University of Connecticut
Center for Excellence in Developmental Disabilities
Consumer Advisory Council
January 31, 2023

<u>Meeting Minutes</u>

The meeting began via Zoom at 9:30am.

<u>In Attendance:</u>
See introductions below

<u>Welcome and Purpose of Meeting – Mary Beth Bruder</u>
The next UCEDD grant is due February 28th. The purpose of today is to have a strategic planning meeting to plan for the next 5 years of the Connecticut UCEDD.

Molly Cole announced that we lost one of the co-chairs of our advisory board, Keith Mullinar, who was instrumental in helping on the last strategic plan for UCEDD. Keith came into the disability world life late in life and immersed himself in the work. His passion was medical education and accessible medical equipment. Fun fact: made boomerangs. He was passionate about his work. When we moved our office to a non handicapped accessible space, Keith went to the Dean's Office and made a powerful statement regarding this. A moment of silence was taken in Keith's honor.

<u>Review of Agenda, Introductions and Updates - Diana LaRocco</u>
Diana reviewed the agenda—updates, strategic planning process, needs assessment (current status and future needs) broken down into healthcare promotion, education and early childhood intervention. She explained that later on they will break out into groups to discuss what other needs does the state have and what are some activities we should do in each area.

Diana requested each person introduce themselves:
Emily Ball – PATH CT, Youth Outreach Coordinator Patch CT, self-advocate
Allan Bergman – suburban Chicago, high impact-based consulting, parent of a child with
     disabilities
Scott Brown – Professor Emeritus
Karen Carney – Parent of a 21-year-old son who will be aging out of transition academy
Molly Cole – Executive Director, CT State Independent Living Council
Tom Cosker – Disability ACT, parent of a child with disabilities
Nicole Cossette – Office of Early Childhood, Part C Coordinator
Vanessa Diaz Valencia – Hartford Public Schools, three boys, youngest child received an autism
     spectrum diagnosis last month
Peter Deckers – Surgeon, retired, former dean of the School of Medicine at UConn, parent
     of a child with disabilities
Walter Glomb – CT Council on Developmental Disabilities, parent of a child with disabilities

Darla Gundler – Early Childhood Intervention Personnel Development - Equity Center

Bryan Klimkiewicz – CT State Department of Education, Special Education Director

Nanfi Lubogo – Co-Executive Director, PATH CT – family support organization; President, Board of Directors of Family Voices; working on the new equity center with Mary Beth and Darla, parent of a child with disabilities

Quiana Mayo – parent and self-advocate, Co-Chair, Proud Parents which is a non-profit organization that advocates for parents living with disabilities and also with children with disabilities

Kim Mearman – Assistant Director of Student Services, CREC, Transition Academy, parent of a child with disabilities

Stephen Morris – Executive Director, ARC FAVRAH,

Regina Owusu – Dept of Public Health, Program Director of Healthy Start

Allyson Powell – UConn Health, Program Direction for Adoption Assistance Program and Program Manager of the Employee Assistance Program

Linda Rammler – DD Network Coordinator working on transition and employment related types of issues, developing products and training, provides individual TA, parent of a child with disabilities

Brian Reichow – Associate Director for Research at UCEDD

Deb Richards – semi-retired from CREC and State Dept. of Education

Ann Smith – Executive Director, African Caribbean American Parents of Children with Disabilities (AFCAMP)

Cristina Wilson –Associate Professor in School of Social Work

Updates from Partners

Molly Cole –CT State Independent Living Council (SILC) – The SILC is the policy advocacy branch of our independent living system in the state, there are 5 centers for independent living. Centers are predominantly staffed with people with disabilities who have lived the experience, being independent in the community. Services provided at no cost. Focus this year is on emergency preparedness and insuring we are adequately prepared for emergencies w/ people with disabilities. Looking at reviving efforts to close Southbury Training School, will try to do it again. A lot of policy work in healthcare and access to healthcare. Hosted a Candidates' Forum in the fall, all but three of the 28 candidates were there to answer questions about disability policy. SILC will also be expanding their efforts to look at supported decision making this year.

Tom Cosker – Disability Rights Connecticut (DRC) – DRC is about 5 years old and replaced the old Office of Protection and Advocacy agency in the state. The focus on protecting the legal and civil rights of people with disabilities in Connecticut. Education work on projects of inclusion of students with disabilities (least restrictive environment), transition (high school and academy). Systemic work with State Department of Education and DDS. Working on employment to reduce segregated employment for those with disabilities. They are running a special education clinic this school year providing some individual assistance.

Walt Glomb – CT Council on Developmental Disabilities - 20 projects in play right now – State plan activities revolve around assistive technology, self-advocacy, access to health care. In addition to the state plan activities, we are the leader of community practice for bridging aging and disability services within Connecticut (one of 5 states in the nation chosen to launch that

initiative nationally), developing training for community health workers in how to accommodate people with developmental disabilities, more vaccine money from the CDC, part of the BRS initiative to develop pathways to competitive integrated employment. Legislative agenda, six items on the agenda 1) housing; 2) healthcare access; 3) eligibility; 4) protecting voting rights; 5) workforce development; 6) quality of information and rights for parents

Overview of the UCEED and Strategic Planning Process Break – Mary Beth Bruder (PowerPoint Presentation attached)
History of UCEDD – President Kennedy, started panel on Mental Retardation, entities to address critical shortages of personnel, need to research and statistical data, numerous government agencies, lack of coordination.

Mary Beth gave a short history of the UCEDDs. The DD Act defines UCEDDs as interdisciplinary education, research and public service units of universities, that implement the four core functions addressing, directly or indirectly, one or more of the areas of emphasis.

The four core functions of the UCEDD are: Interdisciplinary Training, Research, Dissemination and Community Service. Our four emphasis areas are Early Childhood Intervention Systems, Inclusive Schools and Post-Secondary Options, Health Care Promotion, and Leadership and Community Supports.

CT UCEDD Key Personnel is currently looking for three positions to be filled: Director of Training, Director of TA/Model Demonstration, and Dissemination Coordinator

Proposed Areas of Emphasis for next 5 years are two: Early Childhood intervention and education, and Healthcare.

Needs Assessment: Current Status – Allan Bergman (PowerPoint Presentation attached)
- Core values, outcomes, and guiding principles within all disability federal legislation today.
- ADA Findings P.L101-36; 1990 – reason why laws are passed.
- Goals of the Americans w/ Disability Act of 1990 – equality, full participation, independent living, economic self-sufficiency goals for those will disabilities.
- Individual with Disabilities Education Act – 1990 – all children with disabilities, prepare them for further education, employment, and independent living.
- Finding from Congress 2004 – impeded by low expectations and an insufficient focus on applying replicable research proven
- IDEA Findings – high expectations, challenging expectations that have been established for all children; - parents still being told what their children cannot do
- Transition – transition is a journey NOT a place or program
- #1 Factor Predicting Post School Career, work experience during school – youth empowerment, family involvement and supports, academic preparation paired with work experience, connections to ancillary services.
- Expectations Matter – parental and teacher expectations, inclusion, relationships, and location.

- Employment First – Employment is needed and essential to human happiness.
- Adapting to the New Normal – need accountability, measurement, equity in resource allocation.
- Longer Lifespans for individuals with disabilities – living a good life and longer life, but still dependent on the system.
- Current Policies are not fiscally sustainable – have to change the disability policy in this country; need a new paradigm and start moving toward.
- Poverty by the Numbers – this number has gone up every year
- National Data – ID 1 out of 6 children fully included
- Connecticut Racial and Ethnic Demographics – stigma is alive and well

<u>Future Needs:</u>
Molly Cole & Peter Deckers – <u>Health Care Needs</u> – Lack of access to healthcare including specialty care. Biggest issues are lack of providers from diverse backgrounds, bus routes/public transportation, access, and lack to funding Husky C for elderly and disabled who are not working. Accessible (attitudinal) Community based healthcare and accessible (MDE) health care offices. Peter stated one of the biggest issues with his disabled son is what is going to happen to him when they are gone. His son, Michael, is a volunteer at the UCEED office which is an enormous opportunity for him & pure growth for him. Most medical school curriculum do not teach about disability and the care of long-term treatment of disabled patients.

Deb Richards & Linda Rammler – <u>Education Needs</u> – Deb discussed that schools need more qualified and diverse staff (administrators, special ed teachers) and they must be able to retain the current staff that they have. There is a statewide initiative that was a program started at CREC to diversify our teaching force by allowing paraeducators or associate instructors to spend a year taking coursework and working side by side with a teacher and they will become a certified educator in the end. The state is working on a new statewide IEP data system which will provide access to data and high-quality IEP's. This has been somewhat controversial but long-term it will allow compliance within the requirements of IDEA and to have a system that will have standards-based outcomes being measured with data.

Linda spoke about transition from school days to adult life, explained the "charting the life" course which is evidence based and compiles information in one place. This is totally strength based to look at the positives so you can build on the strengths of that individual, allows to have a vision for the future for individuals with disabilities. Life course planning takes all the information and helps families make decisions. Parents will see positive visions for their children at an early age. Think College does wonders for individuals, but we don't have a Think College model in Connecticut yet. We do have a "how to book" that we used but we need to have everyone wo wants to go to college be able to attend college. Work experience needs to be available with real jobs for real pay before they age out of the system. Need to be training and engaging families.

Darla Gundler – <u>Early Childhood Intervention Needs</u> - Need diverse and well-trained staff; equitable and accessible intervention systems in classroom and community inclusion, not just focus on if they are included in the classroom but also included in the community as well; family involvement and participation; engage families in expecting equity—do the staff look like the

families that are receiving the services; non-exclusion discipline practices; collaborative early childhood programs, we need to make sure these programs are working together and not against each other.

