



UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

University of Connecticut
Center for Excellence in Developmental Disabilities
Consumer Advisory Council
June 30, 2020

Meeting Minutes

CAC Council Members in Attendance:

Anton Alerte	Win Evarts	Steven Hernandez
Emily Ball	Bob Joondeph	Keith Mullinar
Julie Ball	Diana LaRocco	Allyson Powell
Chris Blake	Nanfi Lubogo	Deb Richards
Mary Beth Bruder	Walter Glomb	Lolli Ross
Molly Cole		

UCEDD Staff in Attendance:

Julie Coia	Christine Jozef	Tina Rhodes
Erika Egan	Holly LaBrecque	Katie Straka
Gabriela Freyre-Calish	Tara Lutz	Hanni Thoma
Darla Gundler	Heather Petitt	Bethanne Vergean
Betsey Howe	Diana Pistritto	
Jill Isenberg	Linda Rammler	

The meeting began via Zoom at 9:35 am.

1. Introductions and Updates- How is COVID-19 affecting you?

Mary Beth Bruder welcomed all those participating in the meeting and introduced Diana LaRocco to begin the agenda. Diana asked those in attendance to introduce themselves and to share how COVID-19 is affecting them.

2. UCEDD Review - Progress and Changes:

Mary Beth thanked everyone for their dedication and shared a “silver lining” of COVID-19 - that people have been more productive, communicative and supportive of each other and gave some recent highlights: 12 grants were submitted this year, we received four big grants- 1 in collaboration with the state, 2 in collaboration with UConn-Storrs for graduate training, 1 of those is a collaboration with 10 other Research-1 Universities. Our budget has remained stable at approximately 4.7 million, of which only 5% of this is state funded. Mary Beth’s expressed that her goal continues to be to bring in people who can write grants to

keep the UCEDD stable. OSEP funds most of UCEDD grants but has been the most rigid in regard to keeping requirements up during COVID-19 as opposed to NIH which sent out a “dear colleagues” letter saying due dates could be pushed back.

Mary Beth requested Walt Glomb from the CT Council on Developmental Disabilities (CTCDD) share some of his work and research. Walt reported the CTCDD has continued to implement their 5-year plan with the next 5-year plan due in August 2021. Their first step is a comprehensive analysis of the services and supports of people with disabilities in CT. He explained that developmental disabilities is not intellectual disabilities. Developmental disabilities is much more than the population served by the CT Department of Developmental Services (DDS). According to ACL there are approx. 43,000 people in CT with developmental disabilities and DDS only counts 17,000 because they only count people with intellectual disabilities. Walt has been researching people with psychiatric disabilities, substance abuse issues, and physical disabilities who are all individuals who the CTCDD should be serving. He found the system in CT is fractured and there are gaps between the different programs. He invited everyone to contact him regarding thoughts and ideas about areas CTCDD should be concentrating on and to consider in the next 5 years to transform the system and make it more community-based, more individualized and more person-centered. He reported the state’s response to COVID-19 has shown there are institutional biases that exist in CT towards people with developmental disabilities. The state’s focus was on facilities and how to keep them safe, and there wasn’t much thought to the people living person-centered home and community-based lives. Most are reliant on generic services, however there are many in the state that are not aware that this large population of individuals with developmental disabilities who live in the community and rely on these services.

Mary Beth reiterated the CTCDD, Disabilities Rights CT and the UCEDD are all funded by the Developmental Disabilities Act. The UCEDD has a statutory responsibility to work with the network to make sure people with disabilities are getting their needs met. She thanked and commended Walt on a terrific job researching and giving us a picture of the state of the state on disability.

Mary Beth reported the UCEDD is always looking for funding to keep the good work going since we are fully grant funded. The UCEDD’s main job is to be a knowledge-broker, to create evidenced-based practices and translate them into practice in the community. In the DD Act it is written that the CAC leads strategic planning and leads the delineation of emphasis areas out of the 11 emphasis areas within the DD Act. One change due to COVID is UCEDD’s now do not have to (but we will continue to), pull in the CAC in order to change emphasis areas because this pandemic is requiring some UCEDD’s to divert funds.

3. UCEDD Program Highlights: (PowerPoint slides attached at end of document.)

Early Childhood Updates:

Learn the Signs Act Early (LTSAE) –Bethanne Vergean, CT Act Early Ambassador to the CDC, gave an update. The first goal was to collaborate with the CT Department of Children and

Families (DCF) as there was a need for the DCF workers to know how to recognize developmental red flags upon home visits with young children. To date, 330 DCF staff have trained. Next was to add LTSAE training to DCF Workforce Academy for newly hired DCF workers and those in need of Early Childhood Trainings. LTSAE has been selected as a Cutting Edge Practice by the Association of Maternal and Child Health Programs Innovative Station (<http://www.amchp.org/programsandtopics/BestPractices/InnovationStation/Pages/Innovation-Station.aspx>). LTSAE has also trained 670 early childhood professionals in the past year before going virtual in March after which a total of 9 virtual trainings were held.

The CDC/AUCD has recently put out an RFP to help with parent engagement around developmental monitoring and screening during the pandemic. They are offering states who have Act Early Ambassadors a grant to continue this work. We will be reaching out to all our stakeholders to be a part of this – due August 2020.

The UCEDD also received another small grant through AUCD also funded by the CDC - CoP on Parenting, Behavioral Concerns & Strategy to work with early childhood providers and families that struggle with children with behavioral concerns. A family engagement workgroup has been developed with our state early childhood partners and the UCEDD has recently done on-line training for families around routines and transitions. Also, a COVID-19 social story for families has been created to help them talk to children about what school will look like when they return in the fall.

Early Childhood Personnel Center (ECPC): Betsey Howe and Darla Gundler gave an overview of the ECPC project. The ECPC is a nationally funded grant from OSEP to enhance workforce development for all disciplines who serve children under five with disabilities. The project works with a variety of audiences around the country which include: higher education faculty, doctoral students, families, and Comprehensive System of Personnel Development (CSPD) state teams. They are presently working on developing products, materials and resources which are used in the delivery of technical assistance (TA). There are three levels of technical assistance - Universal TA, Targeted TA and Intensive TA.

A CSPD is a primary mechanism by which states can ensure infants, toddlers and young children with disabilities and their families are provided services by knowledgeable, skilled, competent and highly qualified personnel. ECPC works with the state for 18 months to develop a CSPD using four phases: Exploration, Installation, Implementation, and Standardization. Families are included in all aspects of developing a CSPD.

