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|  | INDIANA DEPARTMENT OF CHILD SERVICES CHILD WELFARE POLICY | |
| | Chapter 5: General Case Management | Effective Date: September 1, 2018 |
| | Section 14: End of Life Care | Version: 2 |

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| STATEMENTS OF PURPOSE |
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The Indiana Department of Child Services (DCS) will notify the juvenile court when a physician or hospital determines a child under the jurisdiction of the Court is at imminent risk of death or has a chronic disease that will result in the child’s death in the near future and the physician is recommending a Do Not Resuscitate (DNR) order or other end-of-life care.

DCS staff, resource parents, and Guardian ad Litem (GAL)/Court Appointed Special Advocates (CASA) **do not** have the legal authority to make a final decision about whether a hospital should remove life support or issue a DNR Order for a child under the care and placement of DCS. **The final decision must be made by the juvenile court based on the recommendations of a qualified physician and the decisions of the child’s parents.**

Situations involving the removal of life support, issuance of DNR Orders, or organ donation of children under the care and placement of DCS require thoughtful, sensitive, and thorough communication among all persons involved including the child’s parents or individuals authorized by statute to make such decisions, parent attorney (if applicable), DCS staff, medical personnel, hospital ethics committee, and the court. DCS staff members are not permitted to share personal opinions or give recommendations to families, medical personnel, and/or attorneys in situations regarding the removal of life support or the issuance of a DNR Order and shall rely on the expertise of the medical care providers and the decisions of the child’s parents or other individuals authorized by statute to make such decisions.

The child’s legal parents are to be involved in the decision-making process regarding the removal of life support, the issuance of a DNR Order, or organ donation regardless of the status of the case. The child’s parents will be excluded from the decision-making process only when a court finds and orders that neither parent is physically and/or emotionally available to make the necessary informed decision when needed and proceeding without the parents’ consent is in the best interests of the child.

The decision to donate the organs of a deceased child in the care and placement of DCS should be made by the child’s parents. If Termination of Parental Rights (TPR) has occurred, the individuals authorized to make the decision are identified in IC 29-2-16.1-8. See [Related Information](#) for a listing of these individuals.

Note: If an older youth has an [advanced directive](#), it should be reviewed and discussed during decision making.

Code References

1. [IC 29-2-16.1-8 Revised Uniform Anatomical Gift Act](#)
2. [IC 29-2-16.1-1\(8\) Definition of Donor](#)
3. [IC 29-2-16.1-1\(12\) Definition of Guardian](#)

4. [IC 31-25-2-21 Transitional services plan; participation by child representatives](#)
5. [IC 1-1-4-3 Uniform Determination of a Death Act](#)
6. [465 IAC 2-14-2 Voluntary Transitional Services](#)

PROCEDURE

When a recommendation is made for the removal of life support or issuance of a DNR Order for a child under the care and placement of DCS by a child's attending physician **the Family Case Manager (FCM) will:**

1. Immediately notify the FCM Supervisor and DCS Local Office Director (LOD) of the physician's request to remove life support or issue a DNR Order;
2. Obtain a written statement from the child's attending physician recommending the removal of life support or the issuance of a DNR Order and the supporting documentation for this recommendation. The statement must include:
 - a. A brief medical history for the child,
 - b. The child's current condition and diagnosis,
 - c. The supporting documentation for the recommendation, and
 - d. Compliance with the hospital's ethics protocol, if applicable.
3. Notify the child's parent, DCS Staff Attorney, resource parent, and child's CASA/GAL (if appointed) of the physician's recommendation to remove life support or issue a DNR Order;

Note: The child's parent **must be notified** regarding the medical recommendation unless they cannot be located.

4. If the parents' of the child cannot be located, document efforts made to locate the parent in the case management system. See policy [5.6 Locating Absent Parents](#) for guidance. If possible and appropriate, notify a grandparent, other relative, or other adult who exhibited special care and concern for the child;
5. Discuss the physician's recommendation with DCS Staff Attorney and work with the attorney to prepare and submit a written report to the court outlining the child's medical situation within one (1) business day of receiving the physician's written statement. This report must include the recommendation from the child's attending physician.

Note: If TPR has not occurred, the FCM must include the parent(s) opinions and recommendations when preparing the report to submit to the court, unless the parents cannot be located.

6. Make available to the court any information about the child including but not limited to: child's medical history, [advanced directive](#), family and resource parent information, recommendation of the attending physician, parent(s)' recommendation (if known), and any additional information requested by the court. Specifically note whether or not the child expressed an opinion or desire to enter into a DNR Order or the removal of life support and when, where, and how the child made their wishes known;
7. Consult with the DCS Staff Attorney to request that the juvenile court hold a hearing to make a determination regarding the appropriate medical treatment for the child;
8. Confirm whether the child has a CASA/GAL. If not, collaborate with the DCS Staff Attorney to request that the court appoint a CASA/GAL for the child immediately; and

9. Notify and inform all interested persons, including the child's CASA/GAL, regarding the recommendation from the physician, and discuss any provisions needed for assistance and support to the child's family (both biological and resource).

When a recommendation is made for the removal of life support or issuance of a DNR Order for a child under the care and placement of DCS by a child's attending physician **the FCM**

Supervisor will:

1. Ensure that timely notification of all required persons occurs; and
2. Attend all relevant court hearings and meetings with the FCM.