Breakout Groups to answer the following questions (a notetaker was assigned. Below are their responses to the questions)
1) **What other needs does the state have?**
2) **What are some activities we should do in each area?**

Three group topics – Healthcare, Education School Age or Early Childhood

Healthcare – Nanfi Lubogo, Molly Cole, Diana LaRocco, Peter Decker–

What other needs does the state have?
Looking diversity and equity around the states:
- Access to funding is hard for small non-profits at grassroots who do not have capacity to compete with larger orgs and state agencies
- Value based models need to expand to include access to community-based orgs. (CBO's) *We believe that building the capacity of local/grassroots orgs is the stepping-stone to diversifying the workforce. Grass-roots orgs are trusted messengers in their communities and can help with recruitment and retention and continuous support of the workforce. *

What are some activities we should do in each area?
- Collaborative efforts with state agencies across early childhood and healthcare that would help to build the capacity of CBO's to be able to compete for funding
- Training of healthcare/allied health personnel, with emphasis of recruitment from diverse personnel
- Integrating into primary care training about people with disabilities for 1/ 2nd year medical and allied health students.
  *Primary care should be for everyone; we cannot exclude one population just because people are afraid of them. *

Early Childhood Intervention –Vanessa Diaz-Valencia, Darla Gundler, Cristina Wilson, Brian Reichow, Ann Smith

What other needs does the state have that we did not bring up? What other collaborative activities in each area (funding, partnerships) should happen?
- Transitioning from B3 and PreK…improve communication to parents on what their options are and to do that as early as possible and as clearly as possible…legislature often times makes it difficult to collaborate.
- Workforce related- Ongoing professional development, 27% of the people surveyed said they attended 1-5 hours of PD over the last 12 months (diversification of the work force), how do we ensure that people have the understanding and knowledge.
- Compensation of Early Childcare Providers needs to be considered, providers have gone out of business due to the pandemic

- Large Latino population in Hartford and how are we making sure we understand the cultural context and the representation that reflects our community
- Multi-generational homes how are we deeply understanding the culture in settings

Common thread in the conversation is the diversification of the work force in order to address the above…. cultural competency training

Education School Age (Group 1) - Deb Richards, Kim Mearman, Scott Brown, Tom Cosker

What other needs does the state have?
- Exclusionary discipline practices – restraint/seclusion, suspension/expulsion – segregated environments
- Need staff and parent training – outreach education to general and special education
- Higher Ed – Ed Psych – counselors not well prepared
- Need education for staff and parents – on the job training
- Also need training for nurses – small number of Drs – front line is nurses
- Some found online learning better – had parents and kids together
- Transition – now well equipped for adult life
- Adult services not comprehensive – schools don't know that – think it is not their job
- Underserved kids at age 14 – people don't understand why transition is important at earlier years
- Pressure on students for credit and nothing else
- We have student success plans for all kids – how about kids with disabilities – if they were really being used – good idea if worked – add addendum for SWD
- Need preservice training
- Need training for ed leaders – superintendents, principals, business managers
- Often counselors start college planning in 9, 10 grade with course work – what about SWD?
- SWD could benefit from volunteering

Education School Age (Group 2) – Bryan Klimkiewicz, Emily Ball, Linda Rammler

What other needs does the state have?
Resources and Dissemination of Information
- Getting information to teachers/parents about strength-based services and possibilities (positivity) and students.
    - High Expectations
    - Personal Strengths – Opportunities
- Assistive Technology
    - Use of technology in schools
    - Access to technology during class-time (differentiated practices across schools and districts)
- Universal Design Learning

Structures to support Collaborative Process
- Student Led PPT Meetings

Independent Living Skills:
- Adult Money Management – Understand Smart (Financial Skills)
  - Curriculum Design
  - Online program for families

Post-Secondary Education:
- inclusive college settings

Employment
- Customized and Customizing Employment

Revisit, Revise the Vision/Mission Statement

Mary Beth Bruder covered the next steps. She broke down the emphasis areas for the UCEDD into four possible goals – Health Care, Early Childhood, Schools (early childhood and schools may be combined into one), and Management.

Within the four goals we need to build objectives in core areas:
- Interdisciplinary Preservice
  - Continuing Education
- Research and Evaluation
- TA/Model Demonstration
- Dissemination

We are looking for faculty to live on soft money, open positions:
- Director of Training
- Director of TA / Model Demonstration
- Dissemination Coordinator

The current vision and mission of the center needs to be looked at to make sure that we are not missing things such as equity and to make sure diversity is represented in everything we do.

The next CAC meeting will be February 23, 2023, 10am-12pm
Zoom Link: https://uconn-edu.zoom.us/j/96583685823?pwd=ZjFPVmJTLzRIVVJCYVJJU2RPamxSQT09
Meeting ID: 965 8368 5823
Passcode: 1234

Meeting adjourned at 12:35pm

Submitted by: Judith Curry

Amended: 2/17/2023

A.J. Pappanikou University of CT
Center of Excellence in Developmental Disabilities
Education, Research and Service

Consumer Advisory Council
Strategic Planning Meeting

January 31, 2022

TIME	ITEM	PRESENTER
9:30 am	Welcome and Purpose of Meeting	Mary Beth Bruder
9:40 am	Review of Agenda, Introductions and Updates	Diana LaRocco
10:00 am	Updates from DD Partners': Council, DRC, SILC	Walt Glomb, Tom Cosker, Molly Cole
10:15 am	Overview of the UCEDD and the Strategic Planning Process	Mary Beth Bruder
10:30 am	Break	
10:35 am	Needs Assessment: Current Status	Allan Bergman
11:05 am	Future Needs:	
	Health Care Promotion	Molly Cole
		Peter Deckers
	Education	Deb Richards
		Linda Rammler
	Early Childhood Intervention	Darla Gundler
11:30 am	Break	
11:35 pm	Breakout Groups	Allan Bergman
	1. What other needs does the state have?	
	2. What are some activities we should do in each area?	
11:55 pm	Discussions from Breakout Groups	Allan Bergman
12:10 pm	Revisit, Revise the Vision/Mission Statement	Mary Beth Bruder
12:25 pm	Next Steps and Adjourn	Mary Beth Bruder

History of UCEDDs:
originated from John F. Kennedy's Panel on Mental Retardation, which called for entities to address:

- Critical shortages of personnel

- Need for research & statistical data

- Numerous governmental agencies

- Lack of coordination

The Developmental Disabilities Assistance and Bill of Rights Act defines disability as:

a substantial developmental delay or specific

congenital or acquired condition,

with a high probability of resulting in

developmental disabilities

if services are not provided

Developmental Disabilities

are a group of conditions

due to an **impairment in**

physical, learning, language,

or behavior areas.

DD Act Regulates DD Network

- UCEDD

- Developmental Disabilities Council

- Disability Rights CT (Protection and Advocacy Agency)

The DD Act directs the DD Network Partners to collectively promote Community Integration.

This toolkit highlights the UCEDDs role and identifies the possibilities for collaboration around this activity.

UCEDDs
University Centers for Excellence in Developmental Disabilities

1 or more in every US state

Provide interdisciplinary pre-service preparation

Perform community services and training

Conduct research, evaluations, and information dissemination

DD Council
Developmental Disabilities Council

1 in every US state and territory

Understanding system barriers and changing them through initiatives

Working with stakeholders to achieve enduring change

Empowering advocates

Annual Average Populations of Large State 10/00 facilities, 1960 -2010

275,000
250,000
225,000
200,000
175,000
150,000
125,000
100,000
75,000
50,000
25,000

1960 1965 1970 1975 1980 1985 1990 1995 2000 2005 2010

P&As
Protection & Advocacy

1 in every US state and territory
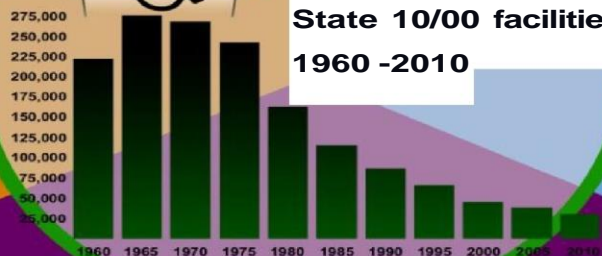
Monitor and investigate conditions in facilities that care for people with disabilities

Provide legal representation to people with disabilities

Ensure equal access to life in the community

The DD Act defines UCEDDs as:

interdisciplinary education, research and public service units of universities, that implement the four core functions addressing, directly or indirectly, one or more of the areas of emphasis:

- quality assurance,

- education and early intervention,

- child care,

- health,

- employment,

- housing,

- transportation,

- recreation and other services available or offered to individuals in a community,

- including formal and informal community supports, that affect their quality of life) [Section 153(a)(1)].

UCEDDs: Connecting Research to Practice

A Knowledge Broker

Between the

University and Community

The Core Functions are the building blocks of the UCEDD

Interdisciplinary Training

Community Service

Impact on People with DD

Research

Dissemination
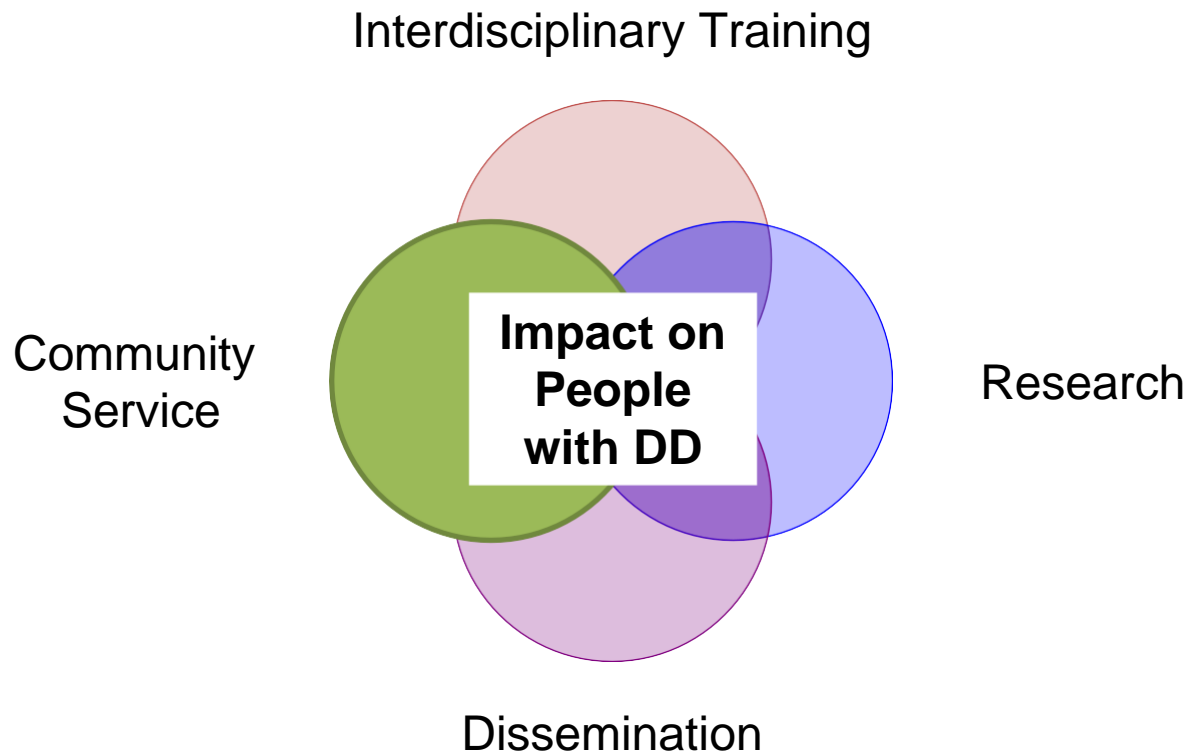
(A) to provide interdisciplinary pre-service preparation and continuing education of students and fellows,

