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Evaluation of Statutory Definitions and Regulations: Intellectual Disability and Related Programs

Prepared for the Connecticut Office of Policy and Management

by the Altarum Institute

Connecticut Evaluation and Recommendations

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Introduction and Background

Purpose

Connecticut's Office of Policy and Management (OPM) aims to evaluate its current statutory definitions and regulations surrounding eligibility for services available for individuals with intellectual disability or autism. As instructed by legislation passed in the 2023 legislative session, this includes potentially (1) recommending new statutory definitions for intellectual disability, (2) identifying related programs that may need to be updated based on the new definitions, (3) evaluating whether intelligence quotient (IQ) should be used in the definitions, and (4) evaluating the level-of-need assessment tool used by state agencies for individual service planning.[1] Such recommendations and eventual implementation would likely impact access to needed services for individuals with intellectual disability or autism and could build upon state processes and best practices to strengthen home and community-based services based on an individual's unique functional and adaptive strengths and needs. Connecticut contracted with Altarum, a nonprofit organization focused on improving the health care system for all individuals, to conduct research, engage key stakeholders, and provide potential recommendations about the current statutory definition considering whether IQ should continue as a defining factor of intellectual disability.

Evaluation and Analysis

This report summarizes research completed by Altarum to evaluate the use of IQ for eligibility for Connecticut's programs and services supporting individuals with intellectual disability or autism. Research was completed to provide OPM with recommended potential revisions to current statutes and necessary program changes due to those revisions. Research included:

- A review of Connecticut's current definitions of intellectual disability and regulatory language for eligibility;
- A review of eligibility criteria for programs closely related to the intellectual disability definition (e.g., Autism Spectrum Disorder);
- Recent Connecticut legislation impacting individuals with intellectual disability or autism;
- Current statutory definitions for intellectual disability within Connecticut and across multiple other states;
- Connecticut's Department of Developmental Services (DDS) and Department of Social Services (DSS) policies and waiver program accessibility;
- Current state eligibility and enrollment workflow;
- Connecticut's Level of Need Assessment and Screening (LON) tool and assessment workflows and level-of-care assessments across five other states;
- Connecticut's current waiver programs and service design;
- Recent public-facing reports from the Office of Legislative Review and DDS; and
- Interviews with states (Washington, Arkansas, Minnesota, Vermont) that revised their definitions for intellectual disability and modified their service pathways for individuals with intellectual disability and autism to increase access, augmenting initial research efforts.

[1] Connecticut Office of Legislative Research Special Report. July 2023. 2023 Acts Affecting People With Disabilities. Available here: https://www.cga.ct.gov/2023/rpt/pdf/2023-R-0155.pdf

Research findings were analyzed to evaluate the use of IQ to define intellectual disability that is used to determine waiver program eligibility. Findings were also used to assess the waiver program service package, workflow, and LON tool's appropriateness to determine LON for individuals with an intellectual disability or autism. This information supported the development of an initial Draft Report that summarized research on the use of IQ for eligibility for intellectual disability services and the appropriateness of the current LON tool and assessment workflows.

Stakeholder Engagement

A summary of the Draft Report was shared with two Advisory Groups established by Altarum in coordination with OPM. Both groups, a State Agency Workgroup and a Consumer and Provider Workgroup, met in September 2024. The 13 participants in the State Agency Workgroup included representatives from OPM, DDS, DSS, Connecticut State Department of Education (CDSE), Department of Public Health (DPH), and the Department of Aging and Disability Services (ADS). The 14 participants in the Consumer and Provider Workgroup included representatives from the Connecticut Council on Developmental Disabilities, the Connecticut Autism Spectrum Disorder Advisory Council, DDS and DSS advocate representatives, and representatives from both the Mohegan Tribe and Mashantucket Pequot Tribal Nation. Both workgroups reviewed all potential recommendations and their impacts across state processes and consumer experiences. A detailed catalog of all feedback provided was developed and shared with OPM to support the next phases of their work. Main points of feedback included, but were not limited to:

- Emphasize more strongly that any changes to the definition and state processes should focus on the individual and their functional needs;
- Include additional information on the quantifiable impacts changes would have on individuals in need of services and impacts to the state budget and service availability;
- Describe the impact of potential changes to state departments and disability providers outside of DDS and DSS; and
- Reference intentional steps toward change to ensure negative impacts can be avoided, framing recommendations using a more stepped approach.

The feedback from each group supported revisions and refinements to the specific recommendations and anticipated impacts across the state for the final report.

Recommendations and Impacts

The final potential recommendations to change Connecticut's statutory definitions, eligibility and enrollment workflows, LON tool, and state approaches are outlined in this report. While these recommendations support Connecticut's goals to improve the statutory structures and service delivery regulations for the state's intellectual disability and autism populations, full adoption of any proposed changes could impact existing waiver program eligibility, LON tool design, assessment processes, and the number of eligible program participants.

Furthermore, making even one minor change to eligibility policy can impact any state program. For example, the clinical criterion for intellectual disability is embedded in eligibility for Medicaid funded Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICF/IID), home and community-based services (HCBS) waiver programs supporting people with intellectual disability and related conditions, and school-based programs aligned with Individuals with Disabilities Education Act (IDEA) requirements.

Changes to programs and policies discussed in this report must begin with an understanding of, and appropriate planning for, any potential impacts. The recommendations contained in this report will require strategic thinking, analysis, and development before implementation, including leveraging a change management process built around strategic impact analysis and consistent stakeholder engagement focused on ensuring continued access for individuals receiving intellectual disability services.

This report outlines proposed recommended changes to Connecticut's statutory definition of intellectual disability and appropriate change management approaches that support implementation. Using research and evaluation findings, it includes an overview of anticipated impacts on the state budget, caseloads, state agencies, and municipalities. Ultimately, this report is designed to provide a framework and the tools needed to consider tradeoffs and potential impacts of any change, enabling Connecticut to thoughtfully pursue solutions that ensure that all individuals can effectively access the services and supports needed to live their lives fully.

Connecticut People with Intellectual Disability and Autism Populations

To understand the current need and potential impact of changing the definition of intellectual disability, use of the LON tool, and eligibility and enrollment workflows, it is vital to first frame the need for services among individuals with an intellectual disability or autism across the state. This understanding of the current landscape is crucial for shaping impactful programs for individuals in need of these services and supports.

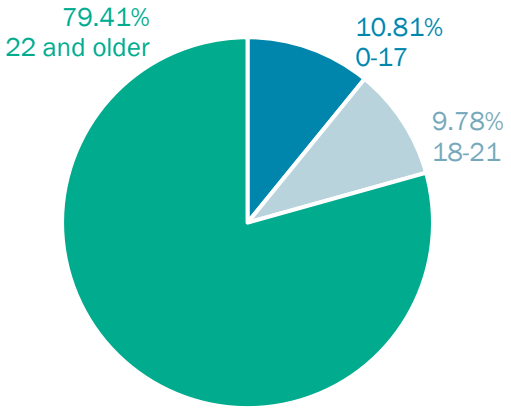
Intellectual Disability

National and local data collected on the prevalence of individuals with intellectual disability is not currently standardized. Connecticut DDS provides regular reports on individuals across the state who have been determined eligible for services based on its current statutory definitions. While these reports do not include every single individual in the state who may have an intellectual disability, they do provide insight into the population and current need for services. This report leverages the quarterly data from the DDS Management Information Report (MIR) of March 2024.

Per the DDS March 2024 MIR quarterly report, the current number of individuals with an intellectual disability diagnosis is 17,405.[2] Of the 17,405 DDS cases, 13,755 individuals are aged 22 and older (79.41%), 1,696 are aged 18-21 (9.78%), and 1,882 are aged 0-17 (10.81%).

The report reveals there are a total of 10,942 individuals with intellectual disability enrolled in the HCBS waivers. This includes 5,019 enrolled in the Comprehensive Supports Waiver, 3,604 enrolled in the Individual and Family Supports Waiver, and 2,319 enrolled in the Employment Day Support Waiver.

Figure 1. DDS Cases by Age



As detailed in the report, many of these individuals with intellectual disability are unable to access the services and supports they need even when enrolled in a DDS waiver. DDS tracks information on unmet residential or service needs to best track and triage access to services due to waitlists, specifically residential services. DDS categories reported unmet needs as emergency, urgent, or future needs.

- **Emergency need** indicates an immediate need for residential placement, support, or services.
- **Urgent need** indicates that the individual requests placement within one year and has the most pressing need for services.
- **Future need** indicates individuals wanting or needing services in two or more years. Individuals categorized with future needs are placed on a planning list.

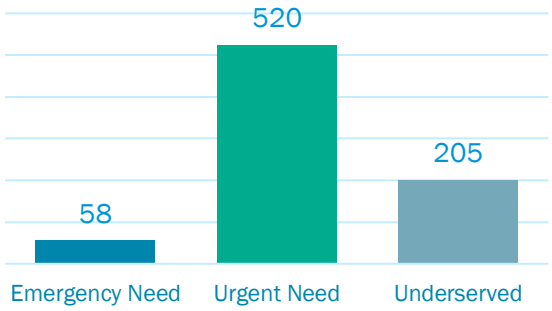
Among the 17,405 individuals with an intellectual disability diagnosis, 578 individuals received no services at the time of this report. Most (90%) were categorized as urgent needs, and ten percent

[2] State of Connecticut Department of Developmental Services Commissioner's Office. DDS Management Information Report March 2024. Available: https://portal.ct.gov/dds/-/media/dds/mir/mir_march_2024_with_attachment.pdf

(10%) were classified as emergency needs.

An additional 205 individuals received services but were underserved due to waitlists for services. Again, most underserved individuals are categorized as urgent (75%).

Figure 2. Individuals on DDS Waitlist by Need



Further unmet needs exist across other waiver programs, including day supports among those who requested employment opportunities, day services, and services from the DDS Behavioral Services Program. The MIR highlights projections of individuals who will meet the maximum age limits of current non-DDS programs and transition to DDS's support. As of March 2024, the projected increase in individuals needing DDS services was 82 individuals for FY 2025, 61 individuals for FY 2026, and 56 individuals for FY 2027.

Autism

Based on prevalence estimates from the Centers for Disease Control and Prevention (CDC), 1 in 36 children were estimated to have Autism Spectrum Disorder (autism) in 2020.[3] When applied to Connecticut's 2020 population census data, this would indicate that 20,481 individuals aged 18 and below live with autism in the state.[4] However, based on a 2023 Annual Report from Autism Speaks, a non-profit autism awareness and research organization, Connecticut's prevalence may be higher than the national average, with an estimated 3.9% of individuals aged 18 and below living with autism based on reports from parents in the state.[5] This would indicate that there may be 27,259 youth living with autism.

Connecticut's DSS reports that there are 243 individuals fully enrolled in the HCBS Autism Waiver, which is based on the determination of eligibility for DSS services and eligibility for HUSKY C (Connecticut's Medicaid program for the aged, blind, and disabled). There are another 87 individuals engaged in the enrollment process and already connected to a case manager to support them through the application and enrollment process. The waiver can support up to 445 individuals based on the current funding and policies. However, 1,973 individuals with autism remain on the waitlist. In the past year, more waiver slots were funded by the legislature, and more are planned to be opened this fiscal year and next to improve access to services for these individuals. These numbers have led to a broad understanding of the need to improve access and services for individuals with intellectual disability and those living with autism across the state.

Connecticut's Legislative Directive

In 2023, Connecticut lawmakers proposed a bill to evaluate and expand supports and services for people with intellectual disability. This bill included provisions to evaluate the definition of

[3] CDC Autism Spectrum Disorder. Data and Statistics on Autism Spectrum Disorder. Available from https://www.cdc.gov/autism/data-research/index.html
[4] US Census Data. Connecticut Profile. Available from https://www.census.gov/library/stories/state-by-state/connecticut-population-change-between-census-decade.html
[5] Autism Speaks. (2023). Autism by the Numbers: Inaugural Annual Report. Available from https://www.autismspeaks.org/sites/default/files/ABN_Annual_Report_2023.pdf

intellectual disability and service eligibility. More specifically, the OPM Secretary is reviewing the impact of new statutory definitions for intellectual disability that approach IQ differently, along with identifying related programs for people with these disabilities that may need to be changed or redesignated under any new definitions. The OPM Secretary is also evaluating the current waiver enrollment processes, including the LON assessment tool used by state agencies that serve people with intellectual disability.[6] This legislation (PA 23-137, § 4) had broad bipartisan support and demonstrated Connecticut's commitment to improving access to the state's intellectual disability waiver services and related programs such as autism services.[7] As described below in the Potential Recommendations section, should Connecticut choose to move forward with any changes, it would require intentional planning and a multi-year implementation approach rooted in ongoing process, systems, and people change considerations. Understanding the potential impacts of proposed changes is a crucial step in any change management approach.

Due to this recent legislation and increased public calls to action,[8] Connecticut contracted with Altarum to conduct research, engage key stakeholders, and provide recommendations outlined in this report. Connecticut is also exploring whether the current LON tool would require revision and how a change in the definition of intellectual disability would impact other programs and services. For example, the eligibility criteria for autism include the existence of cognitive and adaptive functioning above the level of intellectual disability as defined by the state (e.g., IQ equal to or higher than 70). Should the definition of intellectual disability change, the state should evaluate how this would impact eligibility criteria across other programs, as well as administrative operations and budget impacts.