When a recommendation is made for the removal of life support or issuance of a DNR Order for a child under the care and placement of DCS whose parental rights have been terminated, DCS must request that the juvenile court hold a hearing to make a determination regarding the appropriate medical treatment for the child, and follow the above listed procedures. **DCS may not consent to, or make recommendations regarding the appropriateness of the removal of life support.**

Organ Donation

If a family member or a representative of an Independent Organ Procurement Agency (IOPA) contacts DCS regarding potential [organ donation](#), the FCM will:

1. If TPR has not occurred, notify and be available to the child's parent(s) during the decision making process; or
2. If TPR has occurred for both parents, notify other individuals authorized to make a decision about [organ donation](#) as identified by IC 29-2-16.1-8;
3. If TPR has occurred for both parents and no other authorized individual is able to make a decision, collaborate with FCM Supervisor, DCS LOD, RM, DCS Staff Attorney, and DCS Central Office general counsel to determine if [organ donation](#) is appropriate. This team must consider the following factors prior to making a decision:
 - a. Statement on the child's driver's license (if any),
 - b. Possible need for an autopsy of the child,
 - c. Concerns of any involved extended family,
 - d. Previous statements by the child regarding organ donation (if any), and
 - e. Cultural and/or religious preferences of the family regarding organ donation.

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| PRACTICE GUIDANCE |
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Children Not in the Care or Supervision of DCS

If a child has not been detained or is not currently in the custody of DCS and the removal of life support or the issuance of a DNR Order is recommended by the child's physician, DCS may be available as an extended support system for the family. DCS staff members will not provide guidance or advice to family in this situation. The ultimate decision in this situation lies with the parent, guardian, or custodian of the child.

Child's Wishes Regarding Removal of Life Support, DNR, and/or Organ Donation

Previous statements or opinions of a child regarding the removal of life support, issuance of a DNR Order, or [organ donation](#) should be considered in all situations. Although this opinion may not necessarily be followed it is important for all members of the team (including the court) to be aware of previous statements made by the child regarding any of end of life care issues.

Brain Death Situations

According to IC 1-1-4-3, an individual who has sustained “irreversible cessation of all functions of the entire brain, including the brain stem is dead.” If an individual meets this definition for brain death, they may be declared dead by a physician per the hospital’s brain death protocol. This declaration of death by a physician is a medical determination which does not need to be perfected by a court order. When an individual is declared dead per this protocol, the medical team will determine the appropriateness of disconnecting any and all medical equipment connected to the individual. However, a court order must be obtained if the parent, guardian, or CASA/GAL objects; the hospital seeks DCS consent or input; or the physician or hospital is unwilling or unable to make a declaration of death.

FORMS AND TOOLS

[Older Youth Initiatives](#)

RELATED INFORMATION

Advanced Directives

“Advance directives” is a term that refers to spoken and written instructions about an individual’s future medical care and treatment. By stating health care choices in an advance directive, this allows family members and physicians to understand the individual’s wishes about medical care. Indiana law pays special attention to advance directives.

Advance directives are normally one (1) or more documents that list the individual’s health care instructions. An advance directive may name a person of choice to make health care choices for when the individual is unable to make the choices. The individual may also use an advance directive to prevent certain people from making health care decisions on one’s behalf. For more information go to the [Indiana State Department of Health](#) or [Older Youth Initiatives](#) websites.

Do Not Resuscitate (DNR) Order

A medical order to provide no resuscitation to individuals for whom resuscitation is judged to be of no medical benefit. This specifically refers to Cardiopulmonary Resuscitation (CPR). There are circumstances when CPR might seem to lack benefit for a child whose quality of life is so poor that no meaningful survival is expected even if CPR were successful in restoring circulatory stability. A DNR Order may also be used to withhold life-sustaining treatment (to refrain from using life support to artificially prolong a child’s life).

Removal of Life Support

The removal of all medical procedures or interventions that serve only to prolong the process of dying or maintain the individual in a condition of persistent unconsciousness. This does not include the administration of medication or performance of medical treatments deemed necessary to alleviate pain or provide for the normal consumption of food and water.

Organ Donation

The decision to make an anatomical gift of a deceased individual’s body or parts of the body. This gift may be made for the purpose of transplantation, therapy, research, or education.

DCS staff shall never sign consent forms for organ donation on behalf of a child’s family member who has made a decision to donate the child’s organs. DCS may only make a decision regarding organ donation for a child under the care and placement of DCS if TPR has occurred,

the priority order of persons authorized to donate the child's organs has been followed, and a court order has named DCS as the child's guardian as defined in IC 29-2-16.1-1(12). *DCS does not meet the definition of guardian under IC 29-2-16.1-1(12). Instead under these circumstances the court will need to appoint a legal guardian. The definition also does not include a GAL.*

Persons Authorized to Donate a Deceased Individual's Organs

According to IC 29-2-16.1-8 the priority of persons authorized to make an anatomical gift of a decedent's body or parts are as follows:

1. An agent of the decedent at the time of death who could have made an anatomical gift under section 3(2) of this chapter immediately before the decedent's death;
2. The spouse of the decedent;
3. Adult children of the decedent;
4. Parents of the decedent;
5. Adult siblings of the decedent;
6. Adult grandchildren of the decedent;
7. Grandparents of the decedent;
8. An adult who exhibited special care and concern for the decedent;
9. A person acting as the guardian of the decedent at the time of death; and
10. Any other person having the authority to dispose of the decedent's body.