which may include the preparation and continuing education of **leadership, direct service, clinical, or other personnel** to strengthen and increase the capacity of States and communities to achieve the purpose of this title;

(B) to provide community services

(i)   that provide training and technical assistance for **individuals with developmental disabilities, their families, professionals, paraprofessionals, policymakers, students, and other members of the community;** and

(ii)   that may provide services, supports, and assistance for the persons described in clause (i)

(iii)   through demonstration and model activities;

(C) to conduct research,

which may include **basic or applied research, evaluation, and the analysis of public policy** in areas that affect or could affect, either positively or negatively, individuals with developmental disabilities and their families;

(D) to disseminate information

related to activities undertaken to address the purpose of this title, especially dissemination of information **that demonstrates that the network authorized under this subtitle is a national and international resource** that includes **specific substantive areas of expertise that may be accessed and applied in diverse settings and circumstances;**

Goals and Objectives Determined by Statutory Regulations (DD Act)

- Statewide Strategic Planning Led by the Consumer Advisory Council

- 37 members: Majority with disabilities(or having a family member with disabilities); State agency representatives; Advocates; Service Representatives; representing the state's ethnic and racial profile

The CT UCEDD

Campuses of the University of Connecticut

Main Campus: Storrs-Mansfield
Health Center: Farmington
School of Law: Hartford
School of Social Work: West Hartford
Tri-Campus Office: Waterbury
Avery Point - Regional Campus: Groton
Hartford - Regional Campus: West Hartford
Stamford - Regional Campus: Stamford
Torrington - Regional Campus: Torrington
Waterbury - Regional Campus: Waterbury

Location of the Health Center and the A.J. Pappanikou Center for Developmental Disabilities

Location of the UCONN main campus

Locations of the other UCONN campuses

Distance from UCE to the corners of CT

UCONN HEALTH

UNIVERSITY CENTER FOR EXCELLENCE IN DEVELOPMENTAL DISABILITIES

UCONN
CENTER FOR EXCELLENCE
IN DEVELOPMENTAL
DISABILITIES

VISION: Connecticut citizens with disabilities have opportunities and supports that allow them to be valued, fully included, independent, productive, and contributing members of society.

Consumer Advisory Council (CAC)

MISSION: The Connecticut UCEDD will disseminate knowledge and skills by translating evidence-based research into policy, practice, and interdisciplinary learning opportunities.

Developmental Disab ili t ies Network (DDN)

Educatio n

EMPHASIS: The Connecticut UCEDD will address the following areas as listed in the Developmental Disabilities Assistance and Bill of Rights Act of 2000.

Community Services

Research

The Universit y of Con necticut (UConn}

Early Childhood Intervent ion Systems

Inclusive Sc hools and Post-Secondary Opt ion s

Health Care Pr omot ion

Lead ershi p and Communit y Supports

Dissem inat ion

UC□NN
EXCELLENCE IN
DEVELOPMENTAL
DISABILITIES

Areas of Emphasis (DD Act) in Last 5 Years of Uconn UCEDD

- Early Childhood Intervention

- Schools and Post Secondary Education

- Health Promotion

- Leadership

Early Childhood Intervention

- Two Masters Level Programs in ECI

- National Doctoral Consortia

- State Leadership Academy

- National Leadership Academy

- Model Demonstration for Tracking and Screening of Young Children

- Early Childhood Personnel Center

- Early Childhood Intervention Personnel Development Equity Center

Schools and Post Secondary Education

- Masters Program with School Psych
- Thinking College
- Customized Employment
- Adulting Course
- Aspiring Leaders
- Proud Parents

Adulting Series

Topics

- Self-advocacy and self-determination
- How to get to know more people
- Community living
- Adult use of money

- Employment
- Postsecondary education
- Health
- Being a good citizen

- Summer 2020 n=22 Pilot
- Fall 2021   n=20
- Spring 2022   n=9   MTA
- Fall 2022   n=6   STEP
- Winter 2023   n=9   A4A

Health Promotion

- Certificate Program in PH

- Surveys

- Teaching in Medical School

Leadership

- LEND
- Partners in Policy Making
- People First
- Cross Disciplinary Alliance

Preservice Trainees 2022

Preservice by Discipline	#
Audiology	12
Dentistry (pediatric)	1
Early intervention/Early childhood	37
Special education	10
Family/parent/youth advocacy	4
Genetics/genetic counseling	4
Human development/child development	3
Medicine	10
Nursing	1
Occupational Therapy	5
Person with a disability or special health care need	1
Pharmacy	2
Physical Therapy	2
Psychology	7
Public Health	17
Social Work	11
Speech Language Pathology	11
TOTAL	138

CT UCEDD
FY 2022 Funding by Source

Source	Amount
Federal	$7,415,779
State	$637,478
Total	$8,053,257
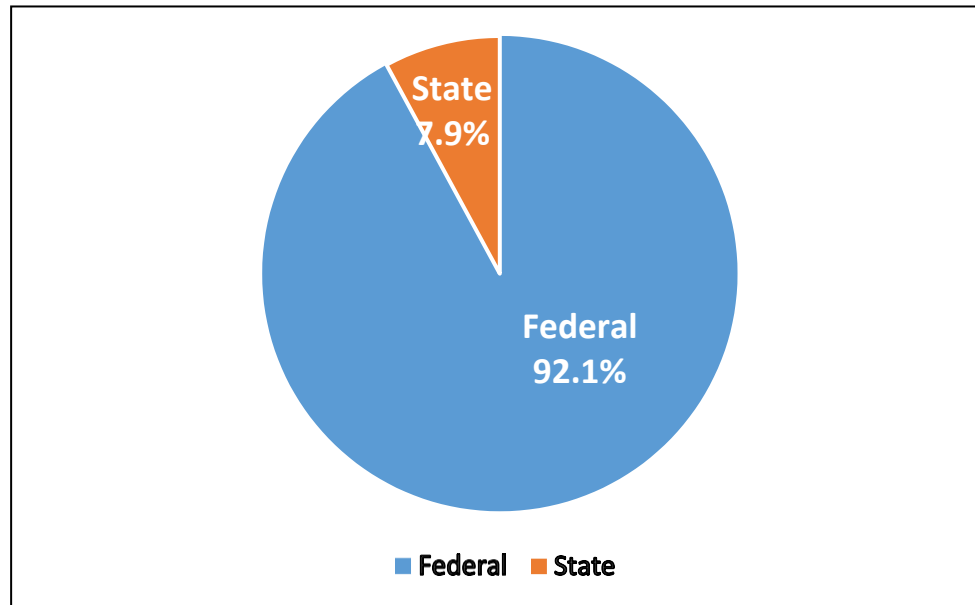
CT UCEDD Key Personnel

- Director: Mary Beth Bruder

- Associate Director: Brian Reichow

- TBH
  - Director of Training
  - Director of TA / Model Demonstration
  - Dissemination Coordinator

Proposed Areas of Emphasis 2023-2028

- Early Childhood Intervention and Education

- Health Care

# Survey on Health Care Access for Adults with Disabilities in CT

Pick all of the below that describe you:

Description of Disability*	%
I am deaf or can't hear very well.	10
I am blind or can't see well even with glasses.	10
It is hard for me to focus, or remember things, or make decisions.	22
It is hard to walk or go up and down stairs.	58
It is hard to get dressed or take a bath or shower.	47
It is hard to do errands like shopping alone.	45
I use a wheelchair, power chair, motorized scooter, walker, cane, or something else to help me get around.	55
I use a device like a phone or tablet or communication or speech device to help me communicate with others.	12
I use American or other type of Sign Language, or pictures to communicate with others.	6

n = 78

Physical Access Barriers to Care

Variable	%
Problems being able to use MDE (equipment or machines) because of special needs	41.0
Felt scared and not safe using MDE such as X-ray machines, MRI machines, CT scan machines, and others	32.1
Problems when asked to use a computer or tablet to talk to a doctor or health care provider instead of seeing them in person	26.9
Not been able to have a test or X-ray image because PWD could not use the available machine	25.6