Broader Considerations for Potential Changes

An alteration to the definition of intellectual disability could potentially impact person-centered service delivery outcomes. Individuals with intellectual disability and autism experience stigma on multiple levels that can limit social inclusion and increase disparities across the health system. Structural stigma, such as social norms and policies that restrict opportunities for individuals with intellectual disability, has historically had negative impacts on individuals' feelings of acceptance and how they can participate in their communities.[9] Stigma and exclusion can have serious impacts on an individual's mental well-being, participation in all aspects of society, and overall quality of life. While experiences of stigma and its effects among individuals with intellectual disability are prevalent, they are continually understudied. Most individuals with an intellectual disability associate negative feelings, such as shame, powerlessness, and frustration, with their ascribed label.[10]

Many people with intellectual and developmental disabilities also experience discrimination,

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[6] OLR Bill Analysis. HB 5001. AN ACT CONCERNING RESOURCES AND SUPPORT SERVICES FOR PERSONS WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY. Available from https://www.cga.ct.gov/2023/BA/PDF/2023HB-05001-R01-BA.PDF

[7] McQuaid, Hugh (March 10, 2023). Bipartisan coalition of lawmakers seek to improve access to autism and IDD services. CT News Junkie. Available: https://ctnewsjunkie.com/2023/03/10/bipartisan-coalition-of-lawmakers-seek-to-improve-access-to-autism-and-idd-services/

[8] Examples of public call for action can be found across Connecticut news sources, such as here.

[9] J. Jansen-van Vuuren & H.M. Aldersey. June 2020. Stigma, Acceptance and Belonging for People with IDD Across Cultures. Current Developmental Disorders Reports. Accessed: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7326393/

[10] E.L. Zeilinger, K.A. Stiehl, H.Bagnall, & K. Scior. October 2020. Intellectual disability literacy and its connection to stigma: A multinational comparison study in three European countries. PLOS ONE. Accessed: https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0239936

prejudice, and social and community exclusion.[11] Changing how IQ testing is used as a criterion to determine eligibility for services and support could be one step toward reducing the stigma experienced among this population. Research highlights the negative impacts of diagnostic labels and calls for communities and society at large to play active roles in raising awareness about behavioral and learning disorders and intellectual disabilities. Findings from a meta-analysis exploring the influence of diagnostic label effects emphasize how many children with a disability diagnosis – whether behavioral, intellectual, or learning – face not only the challenges that come with their diagnosis but also the diagnosis-related stigmatization.[12] Removing IQ testing as an eligibility requirement could help limit the stigma often attached to intelligence evaluations. More work is needed to remove the barriers to successful integration and assurance of equal rights for individuals with intellectual disability and autism.

Furthermore, intelligence testing has inherent biases that raise concerns about equity and injustice. Researchers have raised the question of validity in IQ testing mainly due to the subgroups of people used in samples for norm testing. A wide range of empirical evidence suggests cognitive functions and processes are oriented and developed in context. In a recent article on the need for modern evaluations to be fair and equitable, the authors call on practitioners to better serve populations that current testing standards and testing approaches may marginalize. Improvements include the commitment to use of universal assessments that can be used for everyone "by thinking about more inclusive, culturally sensitive, and representative research."[13] The most widely used intelligence scales are the Wechsler Adult Intelligence Scale, 4th edition, and the Wechsler Intelligence Scale for Children, 5th edition, which contain items that may lack cultural context and application for non-white people, for example. Understanding the impact of culture on cognitive processes and adaptive behaviors is essential to achieving fair assessment practices.

Consistent with other HCBS workforce challenges, psychological services are difficult to access. In 2022, the American Psychological Association gathered data on the post-COVID-19 impact on psychologists. They found that 60% of psychologists were unable to accept new patients, and 38% managed a waitlist for services.[14] Labor shortages lead to delays in required psychological testing, resulting in protracted enrollment in programs that support people's ability to live safely and independently in their communities.

Encouragingly, there is a national self-advocacy movement to minimize the biases, stigma, and inequities so often faced by individuals with intellectual disability or autism. This includes improving access and availability of supports, revising definitions and eligibility criteria, refining level of need assessment tools as necessary to align with changes to the statutory language, and focusing on workforce development to support individuals with intellectual disability and autism to engage with the community more fully. Some states are taking steps to support more forward progress toward a destigmatized, equitable, accessible, and person-centered landscape backed by a solid foundation to meet the needs of the people it serves by assessing the need for concrete labels such as IQ using

[11] Jansen-van Vuuren J, Aldersey HM. Stigma, Acceptance and Belonging for People with IDD Across Cultures. Curr Dev Disord Rep. 2020;7(3):163-172. doi: 10.1007/s40474-020-00206-w. Epub 2020 Jun 30. PMID: 32837827; PMCID: PMC7326393.
[12] D.J. Franz, T. Richter, W. Lenhard, P. Marx, R. Stein, & C. Ratz. February 2023. The influence of Diagnostic Labels on the Evaluation of Students: a Multilevel Meta-Analysis. Educational Psychology Review, 35(17). Accessed: https://link.springer.com/article/10.1007/s10648-023-09716-6
[13] Holden LR, Tanenbaum GJ. Modern Assessments of Intelligence Must Be Fair and Equitable. J Intell. 2023 Jun 20;11(6):126. doi: 10.3390/jintelligence11060126. PMID: 37367528; PMCID: PMC10301777.
[14] American Psychological Association. November 2022. Psychologists Struggle to Meet Demand Amid Mental Health Crisis. Available from https://www.apa.org/pubs/reports/practitioner/2022-covid-psychologist-workload.pdf.

other means for evaluating individuals that are more focused on culturally and age-appropriate expectations. Reviews of state best practices include several states that are moving away from IQ as a primary factor in determining eligibility for developmental disability services by either removing its inclusion altogether or augmenting the use of IQ, among other factors, such as functional abilities to conduct daily activities, ability to remain safe in the community, as well as consideration of other conditions as defined by the state and determined by the clinical judgment of licensed evaluators.

Connecticut's Current Enrollment and Eligibility Pathways

Connecticut DDS and DSS provide services and supports for individuals with intellectual disability and autism that "promote independence while also offering care and support."[15] DSS and DDS offer six (6) waivers for individuals with intellectual disability and autism, as Appendix A details.

Connecticut Waivers

- Comprehensive Supports (COMP) Waiver
- Home and Community Supports Waiver for Persons with Autism
- Employment and Day Supports Waiver
- Katie Beckett Waiver
- Personal Care Assistance Waiver
- Individual and Family Supports Waiver

This report focuses on the eligibility determination and enrollment processes DDS and DSS have for services available to individuals with intellectual disability or autism. These processes directly affect enrollment for three essential waivers overseen by DDS and DSS. They are central to the purpose of this report: the Comprehensive Supports (Comp) Waiver, the Employment and Day Supports Waiver, and the Home and Community Supports Waiver for Persons with Autism.

Application Requirements

Figure 3 provides a snapshot of eligibility for DDS services and the DSS Autism Spectrum Disorder Program. IQ testing is required for both services. Eligibility for DDS services depends on an intellectual disability diagnosis as defined in Connecticut General Statute 1-1g, outlined below in **Figure 5**. The autism program requires a functioning IQ above the level of intellectual disability. **Figure 4** looks at the subsequent steps to access services under the HCBS waivers that support people with intellectual disability or autism. Individuals with intellectual disability and autism in need of services must first meet the eligibility for DDS services and DSS program requirements, respectively. Once the individual meets this eligibility, the individual can seek enrollment through a Medicaid-funded HCBS waiver with additional requirements. [16],[17]

[15] State of Connecticut: Connecticut Developmental Services. Available online: https://portal.ct.gov/dds/eligibility?language=en_US
[16] Eligibility Fact Sheet: Intellectual Disability. Available: https://portal.ct.gov/-/media/dds/factsheets/ifs_eligibility.pdf
[17] Connecticut Department of Social Services. Autism Spectrum Disorder – Eligibility. Available here: https://portal.ct.gov/dss/health-and-home-care/autism-spectrum-disorder---asd/autism-spectrum-disorder---asd/eligibility

Figure 3. Eligibility for DDS or DSS Service

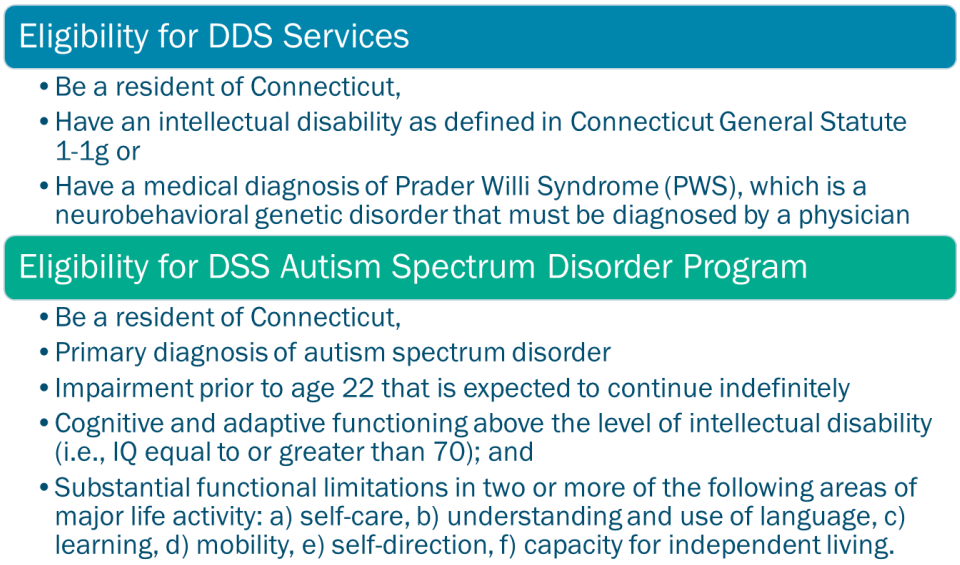


Figure 4. HCBS Waiver Enrollment Criteria

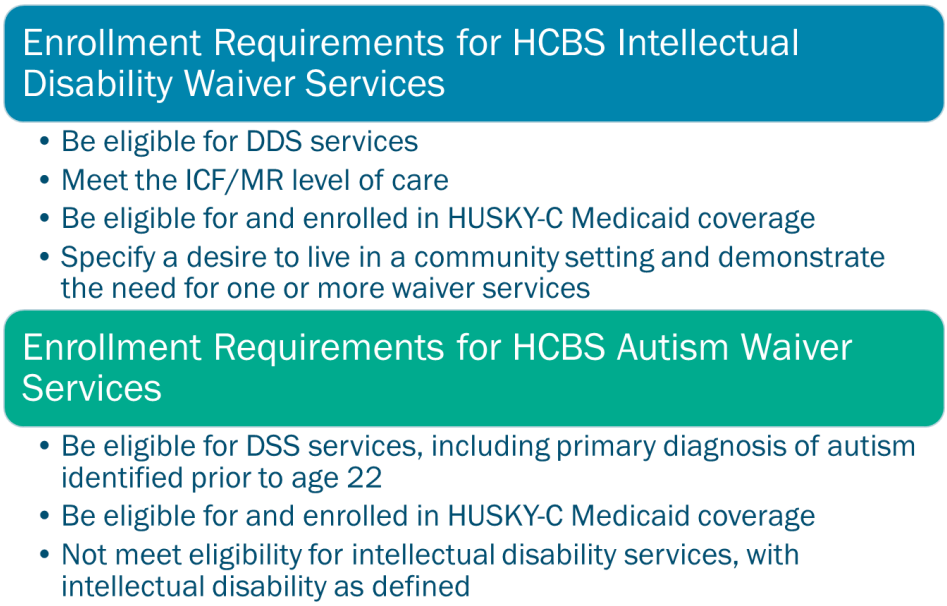


Figure 5. Connecticut General Statute 1-1g

Intellectual Disability defined as:

(a) Except as otherwise provided by statute, "intellectual disability" means a **significant limitation in intellectual functioning** existing concurrently **with deficits in adaptive behavior** that originated during the developmental period before 18 years of age.

(b) As used in subsection (a) of this section, "significant limitation in intellectual functions" means intelligence quotient more than two standard deviations below the mean as measured by tests of general intellectual functioning that are individualized, standardized and clinically and culturally appropriate to the individual; and "adaptive behavior" means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group as measured by tests that are individualized, standardized and clinically and culturally appropriate to the individual.

The IQ score criterion is reportedly limited to no flexibility due to concerns over potential exception requests. Based on the current definition, this has implications for eligibility determination for DDS or DSS services and waiver eligibility.

Eligibility testing for DDS services based on intellectual disability requires documentation from various psychological evaluations, including cognitive and adaptive scores before the age of 18. According to DDS, once an adult is eligible for DDS services based on intellectual disability, that determination is not systematically reevaluated. However, the department may request reevaluations in exceptional cases.[18]

Table 1: Examples of Required Testing for Eligibility Determination

Category	Test Examples	Description
Intelligence and Cognition	Wechsler or Stanford-Binet tests	Assess an individual's intellectual and cognitive ability and generate IQ scores.
Adaptive Skills Testing	Vineland or Behavior Assessment System for Children	Evaluate an individual's ability with daily activities (e.g., dressing, grooming, and social skills).
Autism Diagnostic Testing	Gilliam Autism Rating Scale, Childhood Autism Rating Scale, Autism Diagnostic Observation Schedule	Indicate a diagnosis of an autism spectrum disorder.