We are currently in the process of updating the website at ecpcta.org at which you can find all of our materials.

Early Childhood Intervention Doctoral Consortium: Mary Beth Bruder introduced Hanni Thoma to provide an update on one of our newest grants awarded by OSEP. This grant works across ten universities to have value added for 28 doctoral students over the next

five years, all who will focus on kids under the age of five with intense learning needs. Our goal is to create 28 faculty in the area of early childhood special education.

Hanni explained that currently we have 17 confirmed students from nine of our ten universities. Students have diverse academic backgrounds and we're looking forward to getting to know them during remote orientation this August. There are four main competency areas: population specific pedagogy, research and scholarship, teaching and education and community engagement and service. We will be conducting the courses on-line due to COVID-19. Modules were generated after CEEDAR (TA center at the University of Florida). Our model is to have a value-added curriculum that is above what our students will be getting at their own doctoral programs, and our focus is to pull together learning opportunities for them that will cross all these very specific targeted areas. The modules will be: Etiology, Family-Centered Practice, Data Based Instruction, and Assistive and Instructional Technology.

Mary Beth informed the CAC of the portfolio of higher education funded projects. Jill Isenberg is coordinating the Master's Training Program for students who will be getting their Master's degree across social work, speech and language pathology, and early childhood special education and focus on children with autism and other high need areas. We also have a project working with community colleges in Connecticut focusing on early childhood special education at the two-year degree programs using evidenced-based practice in either classrooms that are inclusive or working in school districts in inclusive programs.

Early Intervention Specialist Program (EISP): Gabriela Freyre-Calish explained that the EISP is a year-long nondegree program which consists of three courses: Family Centered Practice, Evaluation and Assessment, and Intervention Strategies. This is a competency based program where the students need to complete seven competencies for Family Centered Practices, four for Evaluation and Assessment and eight for Intervention Strategies. The target audience is individuals who are currently working in the Birth to Three system. We work closely with the Birth to Three System who also participate in our Community of Practice and our planning to be sure we are providing evidenced-based information. To date, 54 early interventionists have completed the program and 21 are currently going through it and will finish by December 2020. Students who complete this program obtain a Birth to Three state recognized credential through Birth to Three System.

Schools and Post-Secondary Update:

Customized Employment Initiative: Linda Rammler provided an update on the completion of this program which looks at people who previously weren't thought to be employable but match what their specific strengths, interests and talents are with what employers need. It's based on the Federal Workforce Innovations and Opportunities Act of 2014. Mark Gold and Associates were brought in for training. Three training cohorts started in 2017 and ended in 2019 that covered the topics of discovery, which is looking at what an individual is really good at, job development which looks at what employers need, and systematic instruction

which is putting those individuals in a win-win situation with employers. In March 2018 a retreat identified some adjustments to the project that needed to be made. There were 150 plus trainees, a number of which were certified by Mark Gold and Assoc. It's been difficult for some agencies simply because they do not have all the staff needed in the process and don't have broader state buy-in. There are two new projects: one is completed. A curriculum was drafted for a collaborative endeavor that included Bureau of Rehabilitation Services (BRS), DDS and CREC. CREC was to implement the training for private providers, BRS was to do certification for the initial phase and DDS was to provide long-term support. It was supposed to be implemented February 2020 but was put on hold due to administrative issues and COVID-19. Also just applied for a community-based transition partnership grant which will focus specifically on helping youths in Hartford, as a pilot, who are graduates of their transition program but who don't have a job before exiting high school, or exiting their IDEA services. Both BRS and DDS agencies are enthusiastic about this.

People First of CT: Linda Rammler reported People First is a national self-advocacy movement. In CT, it has been in effect since 1983. A number of improvements were made to the organization which include: Zoom meetings and trainings, joined the national inclusive project, creation of a new website, updated the Facebook page, weekly social and networking opportunities and creation of a video about COVID-19. People First are also in process of developing two new videos: "You Say We Have These Rights, But" and "Dear Parents, See Me, Relax, It's Ok." They've increased membership three-fold since the UCEDD became involved.

Thinking College Initiative: Linda Rammler explained in 2017 UCEDD was awarded a mini-grant from the National Center for Think College which focused on capacity-building. In 2018 a statewide collaboration and strategic plan was developed. In 2019 the UCEDD began providing TA to Goodwin University. Weekly meetings are held with staff who have been designated to coordinate this; BRS and DDS are also in collaboration. Three family trainings have been provided on Thinking College to teach what the options are for students with disabilities. Qualitative feedback is this is an amazing resource and very helpful to families.

Linda reported UCEDD is currently writing a grant titled Transition Programs for Students with Intellectual Disabilities (TIPSID) in institutions of higher education. She is doing this to implement a strategic plan will include more support to Goodwin University as well as expansion to two-year community colleges and 4-year public and private institutions of higher education to be determined.

Life Course Trainings: Linda Rammler is a CT Life Course Ambassador and explained Life Course is a particular form of person-centered planning systems and has integrated them into a very flexible working document for everyone else to use. An on-line course has been drafted and will be available soon. Using the 4-point scale of transition evaluations people have been very satisfied with the course. Some individual families have reported: inclusion in school production which developed into more social connections among nondisabled peers, inclusion in college sports, access and increase to assistive technology, successful transition

to adult healthcare, more independence allowed by parents, work experience instead of summer school, self-advocacy improvements that led to a job, move to adult funding but became self-directed, and taught technical assistance for the UCEDD.

Healthcare Promotion: Tara Lutz provided an update of three programs: Certificate, COVID-19 survey and analysis, and the Medical Student Elective that the UCEDD has created. The Certificate began in 2014. The full title is Certificate in Interdisciplinary Disabilities Studies in Public Health, comprised of four courses: Foundations of Public Health and Disability (most popular), Epidemiology of Disability, Disability Law, Policy, Ethics and Advocacy, and Public Health Interventions in Disability, for a total of 222 students. There are 10 essential services of public health upon which the course goals and objectives are aligned. Students are from many disciplines, including those not in a degree program. The Certificate is offered completely on-line so it is available nationally.

Tara described the COVID-19 Survey titled, The Knowledge, Attitudes, and Behaviors of Families of Children with Disabilities during COVID-19. The survey was conducted nationally and provides information on 870 children with disabilities from 608 respondents.

Tara explained the pandemic provided an opportunity to develop an elective course for medical students entitled, "Caring for Health Disabilities in the Medical Home." Some topics covered were the medical home, part B and part C of IDEA, and role of the physician. Anton Alerte added they expanded the course to address health disparities and racial institutional disparities.