Level of Knowledge in CT in ECI sample
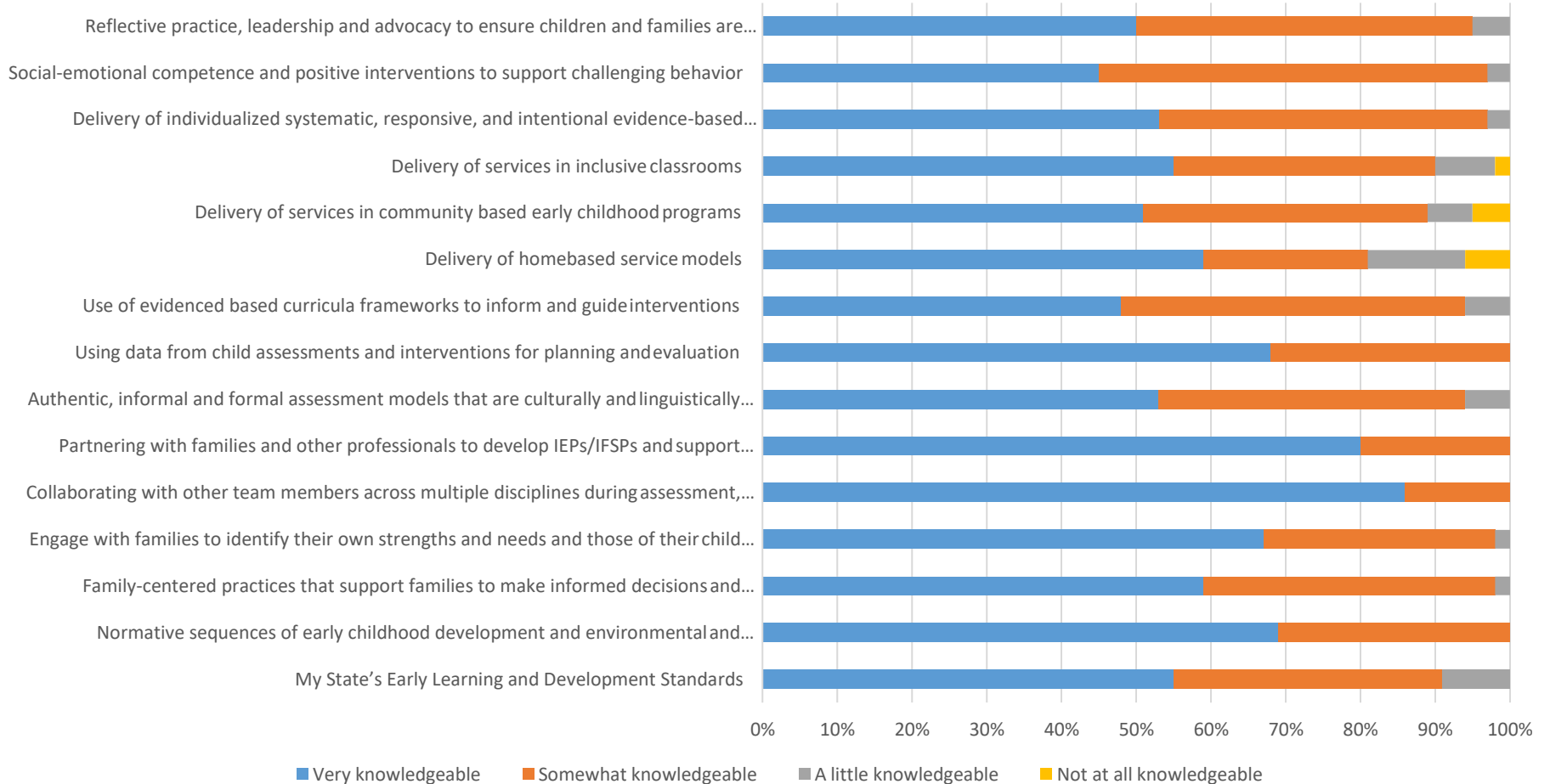
Interpersonal Barriers to Care

Interpersonal Barriers	%
Problems with the doctor or other health care provider showing a negative attitude about them	38.5
Problems having doctors understand medical concerns	30.8
Problems understanding doctor or health care provider	29.5
Problems when asked to use a computer or tablet to talk to a doctor or health care provider instead of seeing them in person	26.9

The Physical Exam for PWD with Mobility Disabilities

About the exam or procedure	%
Stayed in chair for physical exam	69
Stayed in chair for dental cleanings	41
Stayed in chair for medical procedures	33
Stayed in chair for dental procedures	41
No one talked to them about why they stayed in chair	**54**

Strategic Planning

Emphasis Areas for Goals Proposed for Next 5 Years 2023-2028

- Health Care

- Early Childhood and Schools

- Leadership and Management

Objectives In Core Areas

- Interdisciplinary Preservice
  - Continuing Education
- Research and Evaluation

- TA/Model Demonstration

- Dissemination

Early Childhood Intervention Needs

- Diverse and Well-Trained Staff
- Equitable and Accessible Intervention Systems Classroom and Community Inclusion
- Family Involvement and Participation
- Engaged Families in Expecting Equity
- Non-Exclusionary Discipline Practices
- Collaborative EC Programs

School Needs

- More Qualified and Diverse Staff: administrators, sped teachers, related service, paraeducators
- Trained and Qualified Leaders
- Equitable and Accessible Services
- Accessible IEPs and 504s Using CT SEDS
- Life Course Planning Beginning Earlier Than Transition Age
- LRE and Inclusion
- Appropriate and Non-Exclusionary Discipline Practices
- Examination of Prevalence Rate in SPED
- MTSS
- Universal Design
- Trained and Engaged Families in SPED Expecting Equity

Health Care Needs

- Equitable Health Care for All Children, Youth and Adults with Disabilities, Especially Those who Have Diverse Backgrounds

- Health Care Providers Who Are Aware, Knowledgeable and Skillful About the Needs of Children, Youth and Adults with Disabilities

- Accessible (Attitudinal) Community Based Healthcare

- Accessible (MDE) Health Care Offices

Action Plan for Each Sub-component

Goals/Objectives Activities	Timeline for Completion	Resources Needed	Person(s) Responsible	Criteria for Success	Achieved Y/N
GOAL 1.					
Objective 1.1					
Activity 1.1.1.					
Objective 1.2.					
GOAL 2.					
Objective 2.1.					
Objective 2.2					
Objective 2.3.					
GOAL 3.					
Objective 3.1					
Objective 3.2					
Objective 3.3					

Federal and State Policy & Data Review: Challenges and Opportunities Keeping Your Compass on "True North"

Consumer Advisory Council, CT. UCEDD

A. J. Pappanikou Center

Farmington, Connecticut

January 31, 2023

Allan I. Bergman

2023: Happy Anniversary

- 24th   Olmstead Supreme Court Decision
- **33rd   ADA, 1990**
- **48th   IDEA, 1975**
- **53rd   DD Act, 1970**
- 53rd   CRIPA, 1970
- 58th   Medicare and Medicaid, 1965
- 88th   Social Security, 1935

What has been achieved???

Core Values, Outcomes and Guiding Principles within All Disability Federal Legislation Today!
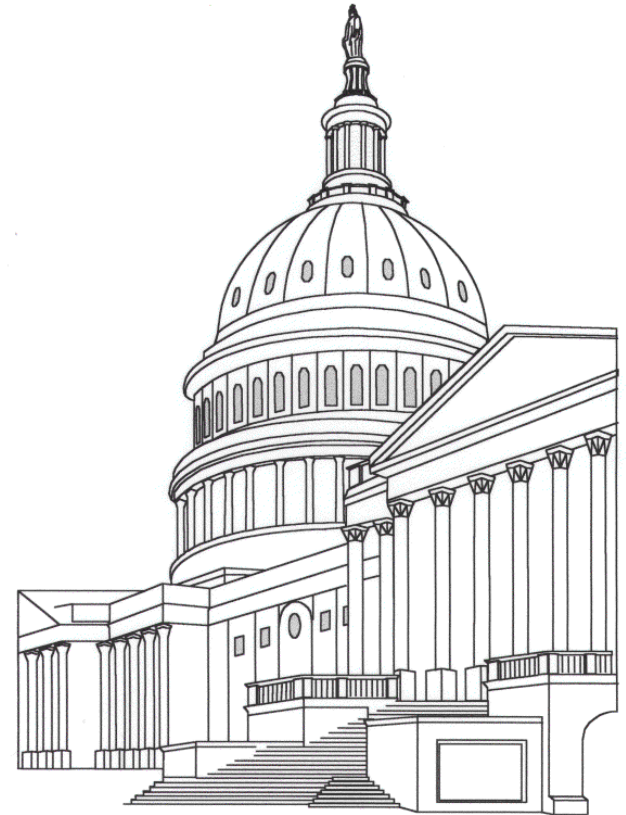
ADA Findings P.L.101-336; 1990

"The continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and **costs the United States billions of dollars in unnecessary expenses resulting from dependency and nonproductivity**."

Goals of the Americans with Disabilities Act of 1990

The nation's proper goals regarding individuals with disabilities are to assure:

- Equality of Opportunity
- Full Participation
- Independent Living
- Economic Self Sufficiency

"Equal Justice Under the Law"

Individuals with Disabilities Education Act

"to ensure that **all children with disabilities** have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and **prepare them for further education, employment, and independent living.**"

20 U.S.C. 1400(d)(1)(A)

IDEA Findings stated by Congress in the law, <u>2004</u> - 1

"…(4) However, the implementation of this chapter has been **impeded by low expectations and an insufficient focus on applying replicable research on proven methods of teaching and learning for children with disabilities.**

(5) Almost **30 years of research** and experience has demonstrated that the education of children with disabilities can be made more effective by -

IDEA Findings, <u>2004</u> – 2

"(A) **having high expectations for such children** and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to –

(i) meet developmental goals and, to the maximum extent possible, the **challenging expectations that have been established for all children**; and

IDEA Findings, <u>2004</u> – 3

(ii) **be prepared to lead productive and independent adult lives**, to the maximum extent possible: ...."

Transition

Transition planning is the student's road map to life after high school…

Transition is a journey … NOT a place or program!

What will the student achieve and
how will he/she get there?

#1 Factor Predicting Post School Career Success

WORK EXPERIENCE DURING SCHOOL

Optimum Career Preparation includes:

- Youth empowerment
- Family involvement and supports
- Academic preparation paired with work experience
- Connections to ancillary services
- WORK

Richard Luecking, Ed.D

13

Expectations Matter…A Lot!!! - 1

"The **best predictor of post school outcomes are the following:**

Parental Expectations

Teachers' Expectations

Expectations change the path of what experiences are made available and what is taught to the child/student…"

Expectations Matter…A Lot!!! - 2

"Changing expectations from deficits and what cannot do, to strengths, preferences, interests, gifts & contributions"

Relationships Matter.

