. When a child is admitted to a hospital with life-threatening injuries suspicious of abuse, the hospital's communication with DFS is important for DFS to accurately assess the situation. Once DFS makes initial contact with the child and hospital staff, communication between the worker and DFS's Deputy Attorney General ("DAG") is important so that the appropriate legal action can be swiftly taken.

After a petition for DSCYF custody is filed, it is critical that counsel promptly communicate with one another concerning records, witnesses, motions, and the timing of the hearings. Making all counsel aware of evidence in advance of hearings and how the matter might be proceeding will ensure that no one is surprised by a witness, piece of evidence, or unusually-timed hearing and avoid potential delays due to lack of preparedness. Similarly, it is important that counsel communicate with the Family Court regarding the scheduling of hearings and to make the Court aware that the matter might be required to move at an expedited pace. To this end, it is recommended that, upon receipt of a motion requesting de-escalation of care, the Court conduct a scheduling conference to establish firm dates for the progression of the case. Communication

between counsel and the Court should continue on appeal, if one is taken, again, to ensure that the proceedings are handled as expediently as possible.

Of course, during the course of the legal proceedings, DFS and the Child Attorney should be in frequent contact with hospital staff about the child's condition. The child's status may help direct the pace of the legal proceedings. Moreover, DFS and the Child Attorney, who will be familiar with the status of the legal proceedings, should keep the medical team informed of the case's legal status and progress so that expectations are realistic.

Should care be de-escalated and the child pass away, communication between counsel and parties continues to be important to ensure that arrangements are made for the child and so that family can be involved in those arrangements as appropriate.

INDEPENDENT MEDICAL EVALUATIONS

One of the biggest delays in the *Hunt* case resulted from the parents' request for, and the parties' subsequent difficulty in locating, a doctor to perform an independent medical evaluation of Adam. A respondent in a state-initiated child welfare proceeding, whether indigent or not, has a right to call witnesses in his or her defense, including experts. It is therefore foreseeable, indeed expected, that when other de-escalation cases come before the Family Court in the future that a parent will request an independent medical evaluation of the child to either confirm or rebut the treating medical team's recommendation. These requests should be granted whenever possible, with the recognition that obtaining such independent medical evaluations poses several challenges and that timing may ultimately preclude the ability to obtain an independent evaluation.

When the Family Court is presented with a recommendation to de-escalate life sustaining medical treatment for a child in the context of a child welfare proceeding, that recommendation is most typically going to come from a pediatric neurologist. Per the Critical Care Board and Nemours/A.I. duPont Hospital for Children policy, only a neurologist, neurosurgeon, or pediatric critical care specialist can diagnose brain death. While the children falling within the purview of this Workgroup will not necessarily meet brain death criteria, they will typically be so close to brain death that any doctor selected to perform the independent medical evaluation should be a neurologist, neurosurgeon, or pediatric critical care specialist. It is highly likely that in future de-escalation cases coming before the Family Court the child will be treated at Nemours/A.I. duPont Hospital for Children because it has the only pediatric critical care unit in the State and employs most of the state's pediatric neurologists, pediatric neurosurgeons, and pediatric critical care specialists.

Because Delaware has such a small medical community, the problem that arose in *Hunt* was that the parties had difficulty locating a doctor who was sufficiently independent from Adam's treatment. Moreover, many doctors are hesitant to become involved in on-going litigation, particularly regarding de-escalation of life support of a child, because of the burdens it entails. Ameliorating this issue requires the Family Court to be careful with its language when considering requests from parents for independent evaluations. Moreover, while a parent is entitled to present witnesses in his or her defense, the parent cannot be afforded an unlimited window of time to procure those witnesses at the expense of the child's well-being. With that in

mind, the Family Court should be cognizant of these competing interests and put a reasonable limitation on the time for a parent to locate an independent expert within the criteria set forth above. The Family Court may be able to facilitate the parties' ability to find a willing doctor by offering that doctor certain protections like in the *Hunt* case, but only if all of the parties agree.

Because of the time constraints and other barriers in locating an independent physician to evaluate the child, counsel should work collaboratively when searching for the expert.

Recommendations

In addition to identifying best practices to be followed as outlined in the De-Escalation of Life Support Protocol, the Workgroup makes the following recommendations to Delaware's Child Protection Accountability Commission to further enable the timely and compassionate handling of these cases:

1. Provide information on the attached protocol to DFS workers, judges, and lawyers regularly involved in child-welfare proceedings.
2. Provide information on the attached protocol to medical professionals and hospital staff involved in the critical care of children.
3. Pursue funding for compatible technology between the Family Court and Nemours/A.I. duPont Hospital for Children that will allow for video testimony if a medical professional cannot attend in person.
4. Explore the feasibility of implementing a separate reporting method for hospitals and first responders to avoid lengthy wait times on the DFS child abuse report line.

Conclusion

Fortunately, cases involving a recommendation to de-escalate medical interventions for a child in the custody of DSCYF are infrequent. Nonetheless, there is no case in the child welfare arena where the stakes are higher. These cases present many unique challenges to the parties, legal counsel, medical community, and the courts. However, by being aware of the issues these cases present and being prepared to address those issues, it is the hope of this Workgroup that future outcomes in these cases can be promptly achieved while thoroughly protecting the interests of all those involved.

Attached to this report is a multidisciplinary protocol that the Workgroup recommends be followed in future de-escalation cases. It is our hope that this protocol provides a framework that will improve outcomes in any future cases that come within this Workgroup's purview.