

Creating Systems Change: Rethinking the Role of Advocacy in Service Coordination Training

JULY 22, 2024

ELIZABETH A. WILKE, MOT, OTR/L

Acknowledgements

- Julie Hall
- Jennifer Michael

CT Leadership Academy Curriculum

- Objective/Performance Indicator 2.1.6, “Identify when and how to inform and educate various decision makers (e.g., state and federal legislators, policy makers and administrators) about needed changes to laws, regulations, and policies to improve programs, services and outcomes for infants and young children with disabilities and their families.”

Capstone Action Plan

Goal: Create a resource for early intervention professionals to learn about how to advocate for state-level policy change

Objectives

1. Learn more about legislative advocacy at the state level (*end of March 2024*)
 - Activity 1: Review resource from The Alliance, “Nonprofit Advocacy 101”
 - Activities 2-4: Review resources from Brazelton Touchpoints re: learning to advocate for children and families

Capstone Action Plan (cont.)

Objectives (cont.)

2. Create in-service to share information learned (*end of May 2024*)
 - Activity 1: Review Leadership Academy coursework re: adult learning/in-services (key characteristics including introduction, illustration, authentic learning opportunities, performance feedback and follow-up support, learner reflection)
 - Activities 2-5: Creation of PowerPoint presentation, formative assessments, & feedback surveys
3. Present in-service/information learned to other early interventionists (*June 2024*)
 - Activities 1-3: Presentation and administration of formative assessments/feedback surveys
 - Activity 4: Analysis of feedback surveys

Learning Objectives

- Understand & describe the difference between policy and procedure
- Identify 2 levels of regulation that govern Connecticut's Birth to Three System (B23) & know how to find these regulations
- Understand & describe the role of the Interagency Coordinating Council (ICC) in B23
- Understand & describe advocacy, including the difference between advocacy and lobbying
- Identify at least 2 avenues for advocating for state-level policy change
- Understand & describe what an “elevator speech” is
- Know the 3 key components of an “elevator speech” and create your own!

WHAT GOVERNS CONNECTICUT'S BIRTH TO THREE SYSTEM?

Statute vs. Regulation

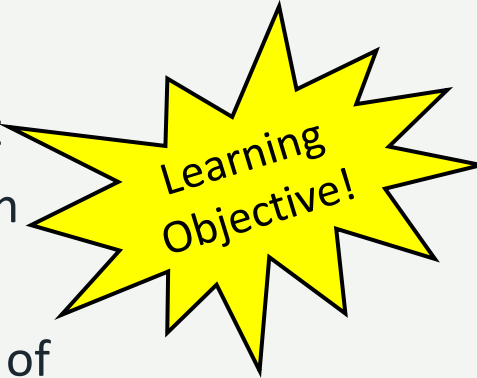
- **Statute:** “A law that has been formally approved and written down”; written by legislators
- **Regulations:** Supplement laws written and passed by the legislature; written by regulatory agencies (e.g., Department of Education). Have the same force of law

[Cambridge Dictionary](#)

[Colorado State University Library - Law Research Guide](#)

Federal Statutes & Regulations / IDEA Part C

- Most of us know that Part C of the Individuals with Disabilities Education Act (IDEA) is the federal law that governs each state's early intervention (EI) program, addressing services for children 0-3 years of age with developmental delays or disabilities
- Most of us DON'T know that there are pages and pages of federal regulations that outline what each state's EI program needs to look like, including Child Find, Evaluations & Assessments, Individualized Family



§ 303.344 Content of an IFSP.

(d) *Early intervention services.* (1) The IFSP must include a statement of the specific early intervention services, based on peer-reviewed research (to the extent practicable), that are necessary to meet the unique needs of the child and the family to achieve the results or outcomes identified in paragraph (c) of this section, including—

(i) The length, duration, frequency, intensity, and method of delivering the early intervention services;

(ii)(A) A statement that each early intervention service is provided in the natural environment for that child or service to the maximum extent appropriate, consistent with §§ 303.13(a)(8), 303.26 and 303.126, or, subject to paragraph (d)(1)(ii)(B) of this section, a justification as to why an early intervention service will not be provided in the natural environment.