Location Matters.

Erik Carter, Ph.D. Vanderbilt University, Dec 3, 2015

15

Employment First

"Employment is nature's best physician and is essential to human happiness."

Galen 129-216 AD, Greek physician & philosopher in Roman Empire

Adapting to the "New Normal"

▸ Metrics and Measurement; accountability

▸ All costs must produce clear measurable benefits; cost effectiveness

▸ Equity in resource allocation

▸ Pockets of excellence must be scalable; disparities in outcomes must translate statewide

▸ Sustainable value that can be quantified

▸ Transformational policy and infrastructure change

Longer Lifespans for Individuals with Disabilities Impacts Multiple Public Funding Sources

- Life expectancy **for PW/IDD** has increased **from average of 19 years in the 30's to 66 years in 2010** (Coppus, A.M.W., 2013)

- Individuals with **Mild ID** have life expectancies similar to the general population of **74 years** (Coppus, 2013)

- As people with disabilities live longer, the number of years that they require a variety of publicly funded supports.

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Current Policies Are Not Fiscally Sustainable

Spending and Revenues as a Share of GDP Under Current Policies
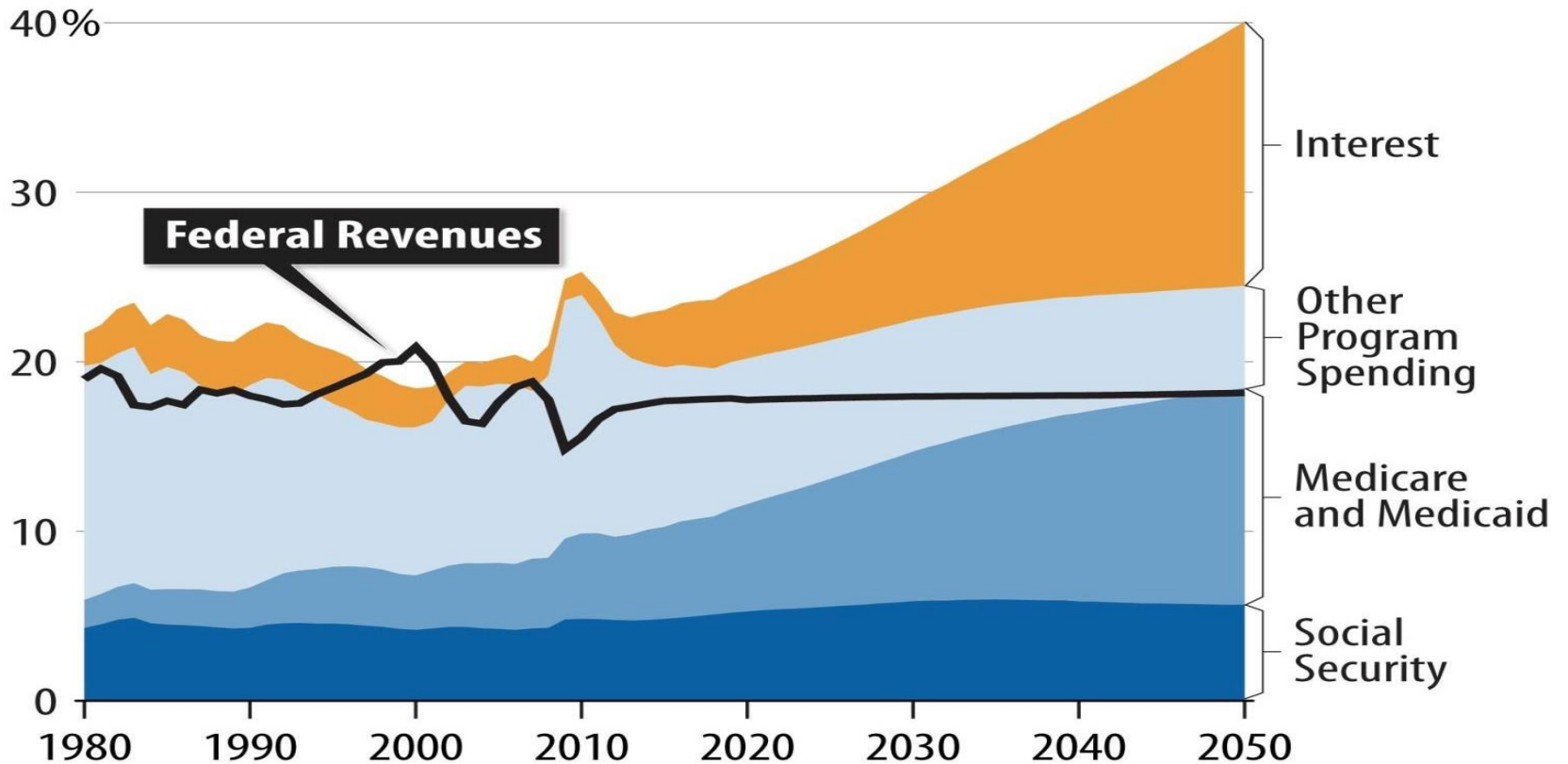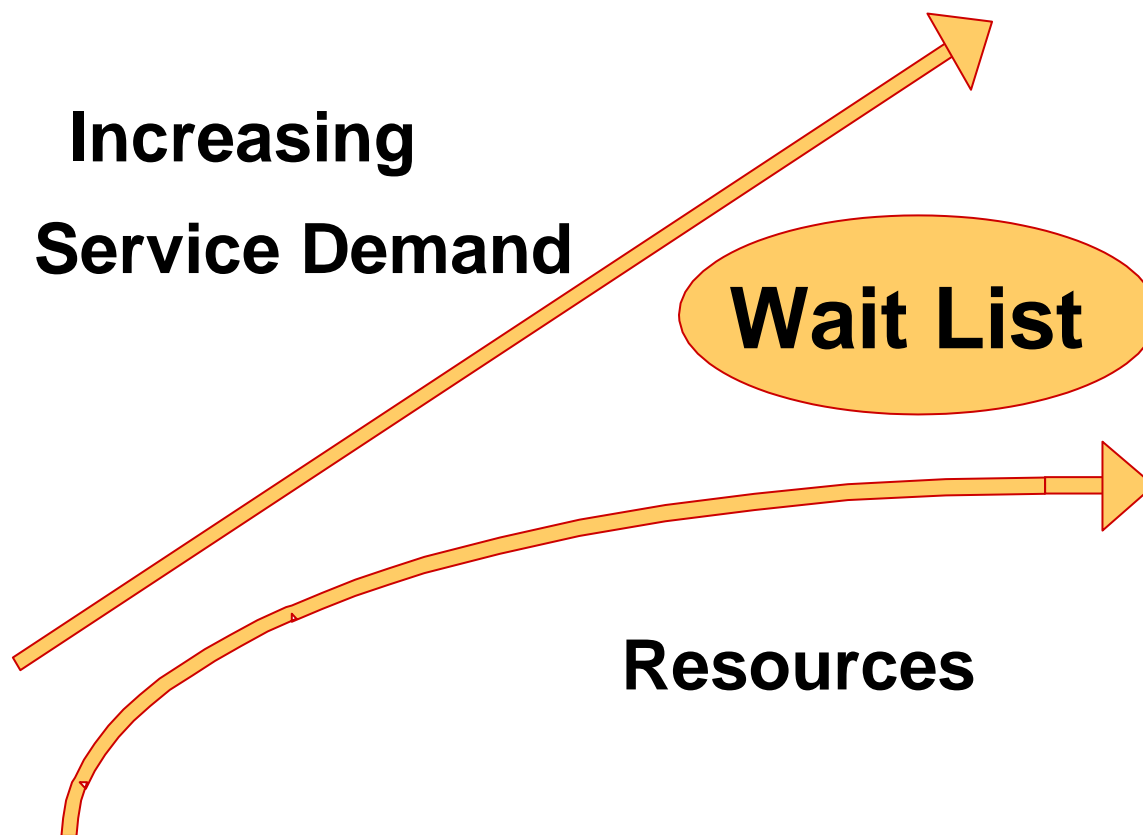
Financial Stability for People With Disabilities

Old Paradigm: One must accept a life of poverty in exchange for public assistance.

New Paradigm: The full promise of the Americans with Disabilities Act (ADA) – equality of opportunity, full participation, independent living and economic self-sufficiency

- Opportunity to earn income through employment
- Ability to use safe and affordable financial services
- Encouragement to save and build assets/resources/savings
- Right to exercise control over personal finances
- Right to develop money management skills, practice self-determination and design a person-centered service portfolio

Poverty *By The Numbers*

SUBPOPULATION	2009 Poverty Rate	2017 Poverty Rate
Children	20.7%	21.1%
African-American	25.8%	22.0%
Hispanic	25.3%	19.0%
Disability	25.0%	24.9%
Total U.S. Population	14.3%	12.3%

U.S. Census Bureau (September 12, 2018)

39.7 million Americans (of 323.4 M) were living in poverty in 2017.

Persons with Disabilities experienced the highest rates of poverty of any other subcategory of Americans for the 16th year in a row.

It is expected that SSDI/SSI annual payments will reach over $1 trillion by 2023.