Leadership Education in Neurodevelopmental and Related Disabilities (LEND): Mary Beth explained LEND is a focus specifically on training interdisciplinary groups of students which include our graduate students from multiple disciplines at UConn as well as community members and families of persons with disabilities. This year we had 10 community participants, including parents and over 15 students. The School of Medicine and the Graduate School pay graduate assistantships. We're going into our eighth year of LEND and will be re-competing for another five years. Mary Beth asked Holly LeBrecque to describe her LEND experience from this past year as a LEND student. Holly shared that LEND has given her the opportunity to learn from other disciplines about current gaps in the disability field. She said the most valuable experience was a match with families of a child or children with disabilities. Through LEND she learned about the importance of interdisciplinary and team practices, family-centered practices that she had not been educated on before. Taking classes with LEND provided her with a holistic graduate education and allowed her to explore specific interests with disability within public health. Mary Beth reported we have a group of 15 graduate students and a smaller number of community participants because of having to do it remotely, starting this fall. There are also parent instructors and family faculty who help teach the content which is very rigorous because students have to take two other classes at the same time to be a LEND Trainee and they have a lot of meetings and projects they to do.

Leadership for Sustainability: Mary Beth reported that in the early childhood field, leadership is usually attributed to a person as opposed to a system so the UCEDD has been focusing a lot of grants on systems because systems can sustain and people will move on. There are a number of initiatives in early childhood, one of which is to combine leadership trainings for 20 leaders-to-be in the system of Birth to 5, both preschool special education and early intervention over the next five years using a curriculum validated across the country through our ECPC.

Emergency Preparedness: Molly Cole provided an update. A flip-book was developed in 2016 to be kept in emergency vehicles to assist emergency medical personnel when they are on a call with a person with disabilities. Over 1,000 of these were disseminated and they continue to be in demand to this day. In March 2019, Molly provided legislative training with a group of LEND students. She did some mock legislative sessions and this group decided to focus on expanding the tips for emergency personnel to include information about effective communication. During the mock training they spent a day at the Capitol, met with a Representative and they proposed legislation that would mandate these booklets be on every EMS vehicle, and they include a component on effective communication. The Representative was very supportive, pursued passage of a bill to mandate the communication aid, and it passed! Public Act 191-147 went into effect July 2019 and it expanded first responder's access to training on handling incidents involving children and adults with disabilities. The document is on our website. Molly and students started to develop the communication aid, and in March 2020, with COVID-19, were encouraged to ensure adequate support for first responders to address the needs of people with disabilities during pandemic. Five books were mailed to every emergency medical manager in each of 169 towns and emails were sent notifying them these booklets were coming in the mail.

South African Resource and Technical Assistance Center (SARTAC): Molly Cole mentioned Chris Blake is our SARTAC Fellow. The UCEDD assisted Chris with his application and he was selected. His focus is on ABLE accounts. Chris is developing materials in plain language to clarify the process of selecting, choosing, opening and using an ABLE account.

Cross Disability Alliance: Molly Cole provided an update. Membership is agencies who are people with disabilities, advocates / self-advocates and parents. There are over 200 people involved. Participation on their calls has increased dramatically with the advent of Zoom meetings. The activities are coordinated by Melissa Marshall. There is also a steering committee and monthly meetings are held. There are Friday legislative issues calls where presence, current concerns or actions during the legislative session are discussed and the focus is on legislative initiatives. On the off-session the focus is on COVID-19 issues. The Alliance had COVID-19 conversations because of recognized isolation and hosted a number of calls to keep people connected. One outcome of these calls is a voting committee has been established. They are working to ensure access to voting opportunities for PWD. Also, during congressional election years, the Alliance has held candidates non-partisan forums for elective state offices. This year the forum is going to be virtual, held on October 7, 2020 and hosted by Diane Smith. Molly then introduced Chris Blake to speak about some of the issues

facing the Alliance right now. Chris said the Alliance is dealing mostly with COVID-19 issues and trying to make sure people's rights don't get violated.

Next Steps:

Mary Beth mentioned as a UCEDD we have been trying to be as responsive as possible to the issues of individuals with disabilities. The issue of racial inequality has surfaced and is something that as a UCEDD we want to figure out how and what we can do. One thought of Mary Beth's is to devote our next CAC meeting on disparities and inequality. Anton Alerte agreed that we should not allow racial inequality to go unchallenged. Curriculum changes and the way they are executed – knowledge, skills and attitudes need to be addressed and this is the best time. Keith Mullinar mentioned the UCEDD should be sure the whole curriculum is thoroughly embedded and keeps going on.

Mary Beth announced that the UCEDD is developing a number of products as a result of COVID-19. There are early childhood materials for families and providers on tele-intervention, a People First video, a social story for young children returning to child care, and a series of national webinars through AUCD specifically about families and some of the issues around special education and early childhood intervention.

The next CAC meeting which will focus on issues of disparities and inequality will be scheduled in September 2020.

Meeting adjourned at 12:30 p.m.

Respectfully submitted,

Julie Coia
Executive Assistant
University of Connecticut Health Center
Center for Excellence in Developmental Disabilities

Learn the Signs. Act Early



Connecticut Department of Children and Families (DCF) Training

- Trained 330 DCF staff in Region 4
- May 1st training for DCF Training Academy (virtual)
 - “Importance of documentation with specific observations of child and interaction with parents”
 - “The most important thing I took away from today’s session is to observe children in here and document based on observation of child’s development. How to properly intervene when there are developmental concerns. How to refer to child developmental infoline”

A Nationwide Act Early State Opportunity Response to COVID-19

- Act Early Ambassadors
- Funding will focus on parent-engaged developmental monitoring, screening, and referral initiatives to ensure that children with developmental delays are identified early and connected with services that can help children and families.