Evaluators who conduct eligibility testing must have a specialty in the age range of the individual engaged in psychological testing and have training, experience, and competency in diagnosing

[18] Office of Legislative Research, Research Report. March 2014. Intellectual Disability. Available here https://www.cga.ct.gov/2014/rpt/pdf/2014-R-0098.pdf.

intellectual disability. In Connecticut, this might include one of the following or any other appropriately trained professional with expertise in intellectual disability:

- Psychiatrist
- Psychologist
- Neurologist
- Developmental pediatrician
- Certified school psychologist

There are unique applications available for different sub-populations, including individuals with intellectual disability, individuals with autism and no intellectual disability over the age of three, and support for children that are three years old or younger. These resources provide checklists for individuals preparing applications to ensure all documentation and required tests are submitted according to requirements. Examples of tests needed are included in **Table 1.**

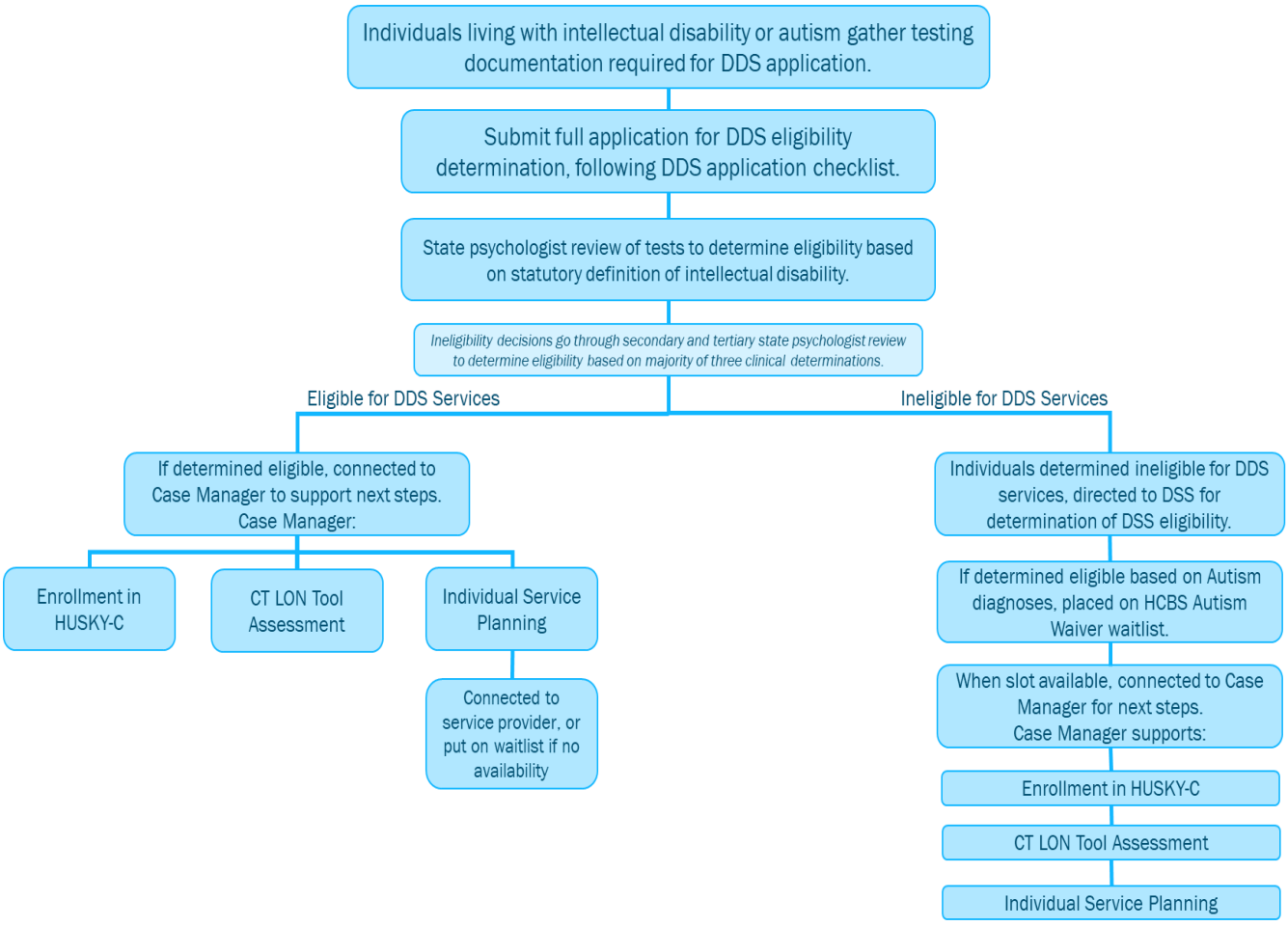
For individuals with autism applying for services and support from DSS, there are additional steps for eligibility determination. As noted in the application for eligibility, a standardized test, such as Gilliam Autism Rating Scale (GARS), Childhood Autism Rating Scale (CARS), and Autism Diagnostic Observation Schedule (ADOS), must be done before the individual turns 21.[19] Testing can typically be obtained from schools, agencies, or private psychologists upon request. Evaluator requirements align with those of DDS eligibility evaluators and are also required to have qualifications to conduct diagnostic evaluation and diagnose autism.

Eligibility Determination

To be eligible for waiver services under Connecticut state law, individuals with intellectual disability must first be determined eligible for state services based on these criteria. As noted, individuals with intellectual disability must apply for DDS service eligibility as the first step to enrolling in a waiver and accessing supports. The full eligibility determination and enrollment process workflow is outlined in **Figure 6** below.

[19] Note discrepancy between CT website and waiver application. The application notes a standardized test must be done prior to the age of twenty-one (21) per the Application Checklist (ct.gov). But the website notes "impairment prior to age 22" Autism Spectrum Disorder - ASD--Eligibility is required to be documented.

Figure 6. Eligibility Workflow Depiction



As indicated, upon applying for eligibility and submission of test results, the application and corresponding documents are reviewed by a state-employed psychologist and confirmed by a second state-employed psychologist.[20] If approved as eligible for DDS services, the individual is assigned to a DDS region and a case manager that supports them through the next steps in the process, including completing the LON tool, enrolling in HUSKY C, and service planning.

The case manager collaborates with the individual and those closest to them—family, friends, and providers—to complete a comprehensive LON tool. The LON assesses several key areas, including health and medical needs, personal care activities, daily living skills, and many others. For details on the LON assessment and tool, please refer to Appendix B. After completing the LON, the case manager works with the individual to develop a service plan, enroll in HUSKY C with the help of eligibility specialists, assist them with enrollment in services, or guide them onto waitlists for services

[20] Should the state psychologist determine the individual would not be eligible under the statutory definition of intellectual disabilities, that case is routed for a secondary review for confirmation of lack of eligibility. Should those two opinions differ, a third psychologist reviews the case and the majority decision is upheld.

that can be approved formally with waiver enrollment. Ideally these three steps occur simultaneously to streamline eligibility determination. This proactive approach minimizes the time between eligibility and actual service delivery, ensuring a smooth transition across state agencies.

If an individual is not determined eligible for DDS services, DDS coordinates with DSS or connects them to the DDS Help Line. When reviewing an application, if that individual may be eligible for services under the Autism Waiver, their application is sent to DSS for eligibility determination and waiver enrollment.

The eligibility determination and enrollment process in the HCBS Autism Waiver is slightly different. The state psychologist reviews the application and the required testing documentation for determination. However, once determined eligible, the individual is placed on a waitlist for the waiver. When they reach the top of that waitlist, a DSS caseworker processes those cases, including enrolling the individual in HUSKY C, conducting the LON tool assessment, and working with them to develop their service plan.

For individuals that are determined ineligible for DDS services and may not qualify for DSS services supporting individuals with autism, DDS connects them and their families to a dedicated DDS Help Line Staff in one of the three regions. The Help Line is available to answer questions and give guidance on accessing DDS resources for support and services for those who do not have an assigned DDS case manager. As case managers do, DDS Help Line staff support individuals and their families through this process and provide guidance to ensure individuals can access the necessary services for which they are eligible.

The eligibility determination and waiver enrollment workflow is designed to support objective determination of eligibility under the statutory definitions and allow for inter-departmental coordination. DDS case managers aim to support individuals through the process as efficiently as possible to decrease the time from eligibility to receiving services. But despite best efforts, Connecticut residents seeking services under Medicaid waivers face challenges in accurately completing their applications, experience long determination wait times, or cannot access services timely. Further, due to the intellectual disability definition currently in place, individuals may be determined ineligible for services based solely on IQ score, regardless of medical diagnosis or the presence of adaptive behaviors indicative of intellectual disability or autism.

Alternative Regulatory Approaches and Best Practices

As Connecticut actively explores potential options to evaluate current supports and services available to individuals in the state, other states are similarly exploring ways to improve their policies and programs, which can lend valuable strategies and lessons learned for consideration. Nationwide, there is a call to action to revisit eligibility criteria and assessments to improve access to intellectual disability services and supports. Connecticut is one of many states evaluating IQ as an eligibility criterion and the impact on its current Connecticut LON tool and service planning workflows. With similar calls to action among other states, Altarum's research included reviewing similar activities within other states and conducting interviews with key states whose experiences would provide Connecticut with key information for potential changes. Multiple states' policies and recent efforts were assessed for inclusion in this report. Best practices from the following states are summarized in this section as they specifically tie to potential recommendations included in this report:

- Arkansas
- Massachusetts
- Minnesota
- Vermont
- Washington

In assessing potential changes to the intellectual disability definition and evaluating the utility of the LON tool, Connecticut's approach should take into account best practices and promising strategies identified through informational interviews conducted with state disability agencies engaged in similar efforts. Informational interviews took place between June and September 2024.

Arkansas

Key Takeaway: Arkansas' definition of intellectual disability includes language that can be inclusive of multiple functional behaviors even if IQ is above 70. Arkansas customized Minnesota's assessment tool to serve as their state-specific LON tool. Additionally, Arkansas created service tier levels based on state-specific logic.

In 2016, Arkansas embarked on a statewide effort to deliver coordinated, person-centered, and efficient services and supports organized around a person's comprehensive health needs across providers and over time. As part of this effort, they adopted the use of a single comprehensive assessment to support eligibility determination, determination of the amount and type of services needed, and service plan development across populations served by three divisions: the Division of Aging and Adult Services (DAAS), Division of Developmental Disabilities Services (DDS), and Division of Behavioral Health Services (DBHS). The Arkansas Independent Assessment Initiative (ARIA) moved the state from determining eligibility based primarily on diagnosis to a system that focuses on the functional needs of people seeking Medicaid-funded HCBS.

Individuals seeking services from Arkansas DDS must first be diagnosed with an intellectual or developmental disability before completing the functional assessment to determine whether the individual meets the institutional level of care and the level of services and supports needed. In 2023, Arkansas clarified the state definition of intellectual and developmental disability during the Legislative session through Act 214, An Act to Clarify the Definition of "Intellectual and Developmental Disability" in the Arkansas Code, and For Other Purposes. While Arkansas still includes an IQ scale, the definition consists of "or" language, as well as the inclusion of language that allows the state to consider the impact of a person's condition(s) on their ability to function daily. This broadens the potential population of individuals with intellectual or developmental disabilities eligible to receive DDS services.

SECTION 1. Arkansas Code § 20-48-101(4)[21] Defines intellectual and developmental disability as "a chronic disability of an individual that:

A. Is attributable to a diagnosis of one of the following:

[21] Arkansas Senate Bill 189. (2023). Available from https://www.arkleg.state.ar.us/Home/FTPDocument?path=%2FACTS%2F2023R%2FPublic%2FACT214.pdf

(i) Cerebral palsy, as established by the results of a medical examination by the individual's primary care provider or a licensed physician;

(ii) Epilepsy, as established by the results of a neurological examination by the individual's primary care provider or a licensed physician;

(iii) Spina bifida, as established by the results of medical examination by the individual's primary care provider or a licensed physician;

(iv) Down syndrome, as established by the results of medical examination by the individual's primary care provider or licensed physician;

(v) Autism spectrum disorder; as established under § 20-77-124; **or**

(vi) Intellectual disability, as established by a full-scale standard intelligence score of seventy (70) or below, measured by a standard test designed for individual administration that is administered by a qualified professional; **or**

(vii) Any other condition that results in impairment of general intellectual functioning or adaptive behavior similar to an individual qualifying under subdivision (4)(A)(vi) of this section.

B. Originates before the person attains twenty-two (22) years of age;

C. Has continued or can be expected to continue indefinitely; and

D. Constitutes a substantial impairment to the person's ability to function without appropriate support services, including without limitation:

(i) Daily living and social activities;

(ii) Medical services;

(iii) Job training; and

(iv) Employment."

Arkansas bases its definition of Autism Spectrum Disorder (autism) on the most recent edition of the Diagnostic Statistical Manual (DSM)[22], a formalized autism evaluation instrument such as the Childhood Autism Rating Scale or Autism Diagnostic Observation Scale administered by an appropriately licensed professional, or a delineation of DSM criteria. An autism diagnosis must be made by at least two of the following three licensed professionals individually or as a team: physician, psychologist, and speech-language pathologist. The autism diagnosis must be the primary contributing factor to the individual's delays, deficits, or maladaptive behavior.

Waivers and Eligibility for Services

Families that believe their child may have an intellectual or developmental disability can contact the Arkansas DDS Intake and Referral line or submit an online request for services. The online form captures demographic information, the services requested, and the reason for the referral. Healthcare providers or other care providers may also submit referrals for Arkansas DDS services using this online portal. For infants or preschool children ages 0-5, developmental scales are administered by primary care providers using an approved instrument, indicating impairment of general functioning similar to that of individuals with developmental disabilities. Arkansas currently has two HCBS waivers for individuals with intellectual and developmental disabilities: the **Community**

[22] Center for Diseases Control and Prevention. Clinical Testing and Diagnosis for Autism Spectrum Disorder. Available from https://www.cdc.gov/autism/hcp/diagnosis/index.html

and Employment Support (CES) Waiver and the Autism Waiver.