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Fall 2019 by Setting/Placement- LRE National Data

	80%+	40-79%	<40%	Other
All	64.8	17.4	**12.9**	5.0
ASD	39.8	18.3	**33.5**	8.4
MD	14.3	17.8	**44.9**	23
ID	**16.6**	**27.9**	**48.7**	6.7

Table A. Employment status of the civilian noninstitutional population by disability status and age, 2020 and **2021** annual **averages**

[N u mbers in thousands]

Characteristic	2021		
	Total, 16 years and over	16 to 64 years	65 years and over
PERSONS WITH A DISABILITY			
Civilian noninstitutional population............................	31,084	15,586	15,498
Civilian labor force...	6,619	5,477	1,142
Participation rate .... …	21.3	**35.1**	7.4
Employed............. .... ….....	5,950	4,886	1,063
Employment-population ratio..	19.1	31.4	6.9
Unemployed..........................	669	591	78
Unemployment rate......	10.1	10.8	6.8
Not in labor force..................	24,465	**10,108**	14,357
PERSONS WITH NO DISABILITY			
Civilian noninstitutional population.............................	230,361	189,669	40,692
Civilian labor force....	154,585	145,127	9,458
Participation rate	67.1	**76.5**	23.2
Employed......................	146,631	137,567	9,064
Employment-population ratio.........	63.7	72.5	22.3
Unemployed..........................	7,954	7,560	394
Unemployment rate......	5.1	5.2	4.2
Not in **labor force ....**	75,776	**44,542**	31,234

NOTE: Updated population controls are introduced annually with the release of January data.

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CT Data

CT Data

The State of Children in Connecticut	
[1] Child Population (under 18 years of age)	727,440
[2] Percentage of children of color	46%
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[1] U.S. Census Bureau, 2022
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State Racial and Ethnic Demographics

	Connecticut	Bridgeport	Hartford	New Haven	Stamford	Waterbury
Total Population	3,626,205	148,333	120,576	135,081	136,309	113,811
White	78.8%	34.0%	27.8%	40.1%	59.3%	57.2%
Black or African American	12.7%	34.7%	36.4%	33.9%	12.9%	20.8%
American Indian or Alaska Native	0.7%	0.4%	0.5%	0.2%	0.4%	0.2%
Asian	5.1%	4.5%	2.6%	5.2%	8.5%	2.2%
Native Hawaiian or Pacific Islander	0.1%	0.1%	0.1%	0%	0%	0.1%
Hispanic or Latino	17.7%	41.7%	45.5%	30.3%	27.8%	36.8%

U.S. Census Bureau, 2022

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DISABILITIES

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Children and Youth with Special Health Care Needs in CT

Number of CSHCN in CT	156,900
0 – 5 years old	9.7%
6 – 11 years old	27.1%
12 – 17 years old	26.8%

National Survey of Children's Health, 2021

Racial and Ethnic Demographics for children with one or more *MEDB problem in CT

Hispanic	29.7%
White, non-Hispanic	26.5%
Black, non-Hispanic	12.33%
Other, non-Hispanic	24.4%

National Survey of Children's Health, 2021
*mental, emotional, developmental or behavioral (MEDB)

CSDE SPP/APR Indicator Summary

| Indicator 5 – Educational Environments	FFY20 Percentage	Target Outcome
A. Children with IEP's were included in regular education 80% or more	67.64%	Met
B. Children with IEP's were included in regular education 40% or more	7.10%	Met
C. Children with IEP's in separate school's residential facilities or homebound	7.26%	Met

Indicator 6 – Preschool Environment	FFY20 Percentage	Target Outcome
A. Special education services are received in regular education program	65.36%	Met
B. Special education services are received in a separate class, school or residential facility	22.15%	Met

CSDE SPP/APR, 2020

Students with Disabilities Spending 70.1 – 100% of Time with Nondisabled Peers (6-21)

District	Disability	2017-18		2018-19		2019-20		2020-21		2021-22	
		Count	Rate (%)	Count	Rate (%)	Count	Rate (%)	Count	Rate (%)	Count	Rate (%)
State of Connecticut	All Disabilities	48,426	68.6	49,075	67.6	50,685	67.8	50,699	67.9	52,234	68.4
	Autism	4,165	48.8	4,209	46.9	4,427	46.5	4,509	45.8	4,786	46.1
	Emotional Disturbance	2,384	43.1	2,440	42.9	2,495	42.8	2,473	43.9	2,313	44.2
	Intellectual Disability	647	25.3	640	24.9	635	23.9	615	22.8	578	20.7
	Learning Disability	21,567	80.3	22,222	79.3	23,129	79.7	23,065	80.1	24,220	80.4
	Other Disabilities	1,117	31.3	1,045	29.6	998	28.9	982	28.8	882	26.4
	Other Health Impairment	11,645	74.6	11,780	73.8	12,213	74.3	11,951	74.0	12,389	75.4
	Speech Language Impairment	6,901	86.6	6,739	86.2	6,788	86.6	7,104	87.5	7,066	88.0

Students with Disabilities Spending 70.1 – 100% of Time with Nondisabled Peers (6-21)
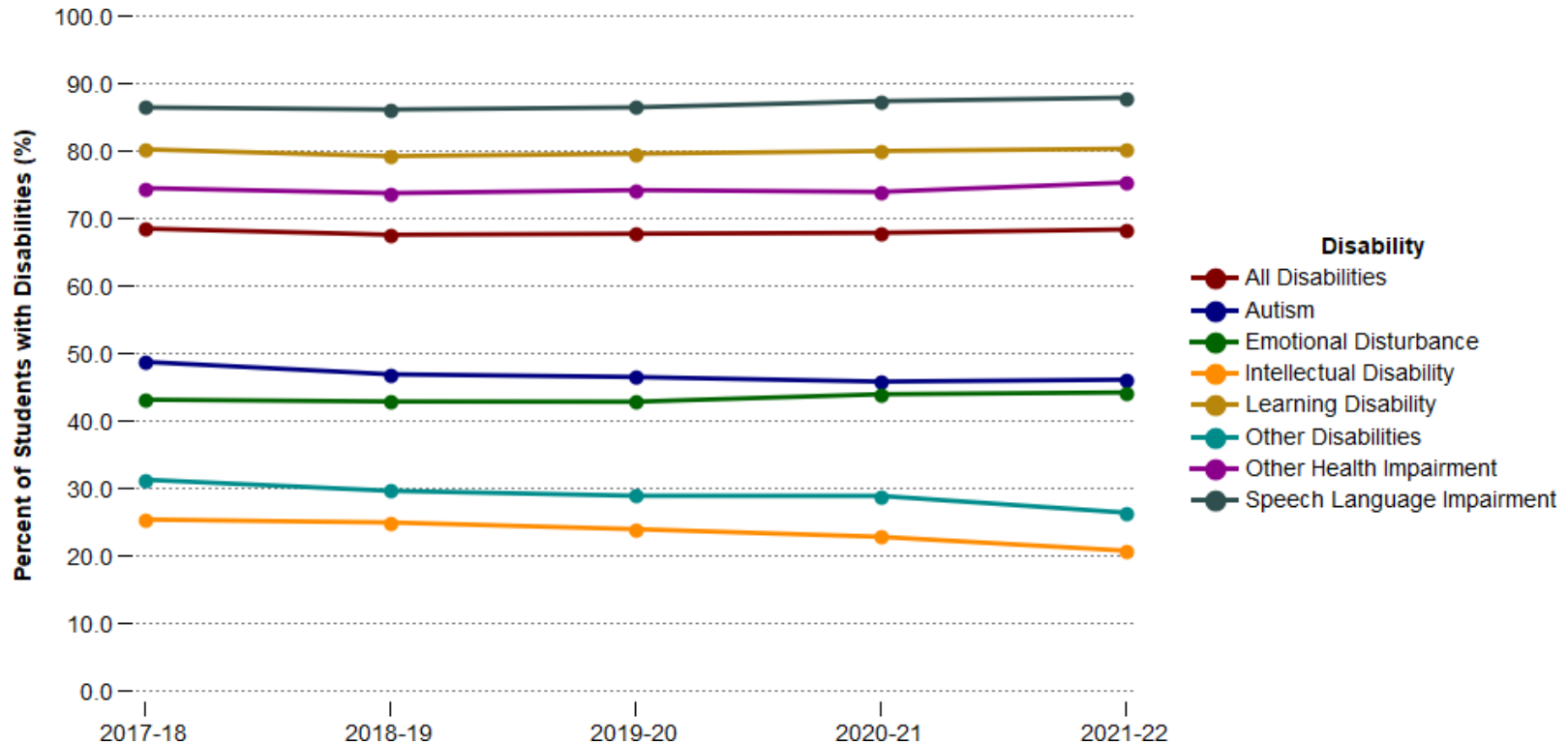
CSDE SPP/APR Indicator Summary

CSDE SPP/APR Indicator Summary		
Indicator 14 – Post School Outcomes FFY20 Percentage Target Outcome		
A. Enrolled in higher education (1)	44.78%	n/a
B. Enrolled in higher education or competitively employed within one year of leaving high school (1 +2)	92.86%	n/a
C. Enrolled in higher education, or in some other postsecondary education or training program; or competitively employed or in some other employment (1+2+3+4)	97.43%	n/a
CSDE SPP/APR, 2020		

Suspension Rates by Race/Ethnicity

| Race/Ethnicity	2016-17		2017-18		2018-19		2019-20		2020-21	
	Count	%	Count	(%)	Count	(%)	Count	(%)	Count	(%)
American Indian or Alaska Native	121	8.4	117	8.4	119	8.3	93	6.6	25	1.8
Asian	442	1.6	501	1.8	530	1.9	309	1.1	97	0.4
Black or African American	10,745	15.2	9,884	14.3	9,897	14	7,157	10.3	1,394	2.1
Hispanic/Latino of any race	12,710	9.7	12,819	9.4	13,214	9.2	10,269	6.9	2,224	1.5
Native Hawaiian or Other Pacific Islander	36	6.8	32	5.8	34	5.7	29	5.3	7	1.4
Two or More Races	1,080	6.7	1,248	7	1,368	7	1,031	4.9	411	1.9
White	11,448	3.9	12,167	4.2	11,696	4.1	7,863	2.9	3,364	1.3
Total	36,582	6.7	36,768	6.8	36,858	6.7	26,751	4.9	7,522	1.4