AUCD CoP on Parenting, Behavioral Concerns & Strategy

- Communities of practice on evidence-based programs for parents of young children who may have behavioral concerns
 - Training for Early Childhood Providers and Department of Children & Families
 - CPAC Family Connections

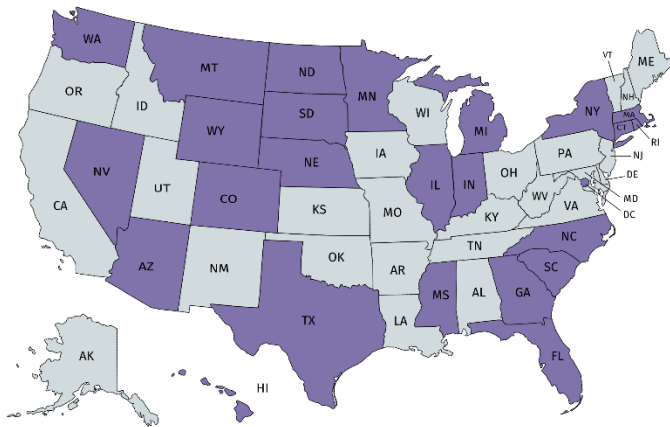
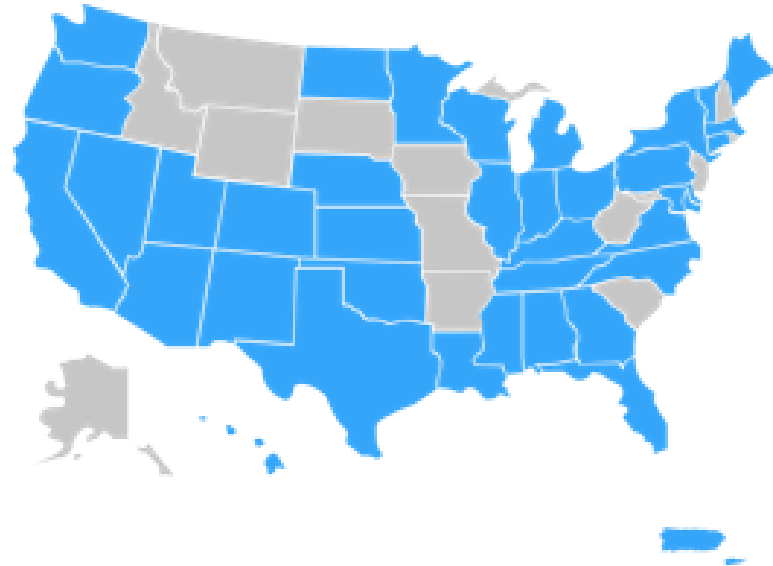