Each waiver uses a different process and instrument(s) to determine eligibility based on diagnoses, included in **Table 2**. Arkansas DDS uses the AR Independent Assessment (ARIA), described more fully in the waiver section below, to determine the institutional level of need for the CES Waiver and works closely with a third-party vendor to assess the level of need for individuals enrolling in the Autism Waiver. When eligibility for services is determined, individuals and their family members or legal guardians are asked to confirm whether they would like to pursue community support or find an institutional setting.

Arkansas' CES Waiver

To receive CES services, individuals must first meet the definition of intellectual and developmental disability described above. Arkansas employs a Psychology Team composed of a chief psychologist and four independently licensed master's-level psychological examiners. This team reviews the standardized evaluation of intellect and adaptive behavior listed in **Table 2** when conducted by the appropriate credentialed professional.

The Psychology Team reviews the evaluations submitted and determines whether the instruments used are appropriate based on age, mental capacity, medical condition, and physical limitations. The review includes the submitted social history, the Department of Human Services (DHS) 703 Form, and a narrative summary of the person's six areas of need: Self-Care, Understanding, and Use of Language, Learning, Mobility, Self-Direction, and Capacity for Independent Living. If the psychology team deems the individual eligible for intellectual or developmental disability diagnosis, Arkansas DDS initiates a referral for an ARIA assessment administered by a third-party vendor. The referral occurs after a participant has been determined at one time to meet the institutional level of care. The following populations receive an independent assessment:

- Individuals enrolled in CES Waiver
- Individuals on the waitlist for the CES Waiver
- Individuals meeting ICF/IID level of care
- Individuals in State-run Human Development Centers (HDC)

Arkansas HCBS Waivers

- Community and Employment Support (CES) Waiver (otherwise known as the Developmental Disability Waiver) supports individuals of all ages who have a developmental disability. The goals of the CES Waiver are to support individuals in all major life activities, promote community inclusion through integrated employment options and community experiences, and provide comprehensive care coordination and service delivery from the Provider-led Arkansas Shared Savings Entities (PASSE) program. Services include respite, supported employment, habilitation or supportive living, specialized medical supplies, adaptive equipment, community transition services, consultation, crisis intervention, home and/or vehicle accessibility adaptation, and supplemental support services.
- Autism Waiver: provides intensive one-on-one intervention services in a natural environment, allowing children to live in the community and preclude or postpone institutionalization. Services available under the Autism Waiver include individual assessment/treatment, development and monitoring, therapeutic aides and behavioral reinforcers, lead therapy intervention, line therapy intervention, and consultative clinical and therapeutic services.

The AR Independent Assessment (ARIA) is based on the MnCHOICES assessment. It has been customized for Arkansas needs across the following populations: older adults, individuals with physical disabilities, individuals with intellectual and developmental disabilities, and individuals with behavioral health needs of all ages. ARIA is used to auto-generate a recommended service tier level based on eligibility criteria as defined by the state's tiering logic built upon categories of need.[23] Assessment areas include the following domains: Quality of Life, Activities of Daily Living (ADL), Instrumental Activities of Daily Living (IADL), Safety and Self-Preservation, Memory and Cognition, Psychosocial, Health, Sensory and Communication, Employment, and Caregiver. For DDS services, there are two-tier levels:

Table 2: Instruments for Determining Eligibility by Waiver

Waiver	Diagnostic Tests
CES Waiver	Wechsler Scales of Intelligence Stanford-Binet Scales of Intelligence Vineland Adaptive Behavior Scale Adaptive Behavior Assessment Scales
Autism Waiver	Vineland Adaptive Behavior Scale Temperament Atypical Behavior Scale (TABS)

- Tier 2: Functional needs scored high enough to be eligible for paid services and supports, requiring paid care or services less than 24 hours per day, seven days per week
- Tier 3: Functional needs scored high enough in certain areas to be eligible for the most intensive level of services, including 24 hours a day, seven days a week paid support and services in a Human Development Center (HDC)

Once eligible, beneficiaries are auto-assigned to a Provider-Led Arkansas Shared Savings Entity (PASSE). PASSEs are a full-risk organized care organization responsible for providing all services to its enrolled members (excluding some services including SNF, school-based, assisted living, Human Development Center services, ARChoices in Homecare Waiver, and AR Independent Choices Waiver services). The PASSE care coordinator is responsible for arranging the person-centered service planning (PCSP) development, which is led by the participant as much as they choose and can use the ARIA assessment to help develop the PCSP. The care coordinator also uses any other information to help develop the PCSP, including evaluation results, psychological testing, adaptive behavior assessments, social, medical, physical, and mental health histories, and a risk assessment.

Individuals with intellectual and developmental disabilities may also apply for Medicaid personal care services. The ARIA is the assessment used to determine eligibility, which requires hands-on assistance with at least one ADL. If determined eligible, individuals are eligible to receive up to 64 hours per month of personal care services. The number of hours the individual is authorized for is determined by the ARIA assessment, which includes an auto-generated task and time calculation for completion of ADLs and IADLs.

Arkansas' Autism Waiver

In line with the Arkansas Act 1008 of 2015, the Autism Waiver serves 180 participants at any point in time for a maximum of three years. Individuals must be determined eligible for the waiver on or before their fifth birthday. Eligibility determination processes align with those for the CES Waiver, but

[23] Categories of need include safety: ability to remain safe and out of harm's way, behavior: behaviors that could place the beneficiary or someone else in harm's way, and self-care: the beneficiary's ability to take care of themselves (e.g., ADLs/IADLs)

Arkansas DDS contracts with a third-party vendor to administer the majority of program operations, including the administration of evaluation instruments to determine program eligibility. That vendor connects individuals with an Autism Waiver Coordinator. The Autism Waiver Coordinator meets in person with the parent/guardian and participant to complete the initial level of care "LOC" evaluation and administer the adaptive functioning and behavior evaluations necessary to determine whether they meet the institutional level of care (outlined in **Table 2** above). These forms are used to complete the DHS 703 Form, which is provided to the DHS Office of Long-Term Care (OLTC) along with the instrument results to formally determine whether the individual is eligible. All staff reviewing eligibility must be a licensed Registered Nurse. Once clinical eligibility is determined, the individual must go through the financial eligibility process. If the individual is determined eligible, they are enrolled in the Autism Waiver if there is an available slot. If a slot is not available, they are placed on a waitlist, which is managed on a first-come, first-served basis. Individuals are reassessed annually for continued eligibility.

Once determined eligible, the participant's Coordinator develops a service plan in collaboration with the parent/guardian, knowledgeable professionals, and others desired. The service plan is driven by the results of the adaptive functioning and behavior evaluations, including the participant's strengths and needs from Vineland, additional behavioral information from the TABS, and the parent/guardian's preferences. Additionally, risk factors are identified and documented in the service plan, including self-injurious behavior, aggressive/destructive behavior, elopement behaviors, inability to communicate needs/wants, and food aversion/pica behaviors. The parent/guardian is the primary informant for the evaluations. Service plans are updated annually.

Three (3) months prior to the participant's term date, the Coordinator initiates transition planning. This includes an in-home meeting with the participant's parent/guardian, during which other services, supports, and appropriate referrals (e.g., Medicaid state plan services, other waiver alternatives, and programs available) are discussed.

Massachusetts

Key Takeaway: Massachusetts' definition of intellectual disability includes multiple considerations for contextual factors that would impact conceptual, social, and practical adaptive skills. These support the personalized approach to determining eligibility based on definition that takes into consideration strengths, environment, and cultural and linguistic contexts. Eligibility determinations are performed by the Regional Intake and Eligibility Team (RIET) that include a licensed doctoral level psychologist, a professional with a master's degree in social work, and a department eligibility specialist.

Massachusetts definitions for intellectual disability, developmental disability, and Autism Spectrum Disorder (autism) are codified in statute and regulations of the Department of Developmental Services (DDS) at M.G.L. c. 123B and 115 CMR 2.01:

1. *Autism Spectrum Disorder* has the same meaning as in the Diagnostic Statistical Manual of Mental Disorders, 5th edition.
2. *Developmental Disability* is defined as:
   (1) An individual five years of age or older with a severe, chronic disability that:
      i. is attributable to a mental or physical impairment resulting from intellectual disability,

autism, Smith-Magenis Syndrome, or Prader–Willi syndrome;

ii. is manifested before the individual attains age 22;

iii. is likely to continue indefinitely;

iv. results in substantial functional limitations in three or more of the following areas of major life activity:
- self-care;
- receptive and expressive language;
- learning;
- mobility;
- self-direction;
- capacity for independent living; and
- economic self-sufficiency; and

v. reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration and is individually planned and coordinated; or

(2) an individual under the age of five who has a substantial developmental delay or specific congenital or acquired condition with a high probability that the condition will result in a developmental disability if services are not provided. A person who has a developmental disability may be considered to be mentally ill, provided, however, that no person with a developmental disability shall be considered to be mentally ill solely by reason of the person's developmental disability.

(3) Intellectual Disability is defined as a person who has an intellectual disability characterized by significant limitations in both intellectual functioning and adaptive behavior as expressed in conceptual, social, and practical adaptive skills and beginning before age 18, and consistent with the most recent definition provided by the American Association on Intellectual and Developmental Disabilities; provided, that in applying this definition the following shall be considered:

vi. limitations in present functioning within the context of community environments typical of the individual's age, peers, and culture;

vii. cultural and linguistic diversity and differences in communication, sensory, motor, and behavioral factors;

viii. limitations often coexist with strengths within an individual;

ix. an important purpose of describing limitations is to develop a profile of needed supports; and

x. with appropriate personalized support over a sustained period, the life functioning of a person with an intellectual disability will generally improve; and provided further, a person who has an intellectual disability may be considered to be mentally ill; provided, however, that no person with an intellectual disability shall be considered to be mentally ill solely by reason of the person's intellectual disability.

Waivers and Eligibility for Services

Regional Intake and Eligibility Teams (RIETs) receive applications for DDS services. Once an application is received, a RIET member contacts the individual applying or their family or legal guardian to schedule a face-to-face meeting. The RIET informs the individual about the criteria for

eligibility, procedures for the determination process and the system of prioritization for receipt of supports based on need, funding, and availability, information required, and appeal rights.

RIETs must include at least one member who is a licensed doctoral-level psychologist with a master's degree in social work and a department eligibility specialist. The RIET interviews the individual and other significant people in their life, if possible. The process may include a) consideration of psychosocial, neuro-psychological, medical, and educational assessments and b) intelligence test results for people applying for intellectual disability services. Only qualified practitioners can administer and interpret psychological tests. The Department RIET psychologist should consider the psychometric properties of intelligence tests, tests of functional assessments, and other assessment instruments, including the standard error of measurement, where appropriate. The RIET psychologist may consider relevant data in making clinical judgments about the presence or absence of intellectual disability, the presence and severity of, or absence of, Autism Spectrum Disorder, or the presence or absence of Smith-Magenis Syndrome, Prader-Willi Syndrome, or closely related developmental conditions.

Should the individual meet eligibility criteria, the information provided from the application process serves as the basis for the development of the individual's support plan and determination of the individual's priority to receive supports, including determining the general types of supports to best meet their needs in the most appropriate and least restrictive setting.

Massachusetts offers three waiver programs for adults with intellectual disability. Each gives participants the opportunity to have certain services delivered under participant direction or using an Agency with Choice option. To be eligible, an individual must first meet the financial and clinical eligibility requirements:

- Have an intellectual disability as defined by Massachusetts DDS
- Meet the level of care needed for an ICF/IID
- Be a resident of Massachusetts
- Be 22 years of age or older
- Need a waiver service monthly
- Be safe to serve in the community within the terms of the waiver enrolled
- Meet Medicaid (MassHealth) Standard in the community

Massachusetts HCBS Waivers for Adults with Intellectual and Developmental Disabilities

- **Community Living Waiver** provides services to adults aged 22 and over who receive a moderate level of assistance and either live on their own in a home or in their family home. The goal is to provide support to participants in their communities to avoid the need for restrictive institutional care. Participants must require less than 24 hours a day of support.
- **Adult Supports Waiver** provides community-based supports to adults aged 22 and over who have a strong natural or informal support system; helps to develop and acquire work skills or provide assistance to the family/caregiver.
- **Intensive Supports Waiver:** provides flexible and necessary supports to adults 22 years an older who are determined to require supervision and support 24 hours, 7 days a week to avoid institutionalization.

Prioritization for adult intellectual disability services and supports provided by Massachusetts DDS are determined by the area director based on the severity of the individual's needs. For individuals eligible for one of the three Medicaid waiver programs, there are two prioritization categories:

1. First Priority: Provision, purchase, or arrangement of supports available through the

Department is necessary to protect the health or safety of the individual or others.

2. Second Priority: Provision, purchase, or arrangement of supports available through the Department is necessary to meet one or more of the individual's needs or to achieve one or more of the needs identified in their Individual Service Plan.

Prioritization for adult community developmental disability supports is also subject to availability of resources, with the area director making the decision based upon the severity of the individual's needs. Massachusetts provides emergency supports if it is determined that in the absence of supports there exists a serious or immediate threat to the health or safety of the individual or others.

Children with Intellectual Disabilities: individuals younger than 22 years of age can access Children's Support and must meet the definition of intellectual or developmental disability per statute. Prioritization for the allocation of available Children's Supports provided by Massachusetts DDS is determined by the area director based on the severity of the child's or young adult's and family's needs.