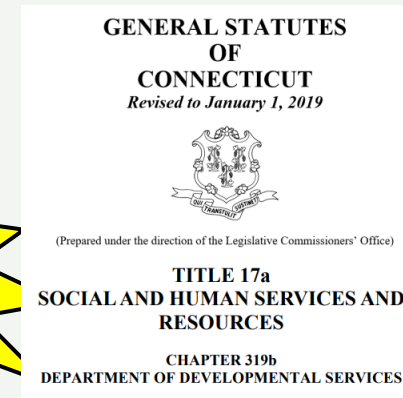
Figure 1 Section 303.344 of IDEA Part C
Note. IFSP content must include specific information about the early intervention services to be provided

Federal Statutes & Regulations / IDEA Part C (cont.)

- You can access these federal regulations here!: [IDEA Part C Federal Regulations](#)

State Statutes & Regulations

- Sec. 17a-248 and associated regulations (pictured to the right) of General Statutes of Connecticut
- Two state insurance statutes
- Public Act 13-178 “An Act Concerning the Mental, Emotional and Behavioral Health of Youths”



(b) The individualized family service plan shall be in writing and contain: (1) A statement of the child's present level of physical development, cognitive development, language and speech development and self-help skills, based on acceptable objective criteria; (2) a statement of the family's priority, resources and concerns relating to enhancing the development of the eligible child; (3) a statement of the major outcomes expected to be achieved for the child and the family and the criteria, procedures and timelines used to determine the degree to which progress toward achieving the outcomes are being made, and whether modifications or revisions of the outcomes are necessary; (4) a statement of specific early intervention services necessary to meet the unique needs of the

eligible child and the family, including the frequency, intensity and the method of delivering services; (5) a statement of the natural environments in which the services shall be provided; (6) the projected dates for initiation of services and the anticipated duration of such services; (7) the name of the approved comprehensive service provider that will provide or procure the services specified in the individualized family service plan; (8) the name of the individual service coordinator from the profession most immediately relevant to the eligible child's or the family's needs who will be responsible for the implementation of the plan and coordination with the other agencies and providers or an otherwise qualified provider selected by a parent; and (9) the steps to be taken to support the transition of the child who is eligible for participation in preschool programs under Part B of the Individuals with Disabilities Act, 20 USC 1471 et seq., as appropriate.

Figure 2 Section 17a-248 of Connecticut General Statutes 11

State Statutes & Regulations (cont.)

- You can access these state statutes here!: [Part C State Statutes](#)

Lead Agency

- **§ 303.22** of IDEA Part C mandates that each state have a *lead agency*, meaning “the agency designated by the State’s Governor under section 635(a)(10) of the Act and § 303.120 that receives funds under section 643 of the Act to administer the State’s responsibilities under Part C of the Act”
- Part C’s lead agency for the State of Connecticut is the Office of Early Childhood (OEC)

CT B23 “Procedures”

- The lead agency/OEC takes the federal and state statutes/regulations and synthesizes them into “procedures” for programs to follow, which are organized by topic
- Programs’ adherence to these procedures ensures their compliance with federal and state regulations regarding Part C services
- You can access these state procedures here!: [CT Birth to Three Procedures](#)

IFSP Section 6. Early Intervention Supports and Services

Overview: This section identifies the early intervention supports and services necessary to meet the unique needs of the child and family. Supports are provided for the family and other caregivers to help them work towards achieving their identified outcomes for their child and family.

Decisions regarding supports and services including type, frequency, location, method, intensity, and duration, can only be made after the development of outcomes. The decision on the type and intensity of the supports should come from an open discussion about what the family needs to help them achieve their outcomes.

Services (including assistive technology devices) that support achievement of functional outcomes or strategies are determined through discussion with the family and must be delivered as indicated on the IFSP. The decision to provide a service or support cannot be based solely upon factors such as: nature or severity of disability, age of child, availability of services, administrative convenience, family preference, payment methodology, or service provider preference but must be tied to supports necessary for the family to achieve their desired outcomes for their child and family.

Services provided under Part C of IDEA (see the Services Procedure for more information) should be listed on the grid on Section 6. However, services and supports provided under IDEA Part C and listed on Section 6 are only part of what will help a family achieve their outcomes. Additional resources and supports that are identified by the family can help them attain their outcomes and should be listed at the bottom of Section 5A as a support to achieve a child outcome or in Section 5C, *Steps That Will Help Your Family and Child*.

Any variance from the services or dates listed on the IFSP (settings, type, frequency, length) must be documented in the visit note. See *Planning and Documenting Services Procedure* for more information.