The Early Childhood Personnel Center

ECPC Audiences

- Higher Education Faculty/Doctoral Students

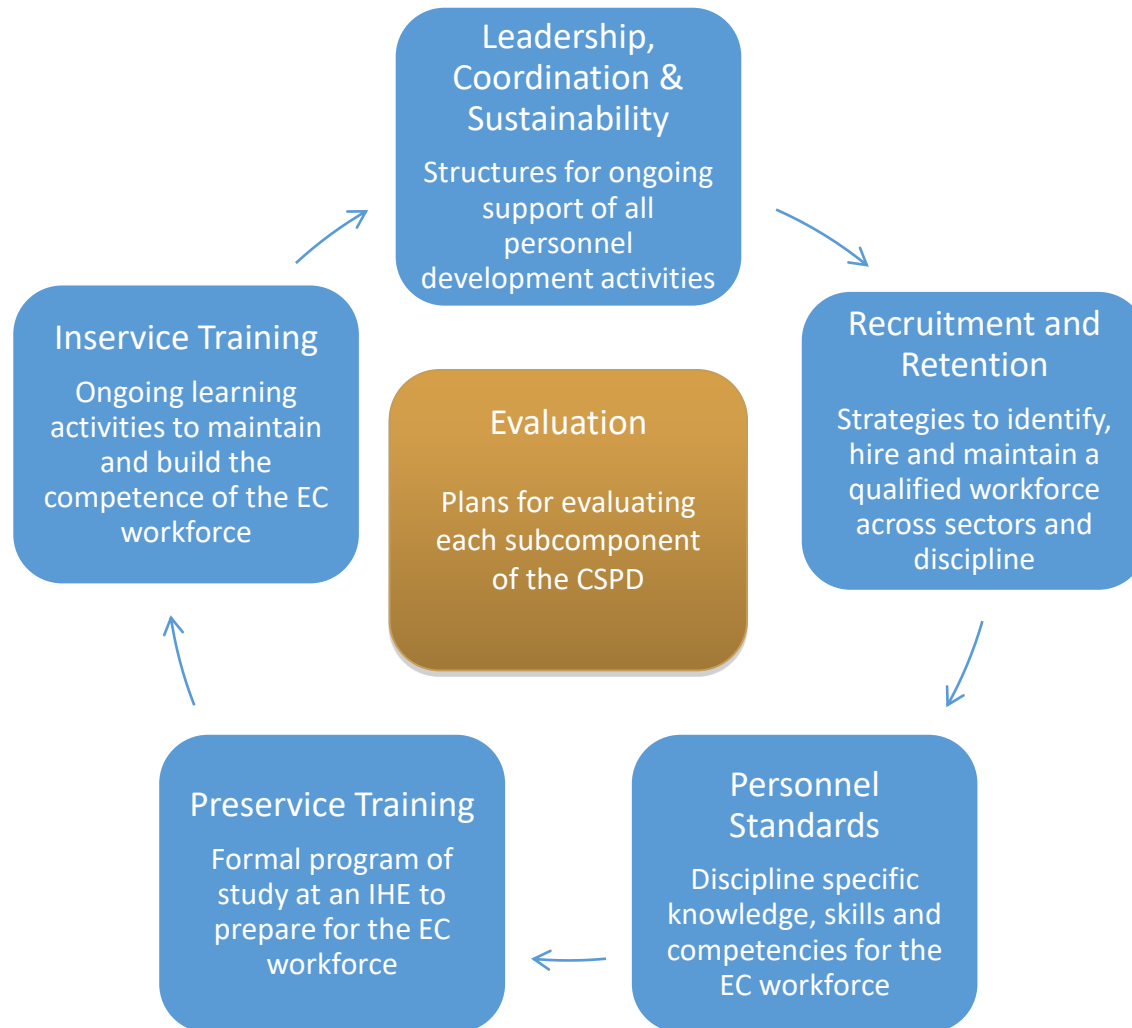
- Families



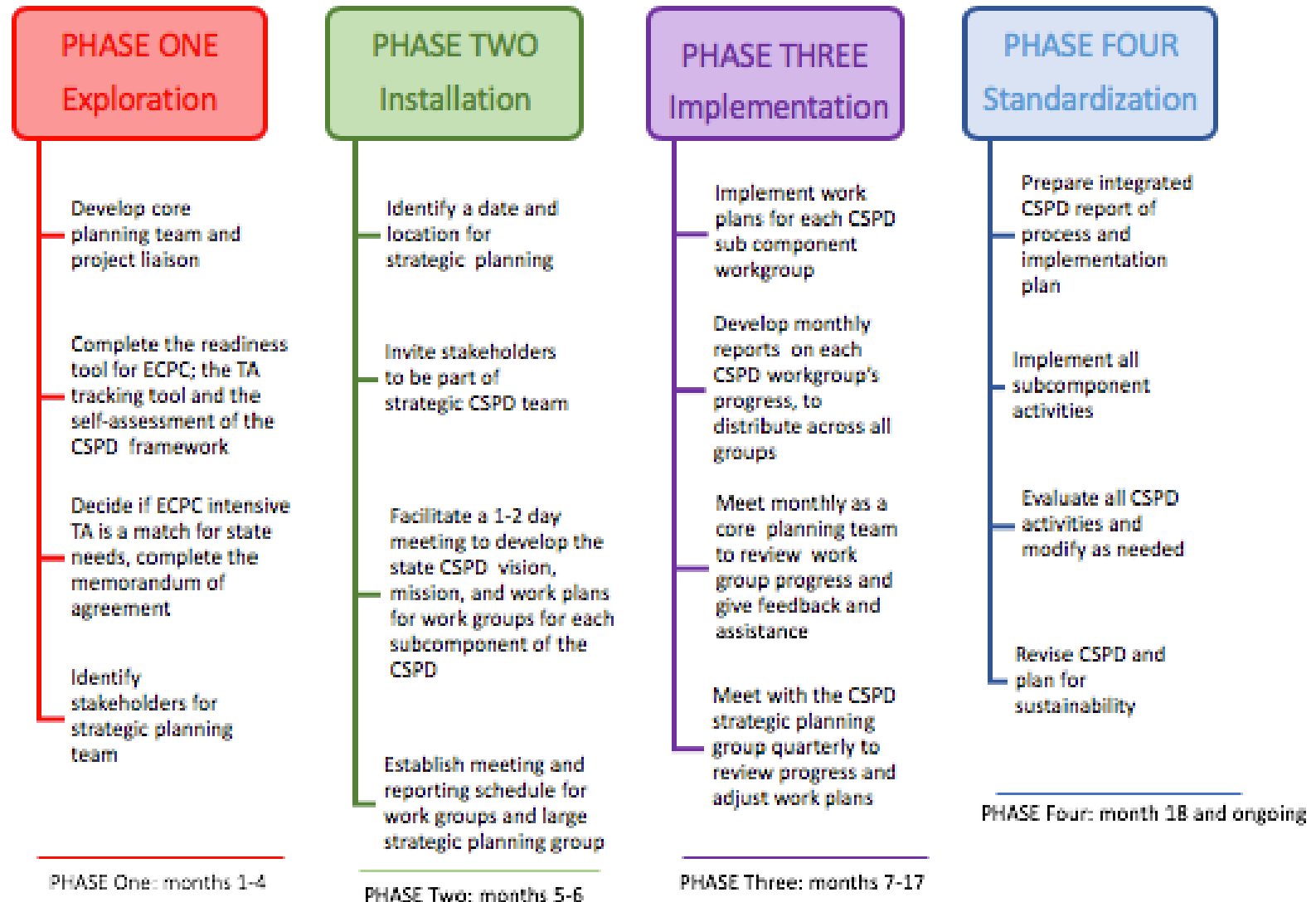
CSPD State Teams

- Part C & Part B/619 Coordinators
- Families
- Higher Ed Faculty/UCEDD Staff
- Early Childhood Representative

Comprehensive System of Personnel Development (CSPD)



ECPC Implementation Stages



WORKING HARD
FOR SOMETHING WE
DONT CARE ABOUT
IS CALLED STRESS.
WORKING HARD FOR
SOMETHING WE LOVE
IS CALLED PASSION.



Early Childhood Personnel Center

www.ecpcta.org

Purpose with Passion

HIBRID

UConn

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Early Childhood Intervention Doctoral Consortium



Early Childhood Intervention
Doctoral Consortium

Creating Leaders in Intensive Interventions for Infants, Young Children and Their Families

UCONN

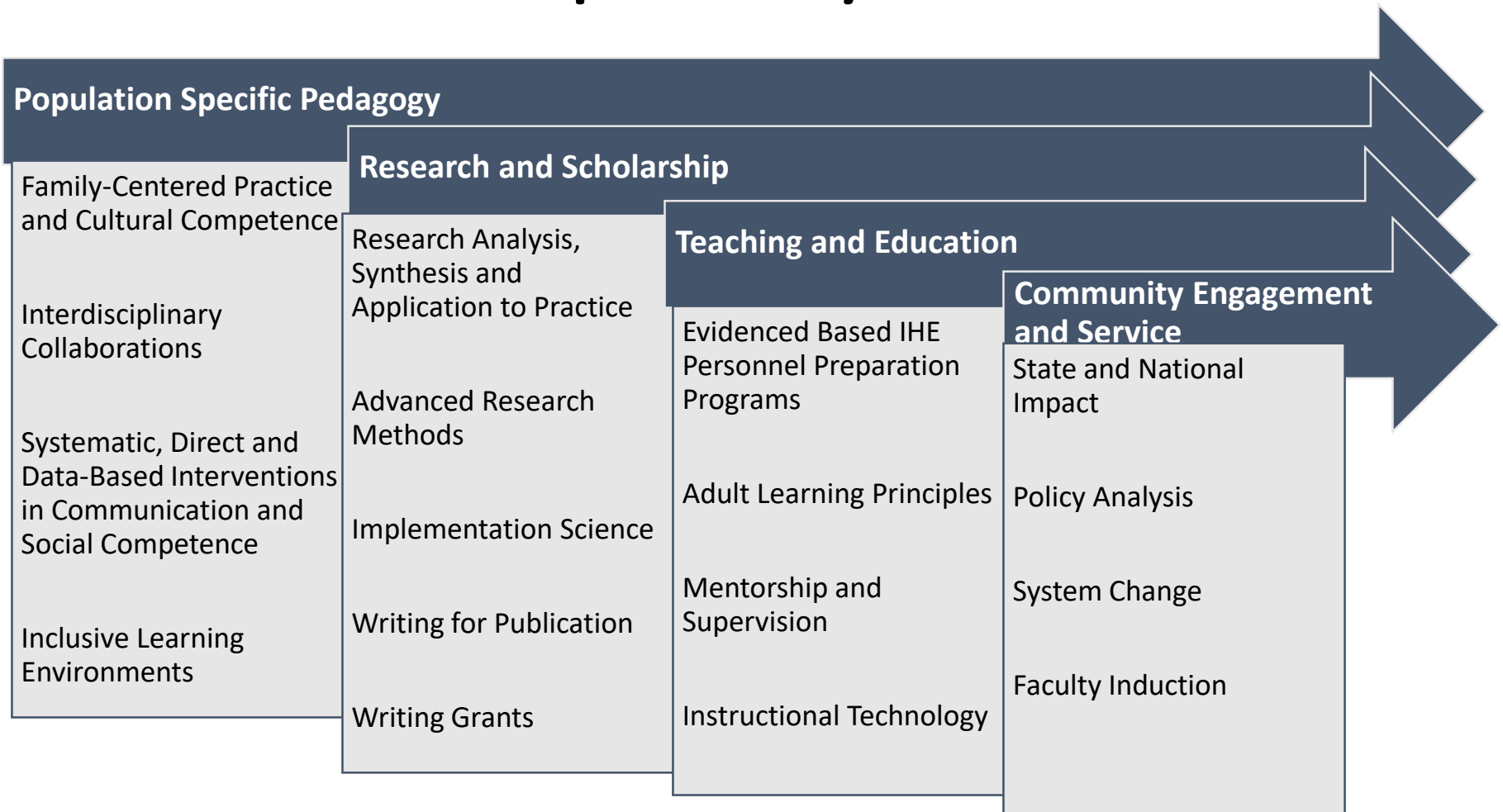
UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Doctoral Consortium Scholars