Level of Need / Assessments and Instruments

Massachusetts uses the Vineland III (or another valid and reliable measure of adaptive functioning as determined by a Massachusetts DDS licensed psychologist, such as the Adaptive Behavior Assessment Scale (ABAS) Revised) to determine the functional needs of participants across the three available waivers. The initial evaluation consists of an assessment of the individual's need for supervision and support and an assessment of the specialized characteristics of the individual and the capacity of the caregiver to provide care. The Inventory for Client and Agency Planning (ICAP) (or other valid and reliable adaptive behavior assessment, the Consumer and Caregiver Assessment (CCA) in conjunction with Vineland III or ABAS, Revised, is allowed. The same instrument is used to assess all individuals in the waiver. The domains assessed by the ICAP include motor skills, social and communication skills, personal living skills, and community living skills. It also assesses maladaptive behavior. These are conducted in addition to the other assessments and materials described above as part of the waiver eligibility process. The CCA is used to assess the caregiver's capacity to provide care and is designed to highlight the caregiver's strengths and needs to provide care in the home for the participant. Factors such as age, health status, mental acuity, ability of the caregiver to drive, and the potential impact of these factors on the participant are reviewed. Reevaluation for the level of care is completed annually using a shortened version of the Massachusetts Comprehensive Assessment Profile (MASSCAP).

Minnesota

Key Takeaway: Minnesota took on a multi-year revision process for improvements to its MnCHOICES assessment tool and platform. MnCHOICES captures information on activities of daily living, instrumental activities of daily living, medical service needs, safety and supervision needs, and informal caregiver support and is administered by certified assessors who go through a four-step training process.

The Minnesota Department of Human Services (DHS) Disability Services Division (DSD) provides funding for home and community-based services for children and adults with developmental disabilities or related conditions through their Developmental Disabilities (DD) Waiver, which includes intellectual disabilities. As defined in the *Minnesota Administrative Rules 9525.0016*

Subpart 2 Item B, a "person with a related condition means a person who has been diagnosed under this part as having substantial limitations in present functioning, manifested as significantly subaverage intellectual functioning, existing concurrently with demonstrated deficits in adaptive behavior and who manifests these conditions before the person's 22nd birthday."[24] Further, "significantly subaverage intellectual functioning" is also defined as "a full-scale IQ score of 70 or less based on the assessment that includes one or more individually administered standardized intelligence tests developed for the purpose of assessing intellectual functioning."

Waivers and Eligibility for Services

To be eligible for DD Waiver services, individuals go through a screening process that includes a determination that the individual has a developmental disability or related condition that is likely to require the level of care provided to individuals in an Intermediate Care Facility for Persons with Developmental Disabilities (ICF/DD), is eligible for Medical Assistance (Medicaid coverage within Minnesota) and makes an informed choice requesting home and community-based services instead of ICF/DD services.[25]

For this process, the determination of developmental disability or related condition and ICF/DD level of care determinations use the results of the diagnostic determination process.[26] This process may be completed concurrently with completion of the MnCHOICES assessment which is used to determine whether the person meets level of care. In this process, a qualified developmental disability professional (QDDP) reviews the individual's diagnosis, functional testing results, social history, and medical record to determine if the individual meets the diagnostic threshold for a related condition such as intellectual disability. If the individual does not meet the threshold of having an IQ of 70 or below, the QDDP uses the Related Conditions Checklist, (DHS-3848) to determine if the individual "IS or IS NOT eligible for case management as a person with a condition related to developmental disability".

Level of Need / Assessments and Instruments

An individual's initial assessment to determine level of care is completed using the MnCHOICES assessment tool. MnCHOICES originated as a combination of three separate assessments, including Personal Care Assistance, Long-Term Care Consultation for HCBS Medicaid waivers, and the Developmental Disabilities Screening for the DD waiver. Through a multi-year process MnCHOICES was refined, with the current 2.0 version removing duplicative questions that existed in version 1.0. MnCHOICES includes an assessment of activities of daily living, instrumental activities of daily living, medical service needs, safety and supervision needs, and informal caregiver support. The certified assessor also uses information from requested medical histories, physician records, and reports from providers to further evaluate and understand the individual's needs. For children, the assessment includes age-appropriate questions, identifying needs that are beyond what is typical for a child to complete. For example, ADL questions address what would be considered a "typical" dependency based on the child's age and how it should be considered (e.g., a child 12 months or

[24] Minnesota Legislature. Minnesota Administrative Rules. https://www.revisor.mn.gov/rules/9525.0016/
[25] Minnesota Department of Human Services. Developmental Disabilities Wavier fact sheet. Available from https://edocs.dhs.state.mn.us/lfserver/Public/DHS-5713-ENG
[26] Connecticut's equivalent to the ICF/DD level of care determination is the ICF/MR level of care, which means an individual must have a level of need that would allow them to enter an institutional setting. Information found from: Connecticut Department of Social Services. Important Information about Medicaid/HUSKY/Title XIX Updated June 2023. Accessed: https://portal.ct.gov/-/media/dds/factsheets/medicaid_title_19_fact_sheet.pdf?la=en

younger is never dependent in dressing as it is "typically" an activity that is performed by the parent, whereas a child aged 13 through 36 months would be dependent if they are unable to physically participate in dressing because "typically" a child would be able to contribute physically to completion of that task).

MnCHOICES is a web-based tool housed within a customized platform by a provided vendor. It is completed in-person by a state-trained, certified assessor, typically where the individual lives. Minnesota desired to ensure consistency, expertise, professionalism, and training across all assessors administering the assessment that determines level of care. Certified assessors include professionals who complete and plan services for people who need long-term services and supports, using the MnCHOICES web-based application.[27] Qualified assessors are those with a Bachelor of Arts degree (BA) in social work, a BA in nursing with current Registered Nurse (RN) licensure, public health certification, a BA in closely related fields, and current RNs. All assessors complete the MnCHOICES certified assessor training (MnCAT) using a web-based learning management system. The MnCAT is a four-step training process. The first three steps – Foundation, Principles, and Application - have a testing component, all of which require a score of 80% proficiency or higher before moving to the next course. The fourth step involves continuing education and professional development, with required recertification every three years and 45 continuing education units in those three years in areas specific to HCBS, person-centeredness, as examples, with a goal of building best practices.[28]

MnCHOICES Revision Project

Minnesota's MnCHOICES Assessment was launched in 2013 by the Department of Human Services (DHS) to support individuals of any age with a disability or in need of long-term services and supports (LTSS) to understand their needs and support service planning. In 2016, DHS began preparing for a revision to the assessment to better support certified assessors and update the MnCHOICES computer application to ensure people's needs are met from a person-centered approach. According to the Revision Project Launch Calendar, the revised tool is being launched in five phases, beginning in April 2023 with a beta phase and extending through September 2024 for phase 4.

1. Beta Phase (May–June 2023) – beta users given access to tool, meet weekly with DHS to plan for successful launch.
2. Phase 1 (July–Sept. 2023) – set up all user accounts and bring 10% of staff onto tool for assessments.
3. Phase 2 (Oct. 2023–March 2024) – continue to bring staff onto tool, increasing to 30% using the tool for assessments.
4. Phase 3 (April–June 2024) – bring 100% of staff into the tool.
5. Phase 4 (July–Sept. 2024) – fully transition to tool and bring all existing assessments in legacy system into tool.

The MnCHOICES assessment has built in scoring and algorithms to remove subjectivity in the determination of clinical level of care eligibility. There are two applications within the MnCHOICES platform: the assessment and the support plan. The assessment helps identify what the person is eligible for. The support plan includes the tools, rates, and results from the assessment that automatically flows into the person-centered support plan.

Minnesota's development and refinement of MnCHOICES involved extensive stakeholder

[27] Additional data and information on the assessment process will be provided in future iterations as conversations with the state of Minnesota are scheduled to occur mid-August.
[28] Minnesota DHS Assessment and Support Planning. MnCHOICES certified assessors. https://www.dhs.state.mn.us/main/idcplg?IdcService=GET_DYNAMIC_CONVERSION&RevisionSelectionMethod=LatestReleased&dDocName=dhs16_176043.

engagement including the alignment of internal departments and divisions to the vision and operational goals of the initiative as well as regional, state, and local engagement of providers, consumers, advocates, and families. Minnesota learned from their original 1.0 rollout that engagement of the assessors using the MnCHOICES system and the lead agencies responsible for administering assessments and developing support plans is critical for buy-in and smooth implementation. During the 2.0 revisions, they engaged assessors to learn firsthand about MnCHOICES frustrations and successes. They included a team of subject matter experts from lead agencies to help refine MnCHOICES 2.0.

Vermont

Key Takeaway: Vermont critically reviewed their processes and found the necessity to standardize their needs assessment processes to improve the way that individuals' needs are assessed by adopting use of a single, fair, and unbiased assessment tool, the Supports Intensity Scale-Adult Version (SIS-A™) for adults with intellectual disabilities. To implement this new system, they worked with a contracted agency to first sample a population to ensure appropriate application.

The closure of the Vermont Brandon Training School in 1993 was a milestone in ending reliance on institutional settings as the model of care for people with developmental disabilities to live with dignity, respect, and independence. Since then, Vermont has relied on community-based regional Designated Agencies (DA) and Specialized Services Agencies, or self or family managed services and supports with the help of Supportive Intermediary Service Organizations,[29] to provide services.

In 1996 the Vermont Legislature passed the Developmental Disabilities Act of 1996 (DD Act), requiring the Department of Disabilities, Aging and Independent Living (DAIL) through the Division of Developmental Disabilities Services (DDS) to adopt a State System of Care Plan, or "Plan" to outline the nature, extent, allocation and timing of services for people with developmental disabilities and their families. The Act was amended twice since then, most recently in March 2023.[30] In addition to the Act, Vermont developed Developmental Disabilities Services Regulations and the production of a DDS Annual Report to operationalize the Act. The Plan is intended to provide broad guidance on how resources for individuals with developmental disabilities and their families are managed, outlines the criteria for determining who is eligible for services, and prioritizes use of resources.

Vermont recognizes that not all individuals with developmental disabilities need or want services. However, for those that do, there is an individual planning process based on the needs and strengths, goals, and availability of naturally occurring supports. Vermont is clear that services for individuals with developmental disabilities are available to those who meet the definition of who has priority for funding and supports, which are defined in the Vermont DDS Regulations and the Plan.

Eligibility for Services

[29] Vermont State System of Care Plan for Developmental Disabilities Services. Effective January 1, 2023, Technical Correction May 1, 2023. FY 2023 – FY 2025
[30] Vermont General Assembly. Title 18: Health, Chapter 204A: Developmental Disabilities Act. Available from https://legislature.vermont.gov/statutes/fullchapter/18/204A

Clinical eligibility criteria are the same for children and adults, with assessments conducted by psychologists who are contracted by the regional developmental service agencies, or DAs across the state. Psychologists submit their findings to the state for review. This process is changing in the future in response to the federal conflict of interest (COI) requirements. Developmental service agencies will no longer contract with psychologists to conduct clinical eligibility. The Vermont DDS is currently analyzing the most effective approach to eliminate COI.

There are three parts to the eligibility process: financial, clinical, and funding eligibility.

1. Financial eligibility is based on state Medicaid guidelines
2. Clinical eligibility requires having a diagnosis of a developmental disability based on a formal, professional evaluation. A person must have a diagnosis of one of the following:
    a. Intellectual Disability (IQ of 70 or below, or up to 75 or below when taking into account the standard error of measurement), or
    b. Autism Spectrum Disorder
    c. And have both of the following:
        - Significant deficits in adaptive function (such as, daily living skills, communication, and/or motor development), and
        - Onset of the disability prior to age 18.
3. Funding eligibility is based on each program and funding source's criteria

Vermont DDS Regulations, which are part of the Agency of Human Services Health Care Administrative Rules 7.100, define developmental disability.[31] The purpose of the regulations is to fulfill the requirements of the statutory requirements of the DD Act of 1996, 18 V.S.A Chapter 204A, and are adopted pursuant to 18 V.S.A. § 8726.

Per statute, developmental disability is defined as "an intellectual disability or an autism spectrum disorder which occurred before age 18 and which results in significant deficits in adaptive behavior that manifested before age 18 (See 7.100.3). Temporary deficits in cognitive functioning or adaptive behavior as the result of severe emotional disturbance before age 18 are not a developmental disability. The onset after age 18 of impaired intellectual or adaptive functioning due to drugs, accident, disease, emotional disturbance, or other causes is not a developmental disability."

Significant deficits in adaptive behavior means deficits in adaptive functioning which result in an overall composite score on a standardized adaptive behavior scale at least two standard deviations below the mean for a similar rage normative comparison group. On most tests, this is documented by an overall composite score of 70 or below, taking into account the standard error of measurement for the assessment tool used.

Criteria for assessing developmental disability in a young child as documented in 7.100.3.(b) includes:

1. The diagnosis of a condition which has a high probability of resulting in intellectual disability (7.100.3(a)(1)) must be made by a physician
2. The documentation of delays in cognitive and other developmental domains (7.100.3(a)(2)-

[31] Vermont Agency of Human Services. Disability Services – Developmental Disabilities. Available from https://humanservices.vermont.gov/sites/ahsnew/files/doc_library/DDAct_Regulations_2023_ADOPTED.pdf

(3)) must be made through a family-centered evaluation process which includes the family. The evaluation process must include:

a. Observations and reports by the family and other members of the assessment team
b. Review of pertinent medical records/educational records, such as assessments used to determine eligibility for Children's Integrated Services – Early Intervention (IS-EI) Team and Early Childhood Special Education (ECSE)

Intellectual disability is defined as "significantly sub-average cognitive functioning that is at least two standard deviations below the mean for a similar age normative comparison group. On most tests, this is documented by a full-scale IQ score of 70 or below, or up to 75 or below when taking into account the standard error of measurement, on an appropriate norm-referenced standardized test of intelligence and resulting in significant deficits in adaptive behavior manifested before age 18. It also includes severe cognitive deficits which result from brain injury or disease if the injury or disease resulted in deficits in adaptive functioning before age 18. A person with a diagnosis of "learning impairment" has intellectual disability if the person meets the criteria for determining "intellectual disability" outlined in 7.100.3(e).