Figure 3 Clip of CT Birth to Three’s Procedure, “IFSP Procedure/Guidance”

Policy vs. Procedure

- **Policy:** “A set of ideas or plan of what to do in particular situations that has been agreed to officially by a group of people, a business organization, a government, or a political party”
 - Big picture
 - Often “rules” or “regulations”
 - Do not change often; generally non-negotiable
 - States *what* and *why*



[Cambridge Dictionary](#)

[New Hampshire Dept of Health and Human Services - Policy vs. Procedure](#)

Policy vs. Procedure (cont.)

- **Procedure:** “A set of actions that is the official or accepted way of doing something”
 - Narrow focus; more detailed as compared to policies
 - Subject to change & continuously improves
 - Describes series of tasks
 - States *how, when, what, and who*



[Cambridge Dictionary](#)

[New Hampshire Dept of Health and Human Services - Policy vs. Procedure](#)

Program-Level Procedures

- Each B23 program is responsible for ensuring their internal procedures comply with state and federal policies that govern Part C services



Completing and Signing Section 6 of the IFSP

In order for the IFSP to be saved, there are 3 mandated field that need to be completed prior to saving. The first is the Type of IFSP as stated in the Header sections of the document (pg.1) The second is the ICD10 code in Section 6 and the third is an LP needs to be assigned in section 6.

An IFSP must be signed by the parent and a Licensed Practitioner (LP) before services can begin. **IFSPs missing parent and/or LP signature will not be entered into SPIDER, and services provided before either signature date will not be billed.**

IFSPs with PT services must also be signed by a physician within a month of start date (or 6 PT visits, whichever comes first).

Once the parent signs the IFSP, the document will lock and no further changes can be made. It is important to have all information completely filled out before having the parent sign.

Prior to having parent sign:

1. Save document (will need LP signature assigned first)
2. Ensure pediatrician, LEA, and Service Coordinator information is correct in section 1.
3. Complete ALL sections of the IFSP except **parent signature**
4. In section 6, make sure all areas are complete:

Service Grid

1. Type of service
2. Discipline, with correct 3 initials of provider
3. Location
4. Frequency
5. Duration
6. Start date
7. End date

What is going to happen	Delivered by: (discipline responsible)	Location/Settings	How Often	How Long	Start Date	End Date
El Visits 1	DT (JRE) 2	Home 3	2x week 4	1 hour 5	10/22/2020 6	01/08/2021 7
El Visits	DT (JRE)	Childcare	1x week	30 minutes	11/02/2020	01/08/2021
El Visits	DT (SAL)	Home	1x week	1 hour	10/22/2020	01/08/2021
El Visits	CF-SLP (HGT)	Home	1x week	1 hour	10/22/2020	01/08/2021
El Visits	DT (MKA)	Home	2x week	30 minutes	10/22/2020	01/08/2021

3 Check if ANY early intervention service listed above cannot be achieved satisfactorily in a natural environment and attach a justification page for each service.
Part C Supports are paid for by the Birth to Three System unless otherwise indicated here:

Figure 4 Program-Specific Procedure for “Completing and Signing Section 6 of the IFSP”

SUBPART G OF PART C REGULATIONS

STATE INTERAGENCY COORDINATING COUNCIL

Subparts of IDEA Part C

- ➔ • Subpart A—General
- Subpart B—State Eligibility for a Grant and Requirements for a Statewide System
- Subpart C—State Application and Assurances
- Subpart D—Child Find, Evaluations and Assessments, and Individualized Family Service Plans
- Subpart E—Procedural Safeguards
- Subpart F—Use of Funds and Payor of Last Resort
- Subpart G—State Interagency Coordinating Council
- Subpart H—State Monitoring and Enforcement; Federal Monitoring and Enforcement; Reporting; and Allocation of Funds

IDEA Part C Meets Service Coordination Training

SUBPARTS A, D, E, & F

- Subpart A (General)
 - Embedded throughout training modules (this subpart of IDEA Part C establishes the purpose of EI, defines terms)
- Subpart D (Child Find, Evaluation & Assessment, IFSPs)
 - Module dedicated to Referral
 - Module dedicated to Evaluation & Assessment
 - Module dedicated to IFSPs

SUBPART G

IDEA Part C Meets Service Coordination Training (cont.)

SUBPARTS A, D, E, & F

- Subpart E (Procedural Safeguards)
 - Module dedicated to Service Coordination Roles and Responsibilities, including informing parents of procedural safeguards
- Subpart F (Use of Funds and Payer of Last Resort)
 - Module dedicated to System of Payments

SUBPART G

Component 15

Part C of the IDEA and the state of Connecticut's Birth to Three legislation established the **Connecticut Birth to Three Interagency Coordinating Council (ICC)**.