Scholar Name	University
Renee Mattson	University of Cincinnati
Haley Lantz	University of Cincinnati
Jennifer McGraw	University of Cincinnati
Renee Charlifue-Smith	University of Colorado Denver
Emily Jackson	University of Connecticut
Thomas-Giyer	University of Connecticut
*Lauren Mangold	University of Connecticut
*Toni Lynn Bercha	University of Connecticut
Catherine Citta	University of Georgia
Juliana Hirn	University of Georgia
Jonathan Alexander	University of Hawaii
La Sonya "Sunny" McCain	University of Hawaii
Nikki Donnelly	University of Illinois
Crystal Williams	University of Illinois
Suzanne Powers	University of North Carolina at Chapel Hill
Kathryn Bailey	Vanderbilt University
Brittany Bennett	Vanderbilt University
Mischa McManus	University of Washington
Molly Poole	University of Washington

17 Confirmed Students (*2 Potential Students)

Competency Areas



Curriculum Overview



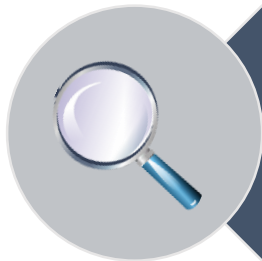
Credits

- 0-3 credits
- Content will be adapted to suit number of credits (increasing in rigor through readings, sessions, and assignments)



Format

- Online
- Modelled after CEEDAR and will be open access



Modules

- Two modules per semester
- Combination of guest speakers, discussion, case studies, and activities

Year 1

Semester
1

- Etiology
- Family Centered Practice

Semester
2

- Data Based Instruction
- Assistive and Instructional Technology

Early Intervention Specialist Program (EISP) 2015-2020

UCONN

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Early Intervention Specialist Program (EISP) 2015-2020

- The EISP credential is a **year-long non-degree program**. Consists of three courses: **Family Centered Practices, Evaluation & Assessment, and Intervention Strategies**
- Designed to **enhance the knowledge and skills** of early interventionists serving infants and toddlers with disabilities and their families.
- Target audience is **early intervention providers**
- **54 early interventionists** have completed the program so far. **21 more** are halfway through the program and scheduled to finish in December.

School-Aged, Transition, and Adult Project Updates

UCONN

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

School-Aged, Transition, and Adult Project Updates

- 1) Completion of DDN Customized Employment Initiative
- 2) TA to People First of CT
- 3) Thinking College
- 4) Charting the LifeCourse

1) Completion of DDN Customized Employment Initiative

- Federal Workforce Innovations and Opportunities Act of 2014
- DD Network Initiative w/CT DDC and DRCT
- Marc Gold & Associates Trainings

Training Topics	Cohort 1	Cohort 2	Cohort 3
Discovery	February 2-13, 2017	January 18-19, 2018	Sept. 26-28, 2018
Job Development	May 10-12, 2017	June 20-22, 2018	March 27-29, 2019
Systematic Instruction	August 2-4, 2017	Dec. 5-7, 2018	May 29-31, 2019

DDN Customized Employment Initiative (cont.)

- Retreat March 2018 to identify adjustments
- Over 150 trainees

• Numbers MG&A* certified	<u>Individuals</u>	<u>Agencies</u>
– Discovery	13	7
– Job Development	9	5
– Systematic Instruction	3	2
– All three		2

- Staff of addition 13 agencies ACRE certified

* Additional 20 hours competency-based fieldwork

DDN Customized Employment Initiative (cont.)

- 26 individuals placed in CE as of Summer 2019

New Project

- Drafted curriculum for collaborative endeavor
 - BRS, DDS, CREC
 - Was to be implemented 2/2020
 - On hold due to administrative issues/COVID-19
- Community-Based Transition Partnership grant

2) TA to People First of CT

- What is *People First*?
 - National self-advocacy movement
 - CT self-advocacy organization since 1983
 - Joined with SABE
 - Now active member of SARTAC
 - CT coordinating with CT KASA

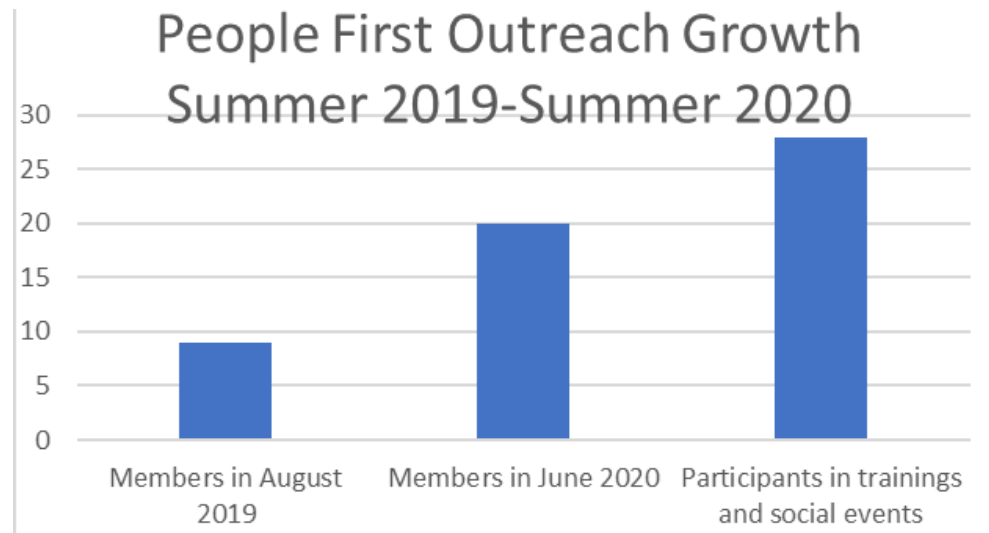


TA to People First of CT (cont.)