To determine whether or not a school-age child or adult has intellectual disability, a psychologist must:

1. Personally perform, supervise, or review assessments that document significant sub-average cognitive functioning and deficits in adaptive behavior manifested before age 18; and
2. Integrate current and past test results with other information about the individual's abilities in arriving at a determination.

A determination that an individual has intellectual disability must be based upon current assessment of cognitive functioning and a review of any previous assessments of cognitive functioning. It is the responsibility of the psychologist to decide whether new cognitive testing is needed. In general, for school-aged children, "current" means testing conducted within the past three years. For adults, "current" means cognitive testing conducted in late adolescence or adulthood. In assessing IQ scores, psychologists are given deference to assessing whether a score above 70 may still indicate that the individual has an intellectual disability. However, that is cut off at scores greater than 75. If the psychologist determines that standardized intellectual testing is inappropriate or unreliable for the person, the psychologist can make a clinical judgment based on other information, including an adaptive behavior instrument.

Autism Spectrum Disorder (autism) is the same as it is defined in the current Diagnostic Statistical Manual (DSM).[32] Vermont grandfathered in people receiving services prior to October 1, 2017, who were determined eligible based on a diagnosis of pervasive developmental disorder under previous versions of the DSM. To determine whether someone has autism requires clinicians with specific training and experience in child development, autism, other developmental disorders, and other childhood psychiatric disorders. At a minimum, an evaluation must be performed by a single clinician, although preferably by an interdisciplinary team of professionals, who is a board certified or board eligible psychiatrist, a psychologist, or a board certified or board eligible neurologist or developmental-behavioral or neurodevelopmental disabilities pediatrician. There are additional requirements for experience and training as well.

The assessment process must include:

[32] Autism diagnostic criteria: DSM-5. Available from https://www.autismspeaks.org/autism-diagnostic-criteria-dsm-5

1. Comprehensive review of history from multiple sources including developmental, psychiatric, medical, educational, and family histories
2. Systematic autism diagnostic interview with primary caregivers
3. Systematic observation with the individual
4. For age-appropriate persons, a systemic clinical interview
5. Referral for a multidisciplinary assessment
6. Comprehensive clinical diagnostic formulation, and
7. Current assessments based on the person's typical functioning.

The detail provided in the outlining of these determination processes makes it clear to the public that IQ score will not necessarily function as a strict cutoff. The approach allows more psychological discretion in determining whether an individual may still need services. Then taking it beyond that determination, Vermont has also recently looked at their state approach to measuring needs for individuals determined eligible. They realized that their previous approach was not standardized across the state, creating inequities in the determination of needed supports and funding across individuals with similar needs.

Level of Need / Assessments and Instruments

In 2021, Vermont embarked on an initiative to assess and evaluate the process of determining individuals with developmental and intellectual disabilities needs and HCBS supports. They aimed to improve and standardize the way that individuals' needs are assessed by implementing a single assessment tool, the Supports Intensity Scale-Adult Version (SIS-A™), and established a budget based on an individual's level of support need. The benefits of a standardized assessment include improved consistency, transparency, and equity. The SIS-A™ is a tool developed by the American Association on Intellectual and Developmental Disabilities (AAIDD) and focuses on individuals' strengths, instead of challenges. It focuses on the value of community tied to self-direction, individual choice and control, and person-centered services. They began contracting with an independent organization to conduct assessments using the SIS-A™ by unbiased and well-trained assessors.

Beginning in the summer of 2021, the contracted organization began leveraging the SIS-A™ with a sample group of 500 people over age 16 who were currently receiving Vermont DDS Home and Community-Based Services. After a year of collecting sample assessments, a six-level framework was developed. Information from the assessments is helping Vermont determine how to use the instrument to create funding for future services, across six levels. They conducted outreach to existing individuals receiving services to complete the assessment with the contracted agency, ensuring that the results would not impact the services or

Global Commitment to Health (Vermont's 1115 Medicaid Waiver Developmental Services)

Services include case management, residential habilitation, day habilitation, supported employment, crisis support, clinical interventions, respite, enhanced dental, and self-directed care.

Non-Waiver Services

Individuals are also eligible for non-Waiver services, which are subject to funding appropriated annually by the Legislature. These include Bridge Program, Non-HCBS Clinical Services, Specialized Services Fund, Employment Supports, Family Managed Respite, Flexible Family Funding, Peer Growth and Lifelong Learning, Post-Secondary Education Initiative for transition age youth 18 to 30, Preadmission Screening and Resident Review (PASRR) Specialized Day Services, Projects for Transition Support, Public Guardianship Fund, and Targeted Case Management (Medicaid State Plan service).

budget. This method will continue to be tested and refined until 2025. In 2022 they expanded use of the SIS-A™ to help determine future services.[33]

Currently, DAs are responsible for completing the application screening process including explaining the process, potential service options, timeliness, notification, rights, and appeal rights to the individual applying. For HCBS waiver services, individuals must meet the following three criteria:

1. Meet ICF/DD level of care
2. Have an unmet need related to their developmental disability
3. Unmet needs must meet one of the following six funding priorities for HCBS:
    a. Health and Safety
    b. Public Safety
    c. Preventing Institutionalization
    d. Employment for Transition Age Youth/Young Adults
    e. Parenting

The DAs conduct the assessment or ensure its unbiased and equitable completion. The assessment includes in-depth information gathering including confirmation of diagnosis, individual and family needs, funding priority criteria, and financial eligibility.

Washington

Key Takeaway: Washington is working to remove IQ from eligibility criteria and conducted research around behavioral indicators that adjust for age and environmental contexts. During the planning phase for changes to criteria, they ran predictive modeling to anticipate impacts, understand gaps in service, and supports access.

Waivers and Eligibility for Services

The Washington Department of Social and Health Services (DSHS)/Developmental Disabilities Administration (DDA) offers an array of services and supports through Community First Choice and five Medicaid 1915(c) waivers. To access services, an individual submits an application requesting a DDA eligibility determination. A Care Resource Manager, a state employee who holds a bachelor's degree in a social science field, reviews evidence that an individual has a qualifying condition that started before age 18 and is not expected to improve or resolve, and substantial limitations. Qualifying conditions are defined as a developmental disability in the Revised Code of Washington (RCW 71A.10.020) which includes developmental delays, intellectual disability, cerebral palsy, epilepsy, autism, and neurological or other conditions similar to intellectual disability. Multiple cognitive tests (e.g., Stanford-Binet, Wechsler Intelligence Scales, Kaufman Assessment Battery for Children) and adaptive assessments (e.g., Vineland Adaptive Behavior Scale, Inventory for Client, and Agency Planning) are accepted evidence of a substantial limitation.

[33] Vermont Department of Disability, Aging and Independent Living, Developmental Disabilities Services Division. (July 2021). Changes to Process for Assessing Individuals Needs for Developmental Disabilities Home and Community-Based Services. Available from https://ddsd.vermont.gov/sites/ddsd/files/documents/Info_About_SIS-A_for_Stakeholders_7.6.21.pdf

Table 3. Cognitive and Adaptive Assessment Criteria

Intellectual Disability	Adaptive functioning assessment with a standard score of ≤69, and psychological assessment with Full-Scale IQ (FSIQ) of ≤69 or Stanford-Binet IV with FSIQ of ≤67 as determined by a Licensed Psychologist or Certified School Psychologist
Autism, Autistic Disorder (DSM-IV-TR-299.00) or Autism Spectrum Disorder (DSM-5)	Evidence of onset prior to age 5, an adaptive functioning assessment with a standard score of ≤69, and for DSM-5 diagnosis, an FSIQ of ≤84 (or a written statement that your autism prevents you from testing) as determined by Board Certified Neurologist; Board Certified Psychiatrist; Licensed Psychologist; Board Certified Developmental and Behavioral Pediatrician; Licensed Physician or Advanced Registered Nurse Practitioner (ARNP) associated with an Autism Center, Developmental Center, or Center of Excellence
Another neurological or other condition similar to Intellectual Disability	Adaptive functioning assessment with a standard score of ≤69, and FSIQ of ≤77 or Stanford-Binet IV with FSIQ of ≤75, or if under age 20, scores in both Broad Reading & Broad Math ≤69 can replace FSIQ testing as determined by a Licensed Physician

Once a person meets DDA eligibility, the person must request the types of services they need by completing a Service and Information Request form, contacting their local DDA office, or contacting a DDA case manager. Once enrolled with DDA, a case manager works with a person to identify needs and access requested services. If a person needs services available through a Medicaid 1915(c) HCBS waiver, the person must:

- Be eligible for Apple Health and determined to meet federal disability criteria including a Social Security Disability Determination
- Meet functional eligibility requirements as determined by the DDA comprehensive assessment reporting evaluation (CARE) Assessment

In 2022, the Washington State legislature passed House Bill 2008, which required DDA to remove the use of IQ scores to determine eligibility for programs and services for individuals with intellectual disability. The legislature found that "requiring intelligence quotient testing to determine if a person has an intellectual or developmental disability is expensive, inaccessible to marginalized communities, complicated to receive, and time consuming for families already struggling to care for their child with an intellectual or developmental disability. Further, the legislature finds that intelligence quotient testing does not accurately indicate whether a person needs support to be personally and socially productive, which is the goal of the developmental disabilities administration outlined in RCW 71A.10.015. Therefore, the legislature finds that requiring intelligence quotient testing in assessing whether a person has an intellectual or developmental disability is not an appropriate diagnostic tool and eliminating the use of intelligence quotient scores has been a goal of the legislature for more than 40 years." .[34]

In response to the legislature, RCW 71A.16.020 was amended requiring that DDA not use IQ scores

[34] Secretary of the State of Washington. Second Substitute House Bill 2008. https://lawfilesext.leg.wa.gov/biennium/2021-22/Pdf/Bills/Session%20Laws/House/2008-S2.SL.pdf?q=20220830105732

as a determinant of developmental disability.[35] Further, "persons determined eligible after the age of 18 who were determined eligible using an IQ score under criteria in place prior to July 1, 2025" will remain eligible for DDA services.

At the time of this report, DDA began work to remove the IQ requirement for intellectual disability and anticipates implementing this change in October 2024. With this change, individuals will continue to submit a completed eligibility packet along with other required documentation to a DDA office when in need of services. DDA maintained the requirement of confirmation by a school psychologist and/or licensed psychologist that a person has the need for services due to intellectual limitations. Despite the pending removal of the IQ score from the definition, individuals must still submit required evaluations and provide evidence of medical diagnoses by a licensed physician, adaptive skills test results and accompanying reports, as well as mental health records to support eligibility determination.

Washington currently has five HCBS waivers, each offering a range of services. These waivers include:

- **Individual and family services** to support individuals who require services to remain in their family home;
- **Basic Plus**, which supports individuals who need services to meet their assessed health and safety needs;
- **Core** waiver offers residential options to individuals at immediate risk of institutional placement or those who have an identified health and welfare need for services not met by Basic Plus waiver services;
- **Children's intensive in-home behavioral support** aimed at supporting youth at-risk of out-of-home placement due to challenging behaviors; and
- **Community protection** that offers therapeutic, residential supports for individuals requiring 24-hour, on-site staff supervision to ensure the safety of themselves and others.

Testing on the impact of the change in the definition of IQ will occur in the last quarter of 2024 with findings resulting in additional operational changes in 2025. DDA anticipates that the removal of the IQ score will result in increased costs associated with more individuals meeting eligibility for DDA services and subsequent increased staffing needed to support case management. Testing the change will provide information on cost, operational efficiencies, provider capacity, backlog in testing, as well as insight into whether the change results in the need for new or different services to meet the needs of people (e.g., non-verbal learning disability) who would not have previously met the IQ cut off.

As these changes go into effect, the state will monitor what program areas may need evaluation or update. For instance,

- What will DDA need to refine in the workflows for reviewing required documentation to determine eligibility?
- How will this change impact training available to DDA employees conducting the DDA Assessment?
- How will the change impact Case Resource Managers to support service planning?

Future conversations with Washington will provide ongoing information from their findings as they progress through the implemented changes. Those findings can be included in future reports to provide additional considerations for Connecticut.

[35] Washington State Legislature. RCWs 71A.16.020. Eligibility for Services – Rules. Available from https://app.leg.wa.gov/RCW/default.aspx?cite=71A.16.020

Level of Need / Assessments and Instruments

DDA Care Resource Managers and Social Service Specialists administer the DDA assessment per the *Washington Administrative Code Chapter 388-828-1080* with the individual and one additional person who has known the individual for more than six months.[36] The DDA assessment contains three sections including the Support Assessment, Service Level Assessment, and Person-Centered Service Plan. Collectively, the sections measure the individual support needs of an individual with intellectual disability over a range of life areas and activities, including personal care, daily living activities, and supports needed to live and engage in the community and community activities. **Table 4** provides a snapshot of the scales used to assess needs, preferences, goals, and health status.

Table 4. DDA Assessment Section Scales

Support Assessment	a. The Supports Intensity Scale Assessment (which includes the ICF/IID Level of Care for individuals aged 16 and above); b. ICF/IID Level of Care Assessment for individual age 15 and under; c. Protective Supervision Scale; d. Caregiver Status Scale; e. Current Services Scale; f. SIS Behavior Scale; and g. SIS Medical Scale.
Service Level Assessment	a. Personal Care assessment tool; b. Employment Support Assessment tool; c. Sleep Assessment tool; d. Mental Health Assessment tool; e. Equipment tool; f. Medication Management tool; g. Medication tool; h. Seizure & allergies tool.
Person-Centered Service Plan	a. Service Summary tool; b. Support Needs tool; c. Finalize Plan tool; d. Environmental Plan tool; e. Equipment tool; f. DDA Referral tool; g. Plan review tool; h. Supported Living Rate Calculator; i. Foster Care Rate Assessment Calculator; and j. Individual and Family Support Calculator.