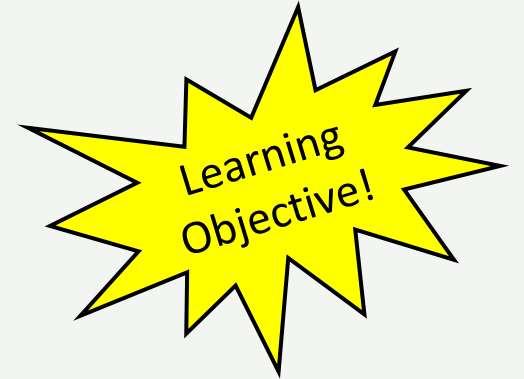
The ICC is made up of representative members appointed by the Governor, of which **at least 20% must be parent representatives whose family currently receives or previously received supports from the Birth to Three System.**



The council's role is to advise and assist the lead agency (the Office of Early Childhood) in the implementation of the Birth to Three System.

Figure 5 Clip of CT Birth to Three's Service Coordination Training Module, "Laws and Regs"

Functions of the ICC (§ 303.604)



- Advise and assist the lead agency (for CT, the OEC)
 - Identification of fiscal and other support for EI services/programs
 - Promotion of methods for interagency collaboration
- Advise and assist the lead agency on issues concerning development of standards/procedures
- Advising and assisting on transition from Part C to Part B
 - Adoption of rules and regulations
 - Identification of barriers to timely and effective services
- Preparation of an Annual Report on the status of EI service programs, and submission of this report to the Governor and the Secretary of Education

Composition of the ICC (§ 303.604)

- At least 20% of members must be parents of infants and toddlers/children < 12 years of age with disabilities
- At least 20% of members must be EI service providers
- At least one member must be from the state legislature (House of Representatives or Senate)
- At least one member must be involved in personnel preparation
- At least one member must be from each of the state agencies involved in provision of/payment for EI services and have sufficient authority to engage in policy planning and implementation on their behalf
- At least one member must be from the State Educational Agency (SEA) responsible for preschool services

Composition of the ICC (§ 303.604, cont.)

- At least one member must be from the agency responsible for the state Medicaid program and Children's Health Insurance Program (CHIP)
- At least one member must be from a Head Start or Early Head Start agency
- At least one member must be from a state agency responsible for childcare
- At least one member must be from the agency responsible for state regulation of private health insurance
- At least one member must be designated by the Office of the Coordination of Education of Homeless Children and Youth
- At least one member must be from the state agency responsible for children's mental health

THE ROLE OF ADVOCACY

What is Advocacy?

- **Advocacy:** “Public support for an idea, plan, or way of doing something”
- Levels of change (Kaufman, 2023)
 - Individual
 - Program
 - System → reminder: the B23 System is governed by policies, which are tied to federal & state regulations



Kaufman, J. (2023, November 13). *Using data to support policy change (or not!)* [PowerPoint presentation]. CT Early Childhood Intervention Leadership Academy, Farmington, CT, United States.

[Cambridge Dictionary](#)

What is Advocacy? (cont.)

- Examples

- Individual: A therapist approaching their boss to ask for raise
- Program: A therapist approaching leadership and asking to hire more staff
- System: A therapist sharing information with the ICC about how current policy affects them or could be improved

Kaufman, J. (2023, November 13). *Using data to support policy change (or not!)* [PowerPoint presentation]. CT Early Childhood Intervention Leadership Academy, Farmington, CT, United States.

[Cambridge Dictionary](#)

Advocating for Change (Kaufman, 2023)

- What is the problem?
- Who needs to get on board (**main players**)?
- What are topics/questions related to the problem? (e.g., will there be unintended consequences?)
- What data do you need to address these questions?
- Put it together and tell a story!

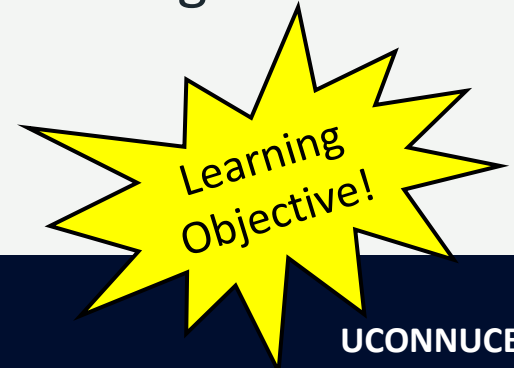
Kaufman, J. (2023, November 13). *Using data to support policy change (or not!)* [PowerPoint presentation]. CT Early Childhood Intervention Leadership Academy, Farmington, CT, United States.

