2
Connecticut Birth to Three System

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DOCUMENT TITLE
Research (Safeguards Support) Procedure

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#### Research (Safeguards Support) Procedure

#### 1.0 PURPOSE AND SCOPE

- 1.1.1. This procedure provides instructions for processing and authorizing research requests made to the Birth to Three System or provider program involving access to personally identifiable data, families, staff, or children in the Birth to Three System while safeguarding the rights, welfare, and confidentiality of children, families, and staff, as well as their personal information.
- 1.1.2. This applies to all researchers or individuals involving Connecticut Office of Early Childhood (OEC) employees or contractors, and non-OEC researchers, including but not limited to:
  - Faculty
  - Staff
  - Graduate and undergraduate students
  - Others

#### 2.0 REFERENCES

#### 2.1 Associated Documents

- 2.1.1. Research with OEC (https://www.ctoec.org/research-with-oec/).
- 2.2 Source Information
- 2.2.1. Research Procedure, Revised Date: Jan. 1, 2022.
- 3.0 INSTRUCTIONS
- 3.1 Processing a Research Request
- 3.1.1. WHEN a request for access to information on any of the following is received:
  - Children, as defined as from the point of referral.
  - Families including parents as defined under IDEA <<li>k to regs>>
  - Providers who contract with the Birth to Three system at the Office of Early Childhood.

**THEN** Birth to Three Program Directors or Staff **PERFORM** the following:

 INSTRUCT researcher to contact Birth to Three System Individuals with Disabilities Act (IDEA) Part C Coordinator and Part C Data Manager to discuss proposed research study.

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- 2. IDEA Part C Coordinator and Part C Data Manager **ADHERE** to the following:
  - a. **DIRECT** researcher to Office of Early (OEC) Childhood webpage Research with OEC for further information containing the following, but not limited to:
    - OEC Data and Reports
    - Researcher's Responsibilities
    - <u>Guidance for Conducting Research with OEC Families, Children or Programs</u>
  - b. **EXPLAIN** required process to request a Letter of Support (LOS) from Early Intervention Division Director.
  - c. **ENSURE** Early Intervention Division Director or administrative designee performs the following:
    - (1) **CONSIDER** potential benefits to the field of early intervention.
    - (2) **WEIGH** merit and feasibility of request to provide a LOS.
    - (3) **AGREE** or **DECLINE** request to provide a LOS.
  - d. **SEND** notification of decision to agree or decline to provide LOS from Early Intervention Division Director or administrative designee.
    - (1) <u>IF</u> Early Intervention Division Director agrees to provide LOS is granted,
      - <u>THEN</u> ENSURE principal investigator still obtains approval from their home institution (for example: university or hospital of employment) Investigational Review Board (IRB).
    - (2) <u>IF</u> Agency, University, or Hospital IRB has already granted approval for proposed research,

**THEN OBTAIN** Agency, University, or Hospital IRB letter of approval.

 KNOW Early Intervention Division Director or administrative designee may still agree or decline invitation to provide LOS.

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3.2 Right of Refusal to Participate

#### NOTE

Letter of Support (LOS) and approvals by Investigation Review Boards (IRB) do not obligate participation in research projects.

- 3.2.1. Birth to Three Staff, Providers, and Families (parent or child) **MAINTAIN** right to decide any of the following at any time, without repercussions, impact on eligibility, or entitled supports.
  - 1. **DECLINE** participation in research project.
  - 2. **AGREE** to participate in research project.
  - 3. **TERMINATE** participation in research project.

## **NOTE**

Each potential research participant has informed consent per the Code of Federal Regulations (Title 45 CFR Part 46; Subpart D, Additional protections for research with children).

- 3.2.2. **ENSURE** families understand the decision to participate in research is:
  - Voluntary
  - NOT to be influenced by involvement in IDEA Part C Birth to Three.
  - **NOT** to take the place of services provided by Birth to Three.

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# 3.3 Distribution of Research Opportunities

- 3.3.1. Service Coordinators **ADHERE** to the following:
  - 1. **SHARE** research opportunities in the community, only if it meets the following criteria:
    - a. It's research.
    - b. It's approved.
    - c. There is a Letter of Support (LOS).
  - 2. **DO NOT ENDORSE** or **PROMOTE** participation in any research that does **NOT** meet all the following criteria:
    - a. It's research.
    - b. It's approved.
    - c. There is a LOS.

#### **END of Instructions**

### 4.0 REVISION HISTORY

Location	Description of Change	
All	New Human Factored Procedure in New Template.	