If the assessment determines the individual is eligible for paid services, the individual receives a copy of their Person-Centered Service Plan, a Planned Action Notice (PAN) legally informing the individual what services they are eligible for, and on-going case management. The Case Resource Manager, using the information produced by the DDA Assessment, will determine the service level,

[36] Washington State Legislature. WAC 388-828-1080. Who must administer the DDA Assessment. https://app.leg.wa.gov/WAC/default.aspx?cite=388-828-1080

and authorize payment for client services. If the assessment determines the individual is not eligible for paid services, the individual receives a copy of the assessment, and the Case Resource Manager provides information and referrals to community resources.[37]

Given the pending change in the use of IQ scores, DDA does not anticipate any change in the assessment process.

Summary of State Best Practices

A summary of state approaches that could potentially serve as best practices for Connecticut is below:

Arkansas
• Connecticut could use Arkansas' learning from their application of the MnCHOICES Assessment Tool by updating their state-specific LON tool, improving their current approach, and ensuring equity across the state. Arkansas took bold strides to emphasize the importance of functional need versus diagnosis when adopting and customizing the MnCHOICES assessment across all its LTSS populations in need of home and community-based services. The adoption of a single tool supports individuals that may present with co-occurring conditions, most importantly individuals with intellectual and developmental disabilities with corresponding behavioral health conditions. In Arkansas they now have a Complex Care population and criteria to identify those with the highest needs who will require the most intense supports and services provided by the contracted PASSE's. • Arkansas also approaches diagnosis of intellectual or developmental disability from a broad lens, taking into consideration the person's social, medical, environmental, natural supports, behavioral/mental health, and self-care alongside consideration of IQ, with the ability to determine eligibility without relying solely on the IQ test. • Connecticut could consider looking further into how Arkansas implemented service tiers and how these tiers impacted their budget. Use of the ARIA assessment and system also offers Connecticut the opportunity to explore how a combination of algorithms and close quality monitoring can support eligibility determination for individuals with intellectual or developmental disability. For example, if an individual referred for an ARIA assessment does not have a Tier 2 or a Tier 3, the assessment is sent back to the Psychology Team for deeper review. Typically, this occurs because the individual or the individual's caregiver or legal guardian does not confirm an intellectual or developmental disability diagnosis and there are no corresponding International Classification of Diseases (ICD) codes sent with the referral. The Psychology Team reviews the individual's medical records and prior application to make a determination as to whether the individual in fact meets the state's definition of intellectual or developmental disability. This provides an important quality check to be sure that individuals are not inadvertently denied services.

[37] Washington State Department of Social and Health Services – DDA Assessment. https://www.dshs.wa.gov/dda/consumers-and-families/dda-assessment

Massachusetts

- Within the codified definition of intellectual disability, Massachusetts included multiple considerations for contextual factors that could impact conceptual, social, and practical adaptive skills. These support the personalized approach to determining eligibility that takes into consideration strengths, environment, and cultural and linguistic contexts.
- RIETs conduct eligibility determination across a team that includes a licensed doctoral level psychologist, a master's degree in social work, and a department assigned eligibility specialist. The RIET interviews the individual and other significant people in their life, if possible, which adds to the person-centered design of their approach. The process may include a) consideration of psychosocial, neuro-psychological, medical, and educational assessments and b) for people applying for intellectual disability services, intelligence test results.

Minnesota

- Connecticut could consider impacts or lessons learned from updates to the MnCHOICES Assessment to support potential LON tool improvements. For instance, MnCHOICES includes assessment of informal caregiver supports, which can provide a direct understanding of the impact of informal caregivers across the state. Their approach includes assessing informal supports to determine what services may typically be provided by a caregiver and what would be outside of the norm.
- The phased approach to implementation that Minnesota took with their MnCHOICES Revision Project is a best practice for any substantial changes made to current approach. This can apply to multiple areas, including making sure to test the assessment tool itself as well as identifying impacts to all downstream eligibility determination processes or enrollment workflows. Additionally, Minnesota embarked on a comprehensive engagement process that included multiple studies, interviews, and meetings with assessors over several years to understand the utility of MnCHOICES both operationally as well as clinically. Two studies were presented to the Legislature prior to embarking on the decision to make sweeping changes to the assessment process and system.
- Review of certified assessor qualifications in Minnesota could benefit Connecticut when thinking about potentially revising LON Assessment and eligibility determination processes. With sufficient training Minnesota found that the caseload could be further distributed across professional roles. In addition, as Connecticut considers revising its statutory definition of intellectual disability to remove IQ requirements, the state could look to Minnesota's process for waiver eligibility determination in instances when an individual does not meet the IQ threshold.
- The state's diagnostic determination process includes the change for the QDDP to determine if the individual meets the diagnostic threshold for a related condition even if their submitted tests and documentation do not meet the threshold of having an IQ of 70 or below. They created the Related Conditions Checklist to determine if the individual's condition would still meet the requirements for waiver eligibility and are able to connect individuals to services that way, even if their IQ is not 70 or below.

Vermont
• When Vermont implemented a new assessment system, they sampled the tool with a small subset of their currently eligible population. Similar to the stepped approach that Minnesota took, this best practice allows them to anticipate impacts and adjust program documentation as needed. • When Vermont realized they needed to improve their assessment for standardization across the state, they looked to available tools and systems that could bring unbiased and equitable structure. When a state-based approach does not support standardization across individuals with similar needs, this can be a best practice to ensure equity.
Washington
• Connecticut could look to Washington for best practices garnered from the early stages of implementing changes to remove IQ from eligibility criteria and lean on research around behavioral indicators that are adjusted for age and environmental contexts. • Washington employed best practice strategies in their planning and preparation for making change, such as predictive modeling to anticipate impacts and gaps. Findings from this type of exploratory research and modeling support mitigation planning to address the potential impacts of statutory changes.

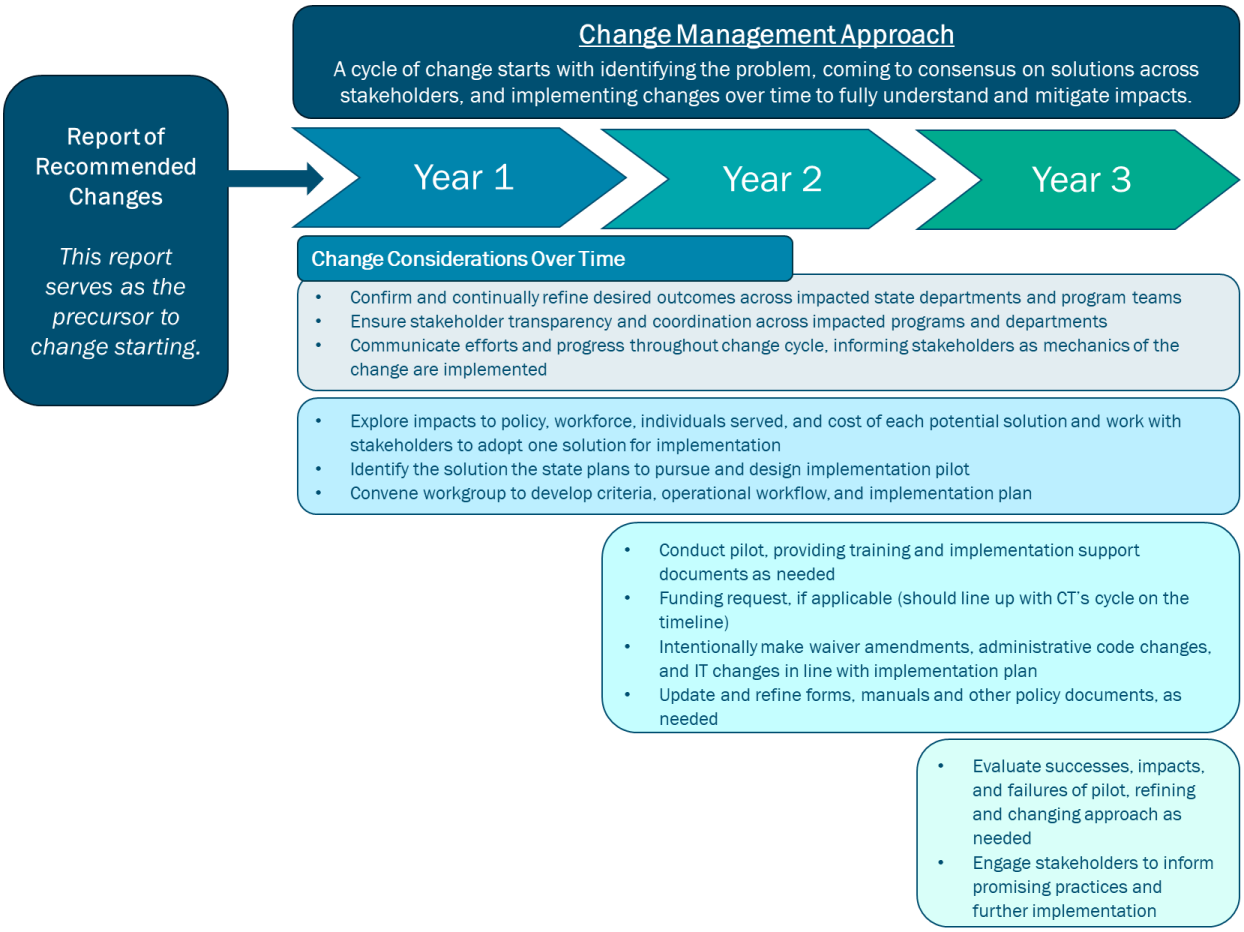
Potential Recommendations and Impacts

Potential recommendations to change Connecticut's statutory definitions, eligibility and enrollment workflows, LON tool, and state approaches are outlined in this section of the report. To meet Connecticut's goals to improve the statutory structures and service delivery regulations for people with intellectual disability or autism, these proposed recommendations include the need for additional research and analysis, a review of options for statutory revisions, and additional evaluation of the impact of these options on current state processes. The following recommendations were refined through iterative state feedback, input from multiple Advisory Groups, and additional details from other state approaches and best practices.

- Recommendation 1: Conduct Additional Research and Analysis on Impact of Changes
- Recommendation 2: Revisit Statutory Definition of Intellectual Disability
- Recommendation 3: Reevaluate Appropriateness of Current Eligibility and Enrollment Workflows
- Recommendation 4: Establish Comprehensive Coordination Approach
- Recommendation 5: Develop Comprehensive Communication Strategy

Because changes to programs and policies impact people, Connecticut should consider leveraging a change management process built around stakeholder engagement, focusing on ensuring continued access for individuals receiving services and mitigation of any potential challenges across all state programs. An intentional change management process will allow Connecticut to consider the many factors that influence successful policy change, including economic shifts, political direction, ethical considerations, any new research, or data that surfaces later in the change lifecycle, legal mandates, and structures and processes that can sometimes hinder policy change. Together with stakeholders, the state can manage these inevitabilities by engaging in actions outlined in **Figure 7** that center on the voices of people who receive these supports and their families.

Figure 7. Change Management Approach to Potential Recommended Changes



This change management process aims to support moving from the current state to a transition state to an eventual future state. State staff are integral to designing the change, developing the operational components of the change, and delivering the change by following all required state and federal requirements. Individuals receiving supports, their families, and other stakeholders, are also integral and should be engaged throughout the change process lifecycle to support the state in adopting the change seamlessly and effectively. As shown above, a typical change process can take multiple years, even extending to up to five years, depending on the impact of the change on people and the level of complexity inherent in the program or policy.

Table 5 provides a snapshot of recommendations and associated actions to move forward in an intentional manner. These potential recommendations and change management actions are provided for Connecticut's consideration.