How to Participate in ICC Meetings

- Per IDEA Part C, ICC members must meet at least quarterly
- CT's ICC has elected to meet every other month on Mondays (unless otherwise noted). Meetings are open to the public!
- Meeting schedule is posted at the following location: [Connecticut ICC Meeting Schedule](#)
- In-person comments must be less than 5 minutes. Can also send comments via email to CTBirth23@ct.gov (with "ICC Comment" in the subject line)
- The ICC is looking for more parent members!
 - Email CTBirth23@ct.gov with "ICC Member Request" in the subject line

Recent Regulatory Activity

- Introduction of EI Over 3 (2021)
- Passage of bill SB No. 2 (2023)
- Inclusion of early intervention programs in raised bill HB No. 5459 (2024)
- CT B23's ICC posts past meeting notes online at the following location – you can review updates from the legislative/fiscal committee members: [Connecticut ICC Meeting Notes](#)
- Public hearings on proposed legislation is announced at the following location: [Connecticut General Assembly](#)



Rece

State Interagency Coordinating Council

April 3, 2023 Minutes
9:00 AM-12:00 PM
American School for the Deaf

cont.)

Family Focus Meeting

Cynthia Jackson
ICC Chair/Provider
Leona Adamczyk
ICC Vice
John Lamb
Dept. of Public Health
Tiffanie Allain
Parent Representative
Donna Maitland-Ward
Dept. for Children and Families
Maris Pelkey
Creative Interventions, Provider
Elaine Balsley
Reachout, Provider
Nicole Cossette
Office of Early Childhood
Senator Ceci Maher
State Senator
Shonda Easley
Parent representative
Sharon Marie
Dept. of Aging & Disabilities Services
Ginny Mahoney
Dept. of Social Services
Anne Giordano
Education Connection, Provider
Louis Tallarita
SDE-Homeless Children
Pending Appointment
SDE-619
Julie Hall
SARAH Inc, Provider
Karen Pascale
Early Head Start
Ann Milanese, M.D.
American Academy of Pediatrics
Representative Liz Linehan
House of Representatives
Tammy Venenga
Dept. of Developmental Services
Mary Beth Bruder
UCEDD
Lisa Opert
Parent Representative
Robb Dunn
Parent Representative
David Gonzalez-Rice
Parent representative
Lauren Black
Parent Representative
Gerard O'Sullivan, pending
Department of Insurance

ICC Members Present: Cindy Jackson, Tiffanie Allain, Ginny Mahoney, Nicole Cossette, Lisa Opert, Leona Adamczyk, Sharon Marie, Julie Hall, Bethanne Vergean (representing UCEDD), Senator Ceci Maher, Robb Dunn, John Lamb, Anne Giordano

ICC Members Absent: Elaine Balsley, Shonda Easley, Representative Linehan, Ann Milanese, Donna Maitland-Ward, Gerard O'Sullivan (pending appointment), Karen Pascale, Louis Tallarita, Maris Pelkey, Lauren Black, David Gonzalez-Rice, Tammy Venenga

Meeting called to order at 9:00 AM by Cindy Jackson ICC Chair

Introductions: Cindy Jackson introduced American School for the Deaf (ASD) Executive Director, Jeff Bravin, who welcomed the ICC and families to their campus. Mr. Bravin shared information about programs offered at ASD. Cindy Jackson introduced both Commissioner Beth Bye and Deputy Commissioner Elena Trueworthy from the Office of Early Childhood.

Public Comment:
No public comment.

Old Business:
Approval of the February 2023 minutes: Tabled until June meeting.

Updates from Committees since February 2023 meeting:

Legislative/Fiscal Committee Members are advocating at the LOB for current proposed bills SB2 and HB6644. SB2 includes reimbursement for interpreters for Spanish Speaking families (ICC Retreat 2022 outcome around Equity) and continuation of GAP rate of \$200 per child. HB6644 includes language around transition.

Education and Outreach Committee Members focus has been on this current meeting in supporting families presenting at today's Family Focus Event. Following today, the focus will return to the planned family engagement event at Camp Harkness this summer.

System Support/Personnel Development Committee Members met on Zoom to discuss some short-term steps: need for continued funding to staff supervising student placements and marketing materials and partnering with new Ed Outreach hire once onboarded with the Office of Early Childhood.