- Organizational changes to resuscitate
- Zoom meetings/trainings
- Joined National Inclusion Project (formerly “Spread the Word to End the Word”)
- New website <https://peoplefirstofct.weebly.com/> and updated Facebook page
- Weekly social and networking opportunities
- Video Things to Know about COVID-19
https://www.youtube.com/watch?v=8s_Evfcvfi0

TA to People First of CT (cont.)

- New video “You say we have these rights but...”
- New video “Dear Parents: See ME, Relax, It’s OK!”
- Increased membership



3) Thinking College

- 2016 Needs Assessment
- 2017 Awarded Mini-grant for Capacity Building
- 2018 CT Think College Statewide Collaborative
 - Developed Strategic Plan
 - DD Network outreach
- 2019 TA to Goodwin University
 - CTP Application success!
 - Weekly meetings to coordinate
 - BRS and DDS collaborating with GU

Thinking College (cont.)

- Goodwin University affected by COVID-19



Craig Drezek, 1971-2020

Superintendent of Goodwin University Magnet Schools and Dean of Early College Programs and Educational Partnerships

“Drezek Certificate in Occupational and Life Skills”

UConn

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Thinking College (cont.)

- Conducted 3 family trainings “Thinking College”
 - May 7 $n=3$ Pre/Post ↑ 28%
 - May 21 $n=7$ Pre/Post ↑ 46%
 - June 10 $n=8$ Pre/Post ↑ 17%
 - Qualitative feedback:
 - “...amazing resource...” “...very helpful”
 - “The idea that college is accessible to my son if he wants to attend”
 - “There's more opportunity for my daughter than I'd thought”

Thinking College (cont.)

- Currently writing TPSID grant due 7/10/20
 - “Hub & Spokes” model for Consortium
 - Implementation of Strategic Plan
 - Support to Goodwin University
 - Expansion to other 2-year CC’s, 4-year public and private TBD

4) Charting the LifeCourse (UMKC)

- CT LifeCourse Ambassador/CT CoP
- Person-centered planning system integrated into:
 - Transition trainings for families (since 2016)
 - Thinking College projects
- Online course drafted (under development soon!)
- Presentation accepted for National Showcase in April
 - Filmed brief version on 6/12/20
 - Will be on 7/20/20 national panel

NIRS Data

Using the 4-point scale of Training Evaluations

<i>Range of average satisfaction ratings</i>	<i>Overall</i>
• Spring 2019 3.61 – 3.84	3.65
• Fall 2019 3.76 – 3.95	3.83
• Winter 2020 3.76 – 3.91	3.88

Pre-/Post-Assessment results

	<i>Pre-</i>	<i>Post-1</i>	<i>Post-2</i>
• Spring 2019	55%	90%	94%
• Fall 2019	64%	74%	76%
• Winter 2020	72%	66%*	71%

Follow-up to Action Plans 11/19-2/20

*n** #/% reporting
 implementation

Participants reached 9/35 7/9 (77%)**

* Number interviewed

** Circumstances changed for foster parents, “no thank you”

Example of Positive Transition Changes Reported from Action Plan Implementation

- Inclusion in school productions (> social connections)
- Inclusion in college sports ($n = 2$)
- Access to Assistive Technology
- Successful transition to adult health care
- Allowed more independence by parents (DoR)
- Work experiences instead of summer school

Examples (cont.)

- Access to Ticket to Work and a job
- Changed adult service provider (>strengths-based)
- Self-Advocacy (“I want to work for you but I can’t do math so I can’t work on the register but I’ll do anything else”)
- Adult funding became self-directed
- Sought TA from UCEDD re: how to increase success in teaching ADLs at home

Health Care Promotion

UCONN

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Highlights & Updates

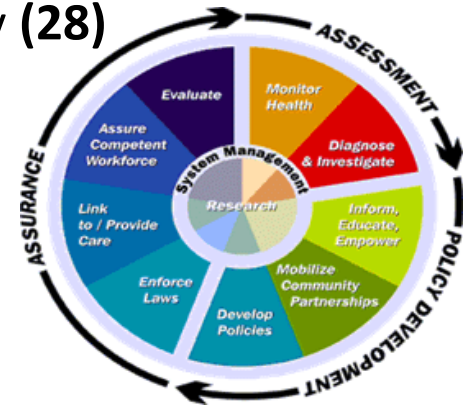
1. Certificate of Interdisciplinary Disability Studies in Public Health
2. COVID-19 survey
3. Medical student elective

Certificate in Interdisciplinary Disability Studies in Public Health

4 courses

- PUBH 5501: Foundations of Public Health and Disability **(115)**
- PUBH 5502: Epidemiology of Disability **(39)**
- PUBH 5503: Disability Law, Policy, Ethics, & Advocacy **(40)**
- PUBH 5504: Public Health Interventions in Disability **(28)**

Total: 222



<https://ph.disability.certificate.uconn.edu/>

<https://www.cdc.gov/stltpublichealth/publichealthservices/essentialhealthservices.html>

UConn

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Who are the Students?