2020-21 Report on Student Discipline in Connecticut Public Schools, April 2022

Suspension Rates by Grade

Grade	2015-16		2016-17		2017-18		2018-19		2019-20		2020-21	
	Count	Percent (%)	Count	Percent (%)	Count	Percent (%)	Count	Percent (%)	Count	Percent (%)	Count	Percent (%)
K	314	0.8	220	0.6	203	0.6	198	0.5	*	*	40	0.1
1	543	1.4	413	1.1	351	0.9	337	0.9	212	0.6	42	0.1
2	789	2	649	1.7	501	1.4	504	1.3	314	0.8	86	0.2
3	1,237	3.1	1,144	2.9	1,022	2.7	986	2.6	647	1.7	161	0.4
4	1,503	3.8	1,593	4	1,305	3.3	1,374	3.5	895	2.3	247	0.7
5	1,874	4.7	1,929	4.9	1,948	4.8	1,861	4.6	1,276	3.2	410	1.1
6	3,187	7.9	3,195	7.9	3,327	8.3	3,387	8.2	2,272	5.6	928	2.4
7	4,341	10.5	4,354	10.7	4,371	10.8	4,494	11	3,285	7.9	1,024	2.5
8	4,373	10.7	4,484	10.8	4,589	11.2	4,598	11.1	3,400	8.2	1,137	2.7
9	6,202	13.9	5,735	13.2	6,023	13.8	6,245	14.1	4,474	10.1	1,205	2.7
10	4,810	11.5	4,679	11.2	4,856	11.8	4,950	11.6	4,022	9.6	902	2.1
11	4,619	11.3	4,195	10.3	4,330	10.7	4,170	10.2	3,044	7.5	759	1.9
12	4,299	10.3	3,987	9.5	3,916	9.4	3,746	8.8	2,762	6.5	581	1.4

2020-21 Report on Student Discipline in Connecticut Public Schools, April 2022

Suspension Rates by Grade
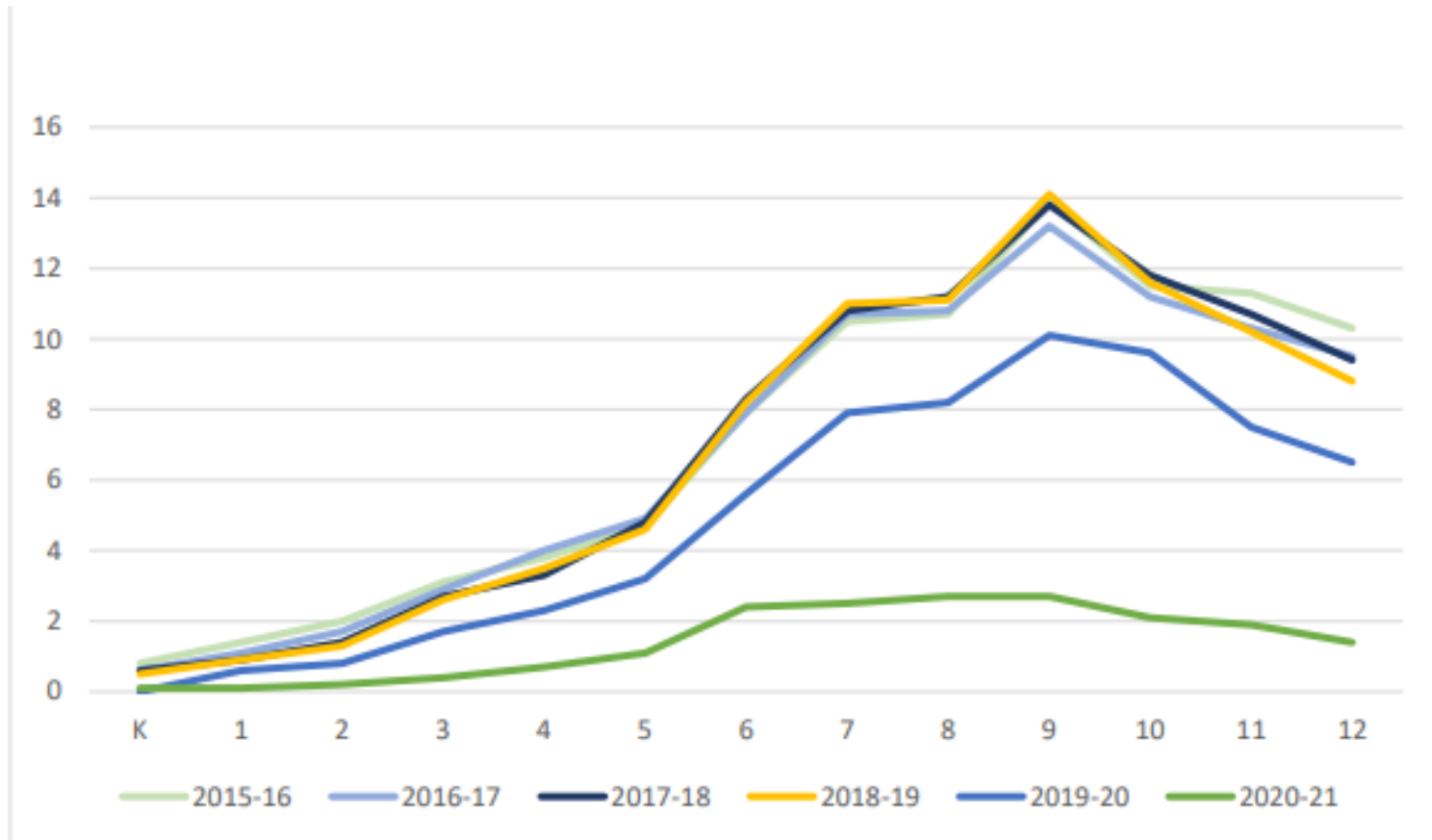
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Asian	5.1%	4.5%	2.6%	5.2%	8.5%	2.2%
Native Hawaiian or Pacific Islander	0.1%	0.1%	0.1%	0%	0%	0.1%
Hispanic or Latino	17.7%	41.7%	45.5%	30.3%	27.8%	36.8%

U.S. Census Bureau, 2022

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*Racial and Ethnic Demographics for children with one or more *MEDB problem in CT*

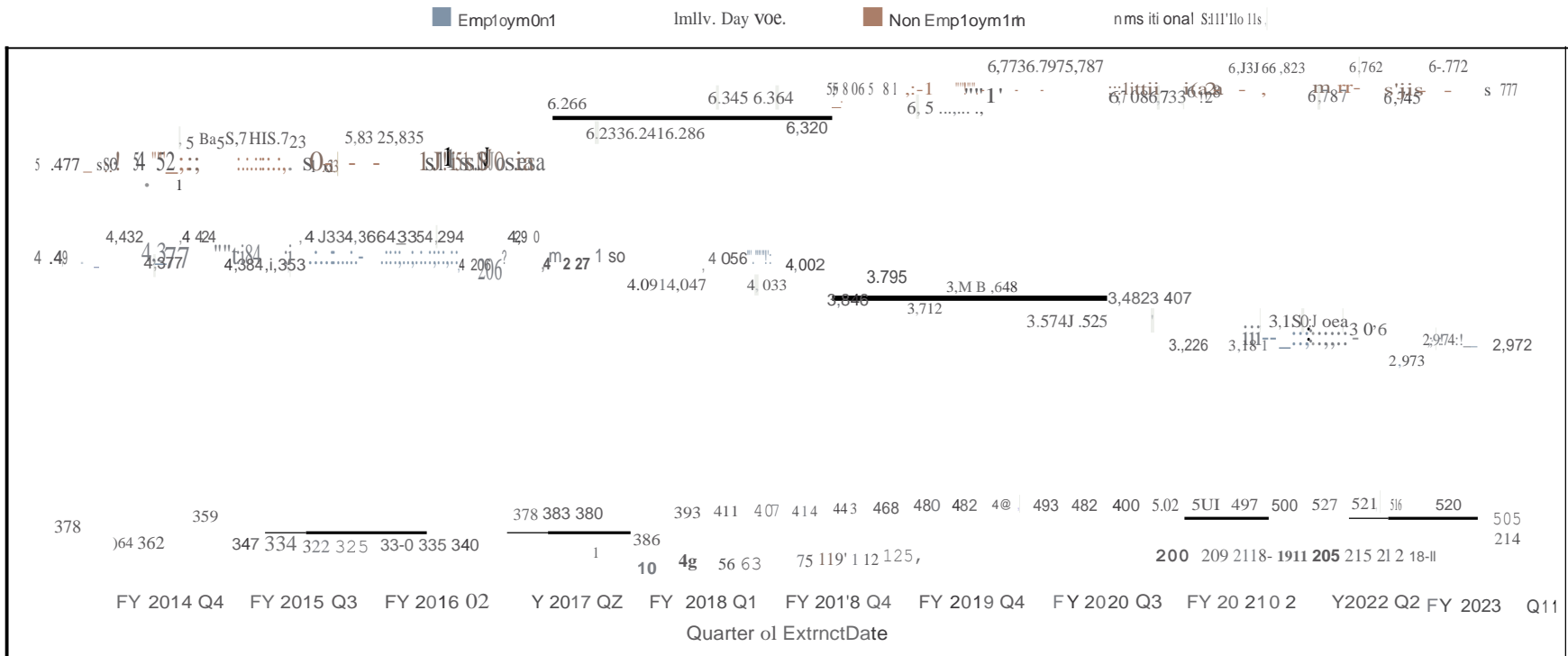|	
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Other, non-Hispanic	24.4%

National Survey of Children's Health, 2021
*mental, emotional, developmental or behavioral (MEDB)

DDS MIR Data, September 2022

Employment Compared to Non Employment Programs
By Fiscal Year and Quarter

NOTE: Employment Programs consist of the following program types: Individuals Supported Employment, Competitive Employment, and Group Supported Employment. Non-Employment Programs consist of the following program types: Pre-Vocational, Day Service Options. Individualized Day (except IDV & IDG), Small Enterprise and Senior Supports. Transitional Services consists of Transitional services Day and Transition School-to-work). Individualized Day Vocation consists of IDV and JDC.

The data does not include Other placement types not included in the descriptions above.
These are primary day placements and do not include the non-primary day program information...