- Introduction of EI Over 3
 - Passage of bill SB No. 2 (2)
 - Inclusion of early interven
- CT B23's ICC posts past mee
from the legislative/fiscal co
Public hearings on proposec
[Assembly](#)

24)

you can review updates
[g Notes](#)

cation: [Connecticut General](#)

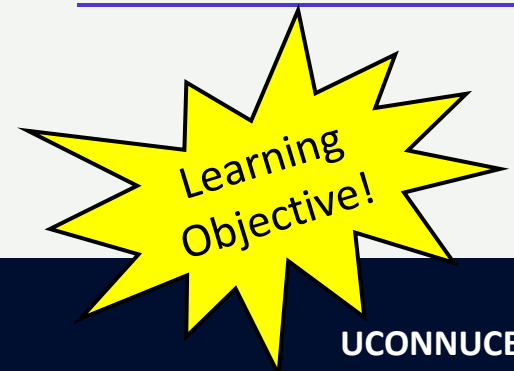


Figure 6 Clip of Connecticut ICC's April 2023 Meeting Notes

Connecticut General Assembly's Website Homepage

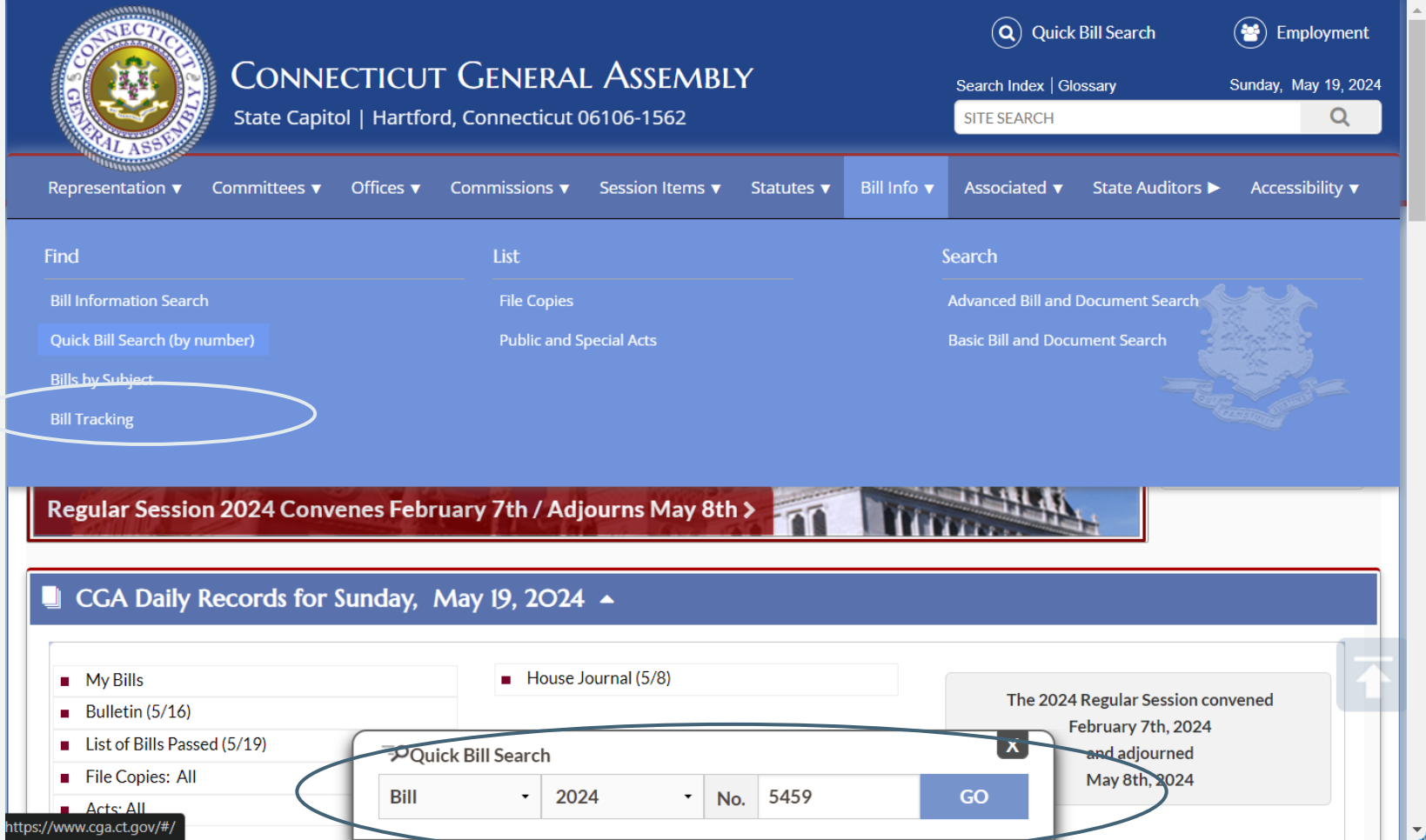


Figure 7 Connecticut General Assembly's Website Homepage

History of Raised Bill H. B. No. 5459

C G A / BILL STATUS

Substitute for Raised H.B. No. 5459 Session Year 2024



AN ACT INCREASING RATES OF MEDICAID REIMBURSEMENT FOR CERTAIN PROVIDERS.