- Public health
- Audiology
- Social work
- Speech, language, & hearing
- Dentistry (UG, & G)
- Medicine (UG & fellows)
- Special education
- Educational psychology
- Nursing
- Clinical psychology
- Public policy
- Human resources
- Dual degrees
- Biomedical engineering
- Physiology/neurobiology
- Undergraduate
- LEND students

The Knowledge, Attitudes, and Behaviors of Families of Children with Disabilities During COVID-19

- 870 children with disabilities from 608 respondents
 - Special health care need
 - Diagnosed disability

Services	Frequency
EI	137
IEP	513
504	139
Adult services	95

State	Frequency	State	Frequency
Alaska	1 (0.2)	Nevada	2 (0.3)
Arizona	14 (2.3)	New Hampshire	3 (0.5)
Arkansas	1 (0.2)	New Jersey	4 (0.7)
California	11 (1.8)	New Mexico	2 (0.3)
Colorado	46 (7.9)	New York	23 (3.8)
Connecticut	118 (19.4)	North Carolina	10 (1.6)
Florida	14 (2.3)	North Dakota	5 (0.8)
Georgia	40 (6.6)	Ohio	57 (9.4)
Hawaii	38 (6.3)	Oklahoma	1 (0.2)
Illinois	2 (0.3)	Oregon	2 (0.3)
Indiana	9 (1.5)	Pennsylvania	8 (1.3)
Iowa	23 (3.8)	South Carolina	4 (0.7)
Kansas	4 (0.7)	South Dakota	1 (0.2)
Kentucky	13 (2.1)	Tennessee	3 (0.5)
Louisiana	13 (2.2)	Texas	11 (1.8)
Maine	10 (1.6)	Utah	3 (0.5)
Maryland	4 (0.7)	Vermont	5 (0.8)
Massachusetts	12 (2.0)	Virginia	6 (1.0)
Michigan	3 (0.5)	Washington	18 (3.0)
Minnesota	22 (3.6)	West Virginia	1 (0.2)
Mississippi	1 (0.2)	Washington, DC	7 (1.2)
Missouri	7 (1.2)	American Samoa	3 (0.5)
Montana	6 (1.0)	Wisconsin	4 (0.7)
Nebraska	10 (1.6)	Wyoming	1 (0.2)
		U.S. Virgin Islands	1 (0.2)

What are the 2 Most Concrete Needs for Your Family Right Now?

Rank	Need
1	School/special education/early intervention (access to, support, related services)
2	Health
2	Food/water (access to, having enough)
3	Routine/structure/schedule/stability
4	Safety
5	COVID-19 related (access to information, testing, concerns for future directly related to virus)
6	Socialization/social opportunities/social supports for child (unless family or other person specified, assumed for child)
7	Job/employment for respondent
8	Mental health/emotional support/counseling

Preliminary Results Highlights I

What issues have your family faced during the crisis?

1. Not able to visit or support older relatives and friends
2. Concern about physical health, mental health, and well-being of family and self
3. Loss of income
4. Loss of job

Preliminary Results Highlights II

Where do you get your information about coronavirus?

1. TV
2. Newspapers/news apps
3. Facebook
4. Health provider/hospital
5. Family

Medical Student Elective

Caring for Children with Disabilities: The Medical Home

- Instructors: Dr. Anton Alerte, Dr. Tara Lutz
- Guest instructors:
 - Emily Ball
 - Julie Ball
 - Chris Ball
 - Tom Cosker
 - Heather Alerte
 - Dr. Rob Keder

Course Highlights

- Offered 4 times since April 2020
- 12 students, 3rd or 4th year

Topics:

1. Medical home
2. Part C & Part B of IDEA
3. Role of physician/pediatrician
4. Resources

Course Evaluation

- There are many resources available for children with disabilities and their families. As pediatricians we need to learn how to support our patients/ their families in the way that they need and how to navigate the many resources available to match their specific needs.
- How interconnected all the professionals in a child with disabilities life are. And how each person plays such an important role in a child's success.

Emergency Preparedness

UCONN

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Tips for Emergency Personnel

- Funded through a grant from the CT Council on Developmental Disabilities
- The Flip Book is designed to be kept in emergency vehicles to assist EMS when on a call with a person with a disability.
- Over 1000 of these were disseminated and have continued to be in demand since first published in 2016.

A Communication Aid for Emergency Personnel

- In March 2019, as part of legislative training for LEND students, a group of four audiology students determined that the Tips for Emergency Personnel needed information about effective communication with persons with disabilities.
- As part of their training during our legislative training, they met with Rep. Liz Lenehan at a mock legislative meeting.
- They proposed legislation that would mandate that these booklets be on every EMS vehicle, and that they include a component on effective communication
- Rep. Lenehan was very supportive of this, and pursued passage of a bill mandating the communication aid.

Legislation Passed: PA 19-147

- Effective July 1, 2019
- Expands first responders' access to training on handling incidents involving children and adults with disabilities
- Requires the UCEDD to develop and publish on its website a communication aid for certain first responders to use to communicate with individuals with disabilities.
- The LEND students and UCEDD staff were in attendance at the bill signing.
- A GREAT LEADERSHIP LESSON!!!

Use of the Booklet During COVID 19

- In March, during a national AUCD call with Directors and Associate Directors, we were encouraged to reach out and ensure adequate supports to first responders in addressing the needs of people with disabilities during COVID 19.
- The booklets had just been printed and had arrived in early March, just before the office staff were sent to work from home.
- Staff worked through a weekend to assemble, address, stuff and send the booklets. Five were sent to the emergency medical managers in each of our 169 towns, and emails were sent notifying them that they would receive these.

Christopher Blake

SARTAC Fellow

UCONN

UNIVERSITY CENTER FOR
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

SARTAC: Self Advocate Resource and Technical Assistance Center

- SARTAC offered six Fellowships nationally to self advocates who had a project they would like to pursue. Each fellow is awarded \$5000.
- Over 40 applications were received.
- Chris Blake, from CT was one of the six selected, and is working with staff from his host agency, the UCEDD, to develop resources and training specific to the ABLÉ accounts.
- These materials will be in plain language and will clarify the process of opening an account for people with disabilities.
- The fellowship will conclude in February 2021.

Cross Disability Lifespan Alliance

- Funded by the Council on Developmental Disabilities, The UCEDD, Disability Rights CT, and the State Independent Living Council.
- Membership includes agencies, advocates and parents.
- There are currently over 200 individuals and agencies on our list.
- Participation on calls has dramatically increased with the advent of ZOOM meetings.
- 50 to 60 participants attend meetings, held every other month.

Alliance Activities

- Alliance activities are coordinated by one person, who works six hours a week. Steering committee meetings are held monthly with ten leaders from the alliance, who assist the coordinator.
- The Alliance holds Friday legislative/issues calls to discuss pressing current concerns/actions.
- The Alliance hosted COVID Conversations through April and May to provide some additional support to individuals experiencing isolation during COVID 19 quarantine.
- The Alliance has an active Voting committee working to ensure access to voting opportunities for all individuals.

Candidates Forum

- During Congressional election years (2014, 2016, 2018, 2020) the Alliance has held highly successful Candidates forums.
- Over 450 attended the last forum in 2018
- These are non-partisan forums, and every effort is made to have representation of ALL candidates for selected state offices (Governor, Lt. Governor, Secretary of State) as well as representatives of presidential candidates, candidates for Congressional seats and Senate.
- This year, the forum will be virtual and will be held on October 7.