DDS Racial and Ethnic Demographics

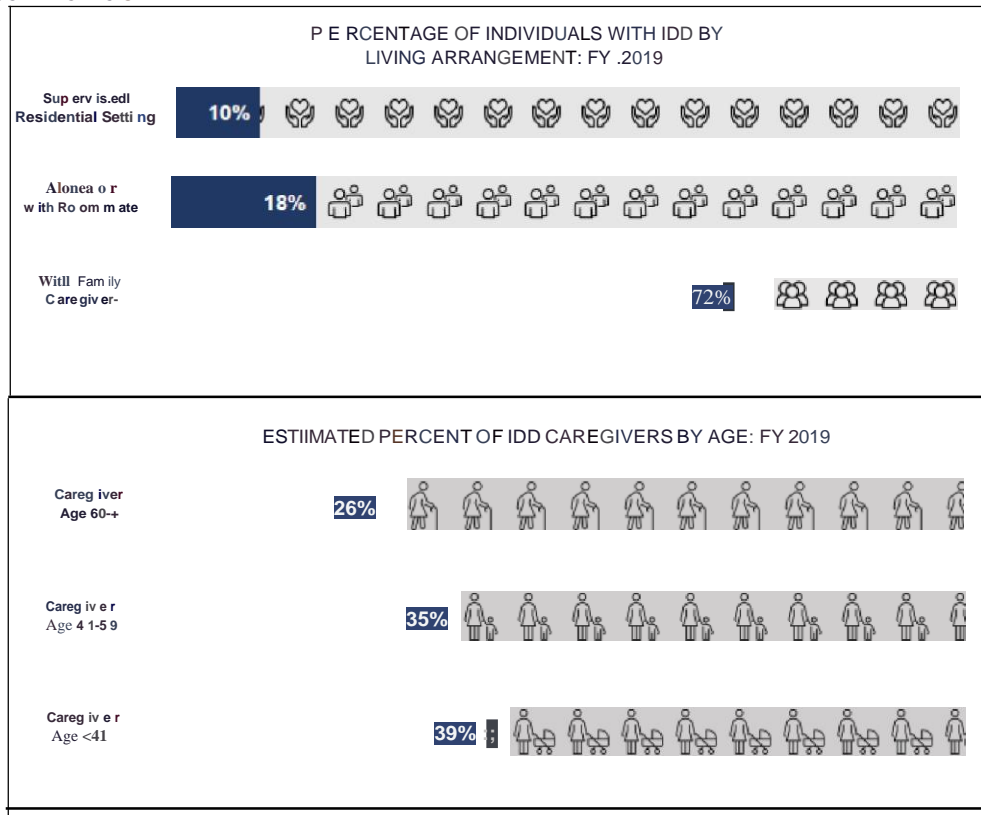|	
American Indian or Alaska Native	0%
Asian	0%
Black or African American	11%
Pacific Islander	1%
White	80%
Hispanic or Latino	2%
Two or More	6%

National Core Indicator Survey, 2019
*n=383

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P E RCENTAGE OF INDIVIDUALS WITH IDD BY LIVING ARRANGEMENT: FY .2019

Sup erv is.edl Residential Setti ng	10%	🤲🤲🤲🤲🤲🤲🤲🤲🤲🤲🤲🤲🤲
Alonea o r w ith Ro om m ate	18%	👥👥👥👥👥👥👥👥👥👥👥👥
Witll Fam ily C are giv er-	72%	👪👪👪👪

ESTIIMATED PERCENT OF IDD CAREGIVERS BY AGE: FY 2019

Careg iver Age 60-+	26%	🧓🧓🧓🧓🧓🧓🧓🧓🧓🧓
Careg iv e r Age 4 1-5 9	35%	🧑🧑🧑🧑🧑🧑🧑🧑🧑🧑
Careg iv e r Age <41	39%	👩👩👩👩👩👩👩👩

Source: Tanis, E.S., et al. (2022). The Slate of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disa bililies, Toe University of Kansas. http://WWW.st at eoftheStates.org
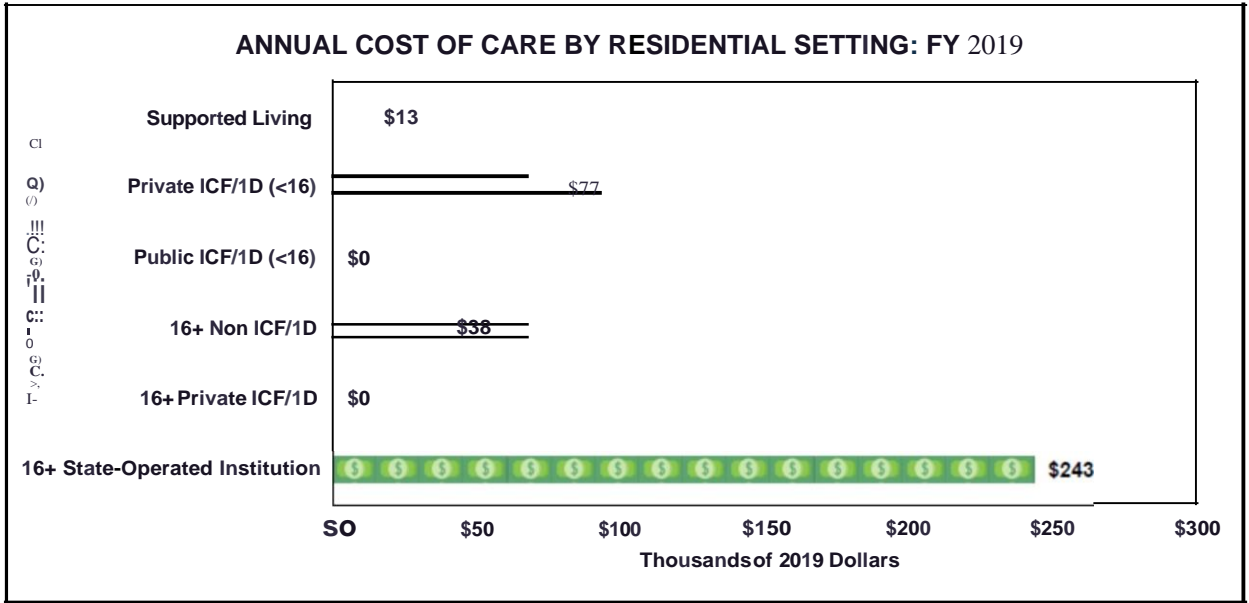
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PERSONS WITH IDD BY SIZE OF SETTING: FY 2009-2019

	2009	2010	2011	2012	2013	2014	2015	2016	2017	2018	2019
TOTAL	8,015	8,413	8,476	8,418	8,451	8,558	8,635	8,610	8,484	8,461	8,560
16+ PERSONS	1,205	1,181	1,151	1,089	1,044	997	913	914	831	830	793
Nursing Facili1ies	356	382	381	376	388	375	343	339	305	311	303
State Institutions	732	685	656	612	552	521	468	429	377	349	324
Private ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Other Resident ial	117	114	114	101	104	101	102	1	1	1170	166
7-15 PERSONS	405	413	419	338	288	279	293	238	209	181	157
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	27	31	38	39	37	22	35	36	29	36	33
Other Resid ential	378	382	381	299	251	257	258	202	180	145	124
<6 PERSONS	6,405	6,819	6,906	6,991	7,119	7,282	7,429	7,458	7,444	7,450	7,610
Public ICF/ID	0	0	0	0	0	0	0	0	0	0	0
Private ICF/ID	328	313	325	333	325	328	311	318	327	307	307
Supported Living	3,001	2,700	2,691	2,731	2,704	2,788	2,823	2,759	2,736	2,720	2,847
ot her Resident ial	3,076	3,806	3,890	3,927	4,090	4,166	4,295	4,381	4,381	4,423	4,456

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DISABILITIES

ANNUAL COST OF CARE BY RESIDENTIAL SETTING: FY 2019

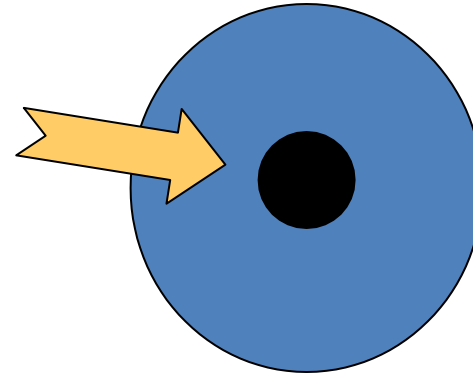| Residential Setting	Cost
Supported Living	$13
Private ICF/1D (<16)	$77
Public ICF/1D (<16)	$0
16+ Non ICF/1D	$38
16+ Private ICF/1D	$0
16+ State-Operated Institution	$243

Thousands of 2019 Dollars

Source: Tanis, E.S., et al. (2022). The state of the States in Intellectual and Developmental Disabilities, Kansas University Center on Developmental Disabilties. The University of Kansas. http:Jtwww.st ateoflheStates.org

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What To Do???

We can't stay on
this spot

We need to rethink what we do – **affirm our values** and resolutely search for "valued outcomes"

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DISABILITIES

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What is the Future for Uconn UCEDD?

Early Childhood Intervention Needs

- Diverse and Well-Trained Staff

- Equitable and Accessible Intervention Systems
  Classroom and Community Inclusion

- Family Involvement and Participation

- Engaged Families in Expecting Equity

- Non-Exclusionary Discipline Practices

- Collaborative EC Programs

School Needs

- More Qualified and Diverse Staff: administrators, sped teachers, related service, paraeducators
- Trained and Qualified Leaders
- Equitable and Accessible Services
- Accessible IEPs and 504s Using CT SEDS
- Life Course Planning Beginning Earlier Than Transition Age
- LRE and Inclusion
- Appropriate and Non-Exclusionary Discipline Practices
- Examination of Prevalence Rate in SPED
- MTSS
- Universal Design
- Trained and Engaged Families in SPED Expecting Equity

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Health Care Needs

- Equitable Health Care for All Children, Youth and Adults with Disabilities, Especially Those who Have Diverse Backgrounds

- Health Care Providers Who Are Aware, Knowledgeable and Skillful About the Needs of Children, Youth and Adults with Disabilities

- Accessible (Attitudinal) Community Based Healthcare

- Accessible (MDE) Health Care Offices