

Access to Health Care by Individuals with Developmental Disabilities



CTCDD

*Connecticut Council on
Developmental Disabilities*



June 14, 2024

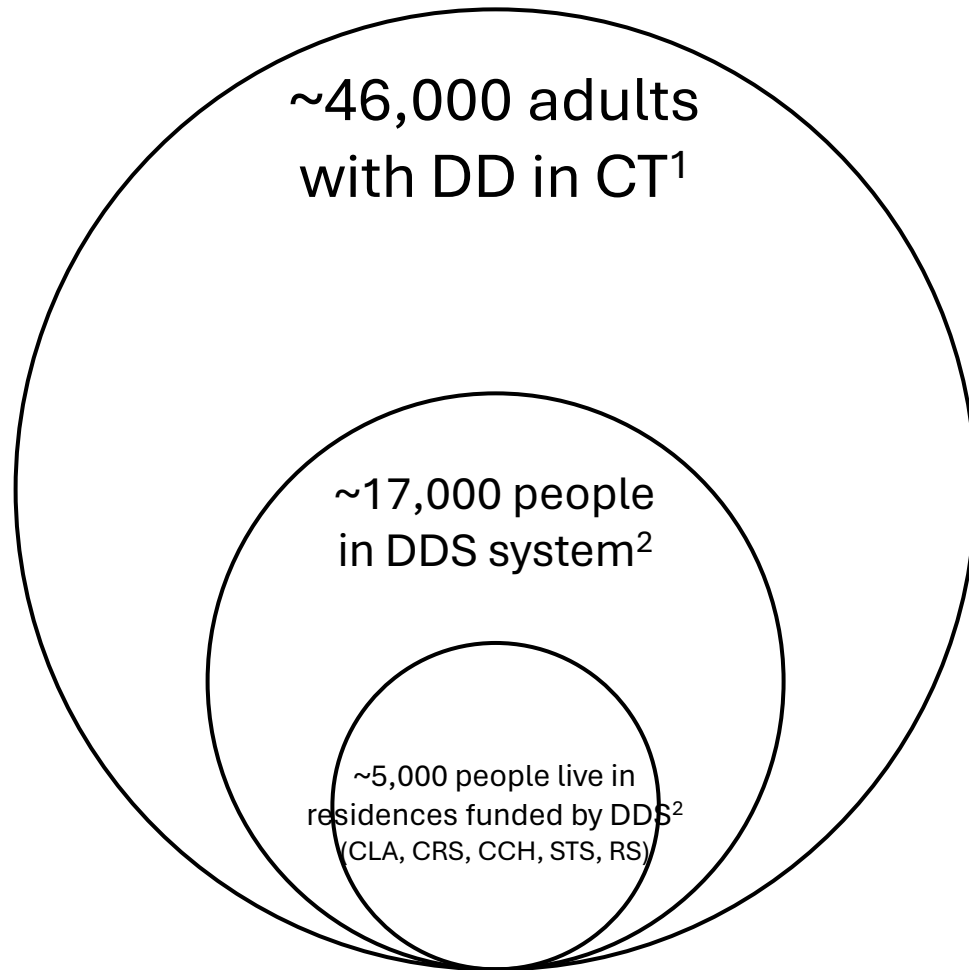
CGA MAPOC



The **Connecticut Council on Developmental Disabilities** is a department of the State of Connecticut that is entirely funded by the federal Administration for Community Living (ACL), which is a division of the U.S. Department of Health and Human Services (HHS), to engage in systemic change activities that enable individuals with developmental disabilities to exercise self-determination, be independent, be productive, and ***be integrated and included in all facets of community life*** -

- since 1971.

There are about 46,000 adults with developmental disabilities in Connecticut and most of them rely on Medicaid for commercial health care.



Sources:

1. According to the federal Administration for Community Living, about 1.6% of the population have a developmental disability.
- Havercamp, S.M., et al. Working Through the IDD Data Conundrum: Identifying people with Intellectual Disability and Developmental Disabilities in National population Surveys. Washington, D.C., Administration on Intellectual and Developmental Disabilities, 2019.

2. Connecticut Department of Developmental Services, Management Information Report, June 2022.



CTCDD State Plan

*Connecticut Council on
Developmental Disabilities*

OBJECTIVE 2.2: Inform individuals with developmental disabilities and their caregivers about their civil rights through pamphlets, graphics, and other digital media.

OBJECTIVE 3.3: Train professionals that provide generic services, including medical professionals, on disability awareness, appropriate responses to challenging situations, and how to identify and interact with people with developmental disabilities.

Recent history of Council work on Health Care



CDC grant to improve access to COVID-19 vaccinations in 2021 revealed that many individuals were not receiving essential primary care because health care providers did not offer accommodations for developmental disabilities.



Research for the Council by the Connecticut Health Policy Project revealed that Connecticut residents with developmental disabilities receive less primary care, with costly consequences.



University of Connecticut

Center for Excellence in Developmental Disabilities

Education, Research & Service

The UConn UCEDD is authorized by the Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act) to be one of three state programs, known collectively as the **Developmental Disabilities Network**, to ensure those with disabilities and their families can participate in all aspects of community life.

UCEDDs serve as liaisons between academia and community through four core functions: interdisciplinary pre-service preparation and continuing education (training); community service and technical assistance; research; and information dissemination.

Health Care Promotion is one of the UConn UCEDD's areas of emphasis.

- **Training**

- UConn Leadership Education in Neurodevelopmental and related Disabilities program (UConn LEND)
- Patient Advocacy in Communities, Teams and Health Systems (medical students)
- Delivery of Clinical Care (medical students)
- Addressing barriers to quality inclusive health care (public health students)
- Student Disability Interest Group: bring awareness to peers

- **Community**

- Webinar series with the Council
- Checklist of best practices to provide health care to adults with disabilities [expected summer 2024].