To increase rates of Medicaid reimbursement for certain providers.

Introduced by:

Human Services Committee

Bill History

Date ↕		Action Taken ↕
3/22/2024		Favorable Change of Reference, Senate to Committee on Appropriations
3/21/2024		Favorable Change of Reference, House to Committee on Appropriations
3/21/2024	(LCO)	Reported Out of Legislative Commissioners' Office
3/20/2024	(LCO)	Filed with Legislative Commissioners' Office
3/19/2024	(HS)	Joint Favorable Change of Reference Appropriations
3/8/2024		Public Hearing 03/12
3/7/2024		Referred to Joint Committee on Human Services

Figure 8 History of Raised Bill H. B. No. 5459

Advocacy vs. Lobbying

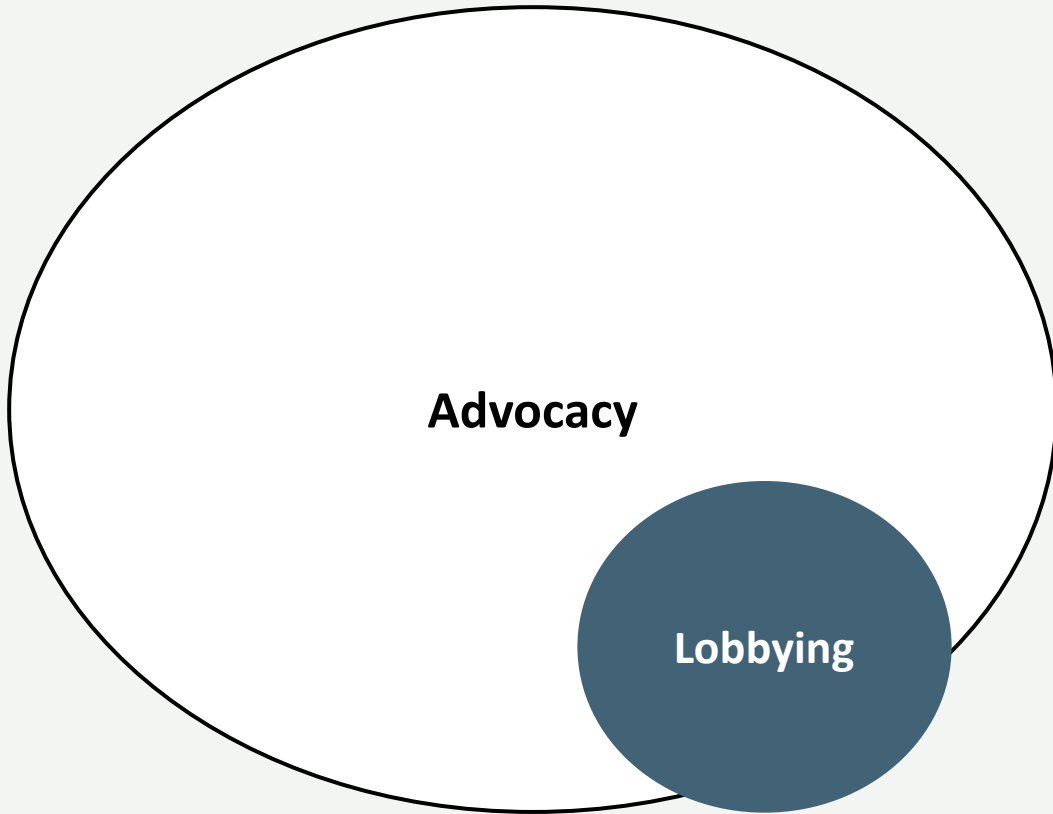
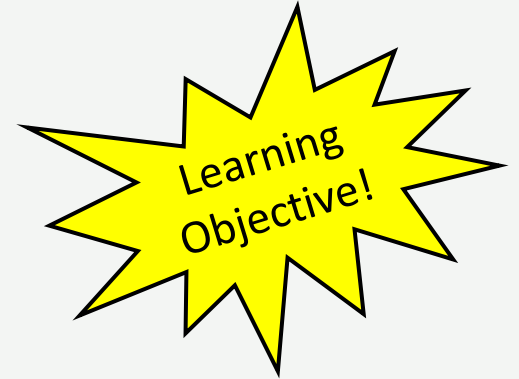


Figure 9 Lobbying as a Subset of Advocacy

Note. Two circles, one large and one small, overlap to show how lobbying is a part of advocacy

- **Advocacy:** “Public support for an idea, plan, or way of doing something”
- **Lobbying:** “The activity of trying to persuade someone in authority, usually an elected member of a government, to support laws or rules that give your organization or industry and advantage”

[Cambridge Dictionary](#)

[National Alliance to End Homelessness](#)

What Do Main Players Say About Lobbying?

- Connecticut Office of State Ethics
 - ANY testimony or communication regarding specific legislation is considered lobbying
 - If an entity spends or an individual earns \$3,000/year on lobbying, the entity should register as a “Client Lobbyist” and the individuals should register as “Communicator Lobbyists”
 - Travel expenses and time spent testifying/waiting to testify = LOBBYING activity!
 - There are no provisions prohibiting an individual from lobbying as a private citizen rather than on behalf of their organization; however, there are no clear guidelines outlining how to distinguish these actions
- Other organizations/regulatory bodies may have more strict guidelines than Office of State Ethics

[Connecticut Office of State Ethics - Lobbying](#)

Connecticut Office of State Ethics

The Office of State Ethics (OSE) is an independent watchdog agency for the State of Connecticut. The OSE administers Connecticut General Statutes, Chapter 10, Part I for Public Officials and Part II for Lobbyists.

The mission of the Office of State Ethics is to ensure honesty, integrity and accountability in state government through education, interpretation and enforcement of the State of Connecticut Codes of Ethics. We encourage you to spend time on this site and to call our office with any questions.

Contact Us

Agency Address:

Office of State Ethics
165 Capitol Avenue
Suite 1200
Hartford, CT 06106

Main Phone Number: [860-263-2400](tel:860-263-2400)

Fax Number: [860-263-2402](tel:860-263-2402)

[Staff Phone Number Listing](#)

[Citizen's Ethics Advisory Board](#)

Business Hours: 8:30 am to 5:00 pm

Specific Contacts

For the most timely responses, please be sure to direct your questions to the appropriate e-mail address; for example, with lobbyist filing concerns such as, "my password didn't work" please be sure to send your query to lobbyist.ose@ct.gov

- Advice Regarding Code of Ethics: ethics.code@ct.gov
- Lobbyist Filing/Reporting Questions: lobbyist.ose@ct.gov
- Public Official Filing/Reporting Questions: sfi.ose@ct.gov
- Enforcement: ethics.enforcement@ct.gov
- All Other Inquiries: ose@ct.gov

FEEDBACK +

What Do Main Players Say About Lobbying? (cont. 1)

- The OEC
 - Considered lobbying “If a Birth to Three program staff member engages (in any form) in attempting to influence” either a state agency or a member of the General Assembly (i.e., legislator)
 - Staff member must register with the Office of State Ethics as a lobbyist if receiving = or > \$2000 per year (including prorated value of salary)
 - Federal dollars CANNOT be used for lobbying activities (funds from Office of Special Education Programs)
 - Staff member’s participation in the ICC, policy-making committee, or task force is NOT considered lobbying

[CT Birth to Three Lobbying Procedure](#)

What Do Main Players Say About Lobbying? (cont. 2)

- The Internal Revenue Service (IRS)
 - Nonprofits must not engage in too much lobbying activity to avoid loss of tax-exempt status

[IRS - Lobbying](#)

How Do You Approach “Main Players”?

- “Elevator speeches” are helpful when approaching a main player so that you pull them in and get them interested in hearing more (which may give you an opportunity to present your data!)
- Convey, as concisely as possible, the following pieces:
 - A specific action/recommendation that you want the person/entity to act on
 - A reason for the person/entity to care based on something they find important
 - The result(s) of these actions



Kaufman, J. (2023, November 13). *Using data to support policy change (or not!)* [PowerPoint presentation]. CT Early Childhood Intervention Leadership Academy, Farmington, CT, United States.



Topics for Continued Advocacy Efforts...

Let's Practice Making "Elevator Speeches"!