- **Research**

- (2024). Barriers to health care among adults with disabilities in Connecticut. [Accepted for peer-reviewed publication].
- LEND trainee projects

Recent forums and events illustrated difficulties accessing health care in Connecticut by people with disabilities.

Public Health and Human Services Committees Joint Informational Forum on Access to Health Care for Persons with Disabilities, on September 13, 2023

<https://ct-n.com/ctnplayer.asp?odID=22112>

September 19, 2023, Webinar on the national perspective on access the healthcare

<https://youtu.be/jUzSooxHWww>

October 3, 2023, Webinar on access to health care in Connecticut

<https://youtu.be/Qi01FJARJIs>

October 17, 2023, Webinar about healthcare disparities in minority communities

https://youtu.be/Zul_UfGmpJY

Report to the MAPOC about access to primary care by people with disabilities on January 12, 2024

<https://ct-n.com/ctnplayer.asp?odID=22486>





Recent federal actions



U.S. Department of
Health and Human Services

Enhancing the health and well-being of all Americans

Final Rule Implementing Section 504 of the Rehabilitation Act of 1973 prohibits discrimination based on disability in health care.



National Institutes of Health
Turning Discovery Into Health

NIH designates people with disabilities as a population with health disparities.

Key take aways

- Individuals with developmental disabilities face significant health disparities.
- ***Many individuals are not offered necessary healthcare accommodations for their developmental disabilities.***
- Data is difficult to find. We don't measure what we don't do.
- There are promising practices in Connecticut and in other states.
 - Maine, New Jersey, Colorado,
- Payment systems must include accommodations.

Collection of data on access to health care by individuals with developmental disabilities is limited.



The screenshot displays the website of the Connecticut State Office of Health Strategy (OHS). The header features the OHS logo and the text "Connecticut State Office of Health Strategy" over a background image of a building. A breadcrumb trail reads: [CT.gov Home](#) / [Office of Health Strategy](#) / [Data and Reports](#) / [To File Data](#) / [Patient Data](#) / [Outpatient Surgery Data Reporting](#).

A left-hand navigation menu includes the following items with right-pointing chevrons:

- Office of Health Strategy Main
- Health Systems Planning
- Data and Reports

Below the menu is a search bar labeled "Search Office of Health Strategy" with a placeholder "by Keyword" and a magnifying glass icon.

Outpatient Surgery Data Reporting

What is Outpatient Surgery Data Reporting?

Connecticut General Statutes Section 19a-654 requires licensed outpatient surgical departments to report patient identifiable encounter data beginning on 10/1/2017, to the Health Systems Planning (HSP) unit of the Office of Health Strategy.

OHS utilizes such data to fulfill its responsibilities such as assessing availability and demand for services; evaluating unmet needs and gaps in services; developing and maintaining a health care facilities and services plan; decision-making in certificate of need; and public health planning. OHS also authorizes HSP to provide access to the data to qualified entities and individuals.

The Council is packaging its research into a website that will open this month.



CONNECTICUT
HEALTH ACCESS
ALLIANCE

Ensuring Equity for Patients with Developmental Disabilities

- Information for patients
- Information for practitioners



Information for patients



Ensuring Equity for Patients with Developmental Disabilities

- Entitlement to accommodations
- How to ask
- How to seek remedies
 - DPH complaints
 - CHRO?
 - U.S. Attorney, HHS OCR



Complaint backlog at CT nursing homes, hospitals is years long



by [Jenna Carlesso](#)

2024 @ 4:30 pm

CT DPH gets funds to help address complaint backlog

DPH has a backlog of 2,400 complaints related to nursing homes and another 1,300 complaints related to incidents at hospitals



by [Jenna Carlesso](#) June 3, 2024 @ 2:32 pm

Information for practitioners



Ensuring Equity for Patients with Developmental Disabilities

- What sorts of accommodations are needed?
 - Extra time
 - Sensory friendly spaces
 - Accessible equipment
- Examples of ***promising practices***:
 - ***Pre-consult with patient*** (Cooper University Health Care)
 - Practice Guidelines (Maine, UConn UCEDD, Quinnipiac)
 - Electronic Health Records (Colorado, Cooper)
- How to bill for accommodations?

How does Medicaid pay for accommodations?

CPT Codes

CPT	Established Patient Visit	CPT	New Patient Visit
99212	10-19 mins	99202	15-29 mins
99213	20-29 mins	99203	30-44 mins
99214	30-39 mins	99204	45-59 mins
99215	40-54 mins	99205	60-74 mins
Prolonged Visit Code			
99417	Only used when the primary service has been selected using time alone as the basis and only after the time required to report the highest-level service has been exceeded by 15 minutes.		

Risk Adjustment Codes

ICD-10 code	Code Description
F71	Moderate Intellectual Disabilities
F72	Severe Intellectual Disabilities
F73	Profound Intellectual Disabilities
F78	Other Intellectual Disabilities
F78.A	Other Genetic Related Intellectual Disabilities
F78.A1	SYNGAP1-related intellectual disability
F78.A9	Other genetic related intellectual disability
F79	Unspecified intellectual disabilities

Source: Brad Richards, CT DSS, presentation to MAPOC on January 12, 2024

How would capitation, value-based payments, or Managed Care compensate health care providers for accommodations?

Two questions

- *What payment model best covers accommodations for primary care to individuals with developmental disabilities?*
- *Are current State statutes, policies, regulations, practices, and capacity adequate to ensure health care for individuals with developmental disabilities?*



Thank you!

Questions?

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