Table 5. Potential Recommendations and Change Management Actions

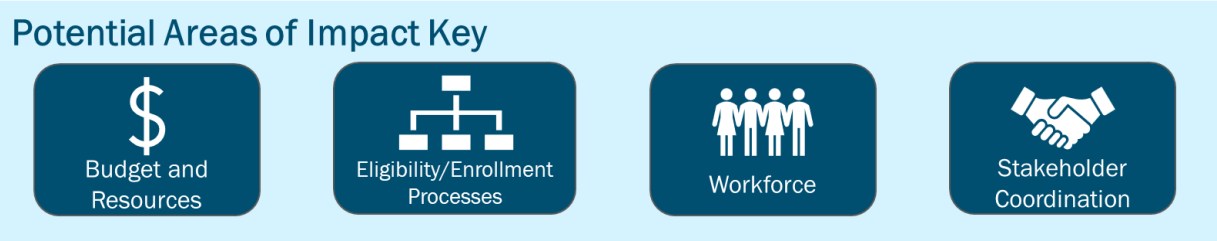
Recommendation 1: Conduct Additional Research and Analysis on Impact of Changes
Change management actions: a. Confirm vision and desired outcomes for a change. b. Develop a logic model or driver diagram to connect vision to measurable actions and outcomes followed by an action plan to drive desired results. c. Conduct additional analyses to better understand the financial, administrative, and operational workflow impacts to the state, and potential increased burden to individuals with intellectual disability or autism and their families. d. Conduct further study on the impact of any change chosen on current eligibility determination processes, waiver enrollment steps conducted by case managers, updates to the Connecticut LON tool, and impacts to service planning. e. Outreach to Washington to understand their approach and methodology for conducting a predictive analysis.
Recommendation 2: Revisit Statutory Definition of Intellectual Disability
Change management actions: a. Convene an Advisory Group of psychologists and other qualified professionals, leaning on additional outreach to Minnesota to learn more about their inclusion of stakeholders throughout their change management processes. b. Explore changes in eligibility to remove IQ scores as a component of eligibility or expand to a broader developmental disability definition that includes intellectual disability and autism. c. Develop guidelines for intellectual disability similar to "Connecticut Guidelines for a Clinical Diagnosis of Autism Spectrum Disorder". d. Outreach to Washington and Arkansas to understand their approaches and strategies leveraged when changing their definitions.
Recommendation 3: Reevaluate Appropriateness of Current Eligibility and Enrollment Workflows
Change management actions: a. Consider expanding the team of professionals that conduct clinical reviews. b. Evaluate current staff roles, responsibilities, and credentials for completing the LON tool including a review of how Minnesota manages the experience, processes, protocols, and training requirements for certified assessors of eligibility and service need. c. Explore Washington's considerations for shifting to a one-step enrollment process. d. Develop a cross walk with the current behavioral and functional elements included in the LON tool to ensure alignment with changes in eligibility requirements. e. Leverage literature on behavioral indicators related to intellectual disability and autism and other state practices. f. Explore the Minnesota MnCHOICES tool and Arkansas' ARIA assessment for the ways they support informal caregivers and identify their needs. g. Consider establishing methodologies to support implementation of service tiers that drive the type and amount of support an individual requires including conversation with Arkansas on the process and methods they used to establish tiers.
Recommendation 4: Establish Internal Coordination Approach
Change management actions:

a. Consider leveraging internal workgroups, dedicating staff to development of an in-person strategy session to re-imagine internal processes, workflows, vendor contracts, partnership with payers and providers, system changes, or structural changes across departments, and quality assurance to determine downstream impacts of making a change to the definition for intellectual disability. b. Involve external stakeholders such as intellectual disability service providers, state psychologists, school-based program staff, advocacy groups including and representing individuals with lived experience, and other entities or departments in the state to ensure a comprehensive lens is brought to understanding possible impacts and to support refinement of eligibility and enrollment workflows.
Recommendation 5: Develop Comprehensive Communication Strategy
Change management actions: a. Consider collaborating with community partners and existing committees and workgroups to develop a plan to communicate proposed changes and strategies. b. Develop culturally and linguistically competent materials distributed in multiple formats and modes to ensure that individuals with intellectual disability, individuals with autism, and their families fully understand expected changes and how it may or may not impact their pathway to services.

Importance of Impacts

Due to the potential for impacts across multiple policies and people, all of these recommendations should be considered by Connecticut for implementation after appropriate steps are taken to assess potential impact and plan out an intentional change management process. Connecticut could use a phased approach to implementation to mitigate any potential challenges or negative impacts to individuals with intellectual disability or autism, as well as across all state programs.

These proposed recommendations should include additional consideration for support due to the potential impact to state eligibility determination and enrollment policies, state resources and budget, workforce strain, and the need for interagency and stakeholder coordination. All five recommendations could have potential impacts that can be anticipated but require further research to accurately depict a quantifiable shift or outcome of the change. As changes are made and implemented, and Connecticut leans on continuous quality improvement processes to evaluate and mitigate challenges as part of change management, impacts may continue to shift. For each recommendation below, potential impacts that can be identified at the current stage are noted by the following legend but further details for each can be found in the Impact of Changes section.



Recommendation 1. Conduct Additional Research and Analysis on Impact of Changes

Changes to programs and policies should begin with understanding and appropriately planning for any potential challenges. At this time, Connecticut does not have a complete understanding of how potential changes would impact individuals receiving services and what specific steps would be

necessary to establish appropriate policies and procedures to support state staff, providers, and individuals that are in alignment with proposed changes.

Before any changes to definitions could be contemplated, the state should consider conducting additional analyses to better understand the financial, administrative, and operational workflow impacts to the state, and potential increased burden to individuals with intellectual disability or autism and their families. Additional analyses could help the state better plan for and communicate any potential changes to mitigate any unanticipated or undesirable impacts of eligibility definition changes. Predictive modeling and analyses of the current waiver population are approaches other states have used to inform change. Outreach to Washington to understand their approach and methodology for conducting a predictive analysis could be very valuable in supporting the state's ability to adequately plan a successful implementation strategy for addressing those that are ineligible based on IQ.

Questions for consideration in using predictive modeling might include:

1. Why: Identify individuals who do not meet state requirements for a diagnosis of a developmental disability or autism currently and why they do not – is it due to IQ, adaptive factors, behavioral factors, or other factors?
2. How Many: Identify how many individuals who previously were determined not eligible due to the IQ requirement would now be eligible due to changes to the definition (e.g., adaptive factors or behavioral factors).
3. Impacts: Identify how many individuals currently determined eligible for services due to the current definition would no longer be eligible based on the proposed changes to the definition and why.
4. Unknown Factors: Identify other chronic conditions or disabilities that may not be considered under the current statute but might be desirable to include (e.g., non-verbal learning disability).

Exploring the suggested areas of impact could support the state in understanding increases in the potential waiver eligibility pool, the need for additional services within waivers, administrative burdens associated with changes to the eligible population, and budget planning and investment in additional workforce capacity to meet the needs of a larger population. Exploring the suggested areas above could support the state in understanding increases in the potential waiver eligibility pool, the need for additional services within waivers, administrative burdens associated with changes to the eligible population, and budget planning and investment in additional workforce capacity to meet the needs of a larger population. Washington took this approach to understand the anticipated budget and service impacts. They ran preliminary studies using available data to make projections based on whether increasing half a standard deviation from the norm would have significant impacts and gauged the number of staff they would need to impact those particular groups, such as case managers, supervisors, etc. They found that an increase of one point of standard error of measurement in the IQ range had the potential to increase caseload by 1-2% per year.

In comparison to previous trends in eligibility available through the Kaiser Family Foundation Medicaid HCBS Waiver Waiting List data, this may have a lower impact than Connecticut has seen

year over year.[38]

Secondly, when planning to implement a substantial change in statutory regulations, it is important to consider the impact on the current eligible population by analyzing available data. In learning from other states, Connecticut could mirror stepped approaches to sample existing individuals receiving services and run them through the proposed eligibility process to determine impact. Additionally, Arkansas sampled existing clients, running them through hypothetical eligibility determination and service planning with proposed changes to definitions to understand what the new environment would be. This approach was used multiple times in Arkansas over the course of several years including beta testing prior to the new assessment 'Go Live', through ongoing quality monitoring, and resulting modifications and refinements to the tiering methodology. This Test of Change includes five steps: design, test, mitigate, test, and implement. Such an approach would allow Connecticut to leverage available data to analyze a redesigned eligibility workflow, identify challenges that persist, mitigate those challenges, and retest prior to implementation. Quantitative analyses could provide a more accurate estimate of the increase to the eligible population and resulting impacts on resources and services. Similar to other efforts the state is taking to assess how new changes would impact individuals with regard to acuity and quality rates, this analysis would support preparation for any action taken or change made.

Recommendation 2. Revisit Statutory Definition of Intellectual Disability

Exploring potential revisions to Connecticut General Statute (CGS) 1-1g could advance the DDS person-centered service delivery system, aligning eligibility to a person's functional needs instead of relying solely on IQ testing. To inform a change in definition, the state could consider convening an Advisory Group of psychologists and other qualified professionals, capitalizing on deep subject matter expertise and experience to support determination of the most appropriate path forward for Connecticut's intellectual disability policies. Gauging input from experts knowledgeable about Connecticut's existing system and eligibility processes can help ensure that the determination of intellectual disability is based on high-quality evidence-based literature and experience, resulting in recommendations for assessment of intellectual and adaptive functioning as a substitute to IQ testing.

The following section outlines two proposed options for how Connecticut could consider changing its current definition of intellectual disability. The potential revisions to the statute are enumerated below in order of estimated level of effort, although both would necessitate a comprehensive change management approach as referenced earlier.

Option 1: Remove the requirement to meet a specific IQ score for the determination of intellectual

[38] KFF Medicaid HCBS Waiver Waiting List Enrolment, by Target Population and Whether States Screen for Eligibility. Available here: Medicaid HCBS Waiver Waiting List Enrollment, by Target Population and Whether States Screen for Eligibility | KFF

disability and eligibility for services and shift the eligibility focus to clinician-determined limitations in intellectual functioning that are clinically, culturally, and age-appropriate. The proposed revision includes a change from "significant limitation in intellectual functioning" in CGS 1-1g to a focus on limitations on intellectual functioning across cognitive capabilities to include reasoning, problem-solving, planning, abstract thinking, judgment, academic learning, and learning from experience, confirmed by a clinician diagnosis. This option would require moderate regulatory and operational changes to implement. This could also have a significant impact on eligibility for state waivers (including administration, service arrays, and waitlists), the birth to three program, and public schools. Addressing concerns about increases in eligibility, Connecticut could consider piloting or testing implementation of a tiering or stratification process for all applicants, ensuring that those individuals with the greatest needs, as defined by the state, are served first.

Were Connecticut to go with Option 1, suggested language for a potential updated definition is:

Section 1-1g - "Intellectual disability" defined as

(a) Except as otherwise provided by statute, "intellectual disability" means a significant limitation in intellectual functioning existing concurrently with deficits in adaptive behavior that originated during the developmental period before 18 years of age.

(b) As used in subsection (a) of this section, "significant limitation in intellectual functions" means ~~an intelligence quotient more than two standard deviations below the mean as measured by tests of general intellectual functioning that are individualized, standardized and clinically and culturally appropriate to the individual~~ that the individual has limitations in intellectual functioning that are clinically and culturally expected based on the individual's age and the context of the environment as determined by a clinician; and "adaptive behavior" means the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group as measured by assessments that are individualized, standardized and clinically and culturally appropriate to the individual.

Option 2: State research revealed states embedding intellectual disability definitions under a broader umbrella of developmental disabilities. Conditions within this broader umbrella include, for example, intellectual disability, autism, spina bifida, cerebral palsy, Down syndrome, and epilepsy while also allowing for consideration of "any other condition that results in impairment of general intellectual functioning or adaptive behavior". This approach relies on the effectiveness or degree to which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group as measured by assessments that are individualized, standardized, and clinically and culturally appropriate to the individual.[39] As a result, determination of eligibility does not preclude individuals with an IQ score above 70 but rather considers individuals with persistent functional limitations in daily life. Placing intellectual disability under a definition of developmental disability would require moderate changes in regulation and if IQ remains in place, minimal operational changes.

Washington is a state that has intellectual disability under the definition of developmental disabilities and removed the requirement for IQ score within those criteria. The Revised Code *of Washington 71A.10.020*, defines developmental disability as "a disability attributable to intellectual disability,

[39] Arkansas Senate Bill 189. Available from https://www.arkleg.state.ar.us/Home/FTPDocument?path=%2FACTS%2F2023R%2FPublic%2FACT214.pdf

cerebral palsy, epilepsy, autism, or another neurological or other condition of an individual found by the secretary to be closely related to an intellectual disability or to require treatment similar to that required for individuals with intellectual disability, which disability originates before the individual attains age eighteen, which has continued or can be expected to continue indefinitely, and which constitutes a substantial limitation to the individual."[40] This definition includes individuals formally diagnosed with an intellectual disability by a clinician but also ensures that individuals who need a similar level of support with functional and behavioral factors are still eligible for services.

Arkansas, while still including IQ in its statutory definition of developmental disability, includes an "or" statement allowing evaluators to consider "or (vii) Any other condition that results in impairment of general intellectual functioning or adaptive behavior similar to an individual qualifying under subdivision (4)(A)(vi) of this section". In light of these examples and the interest among policymakers to revisit/explore the continued use of IQ in Connecticut, we recommend the state consider the following suggested language for an updated definition as follows.

"Developmental disability" defined as

A disability of an individual that is expected to last the entire lifespan that originated during the developmental period before 18 years of age and is attributable to a diagnosis of one of the following:

1. Cerebral palsy, as established by the results of a medical examination by the individual's primary care provider or a licensed physician;
2. Epilepsy, as established by the results of a neurological examination by the individual's primary care provider or a licensed physician;
3. Spina bifida, as established by the results of medical examination by the individual's primary care provider or a licensed physician;
4. Down syndrome, as established by the results of a medical examination by the individual's primary care provider or a licensed physician;
5. Autism spectrum disorder, as established by the results of a medical examination by a psychologist in line with the criteria established within the American Psychiatric Association's Diagnostic and Statistical Manual, Fifth edition (DSM-5)
6. Intellectual disability, as established by the results of a clinical determination by a psychologist finding a significant limitation in intellectual functioning existing concurrently with deficits in adaptive behavior that originated during the developmental period before 18 years of age, with "significant limitation in functioning" defined as the individual having limitations in intellectual functioning that are clinically and culturally appropriate based on the individual's age and the context of the environment as determined by a clinician; or
7. Any other condition that results in impairment of general intellectual functioning or adaptive behavior, meaning the effectiveness or degree with which an individual meets the standards of personal independence and social responsibility expected for the individual's age and cultural group as measured by assessments that are individualized, standardized and clinically and culturally appropriate to the individual.

To support clinical evaluation in alignment with these two proposed options, Connecticut could consider developing guidelines for intellectual disabilities similar to "Connecticut Guidelines for a

[40] Washington State Legislature. RCW 71A.10.020 – Definitions. https://app.leg.wa.gov/rcw/default.aspx?cite=71A.10.020

Clinical Diagnosis of Autism Spectrum Disorder". These guidelines for service eligibility determination could describe:

- The components of a diagnostic evaluation of intellectual disability and any other condition that results in impairment of general intellectual functioning or adaptive behavior,
- How to evaluate using behavioral indicators and adaptive behavior,
- Diagnostic considerations,
- Training to ensure consistent clinical judgment,
- How to ensure inter-rater reliability across clinicians and monitor for inequities and biases,
- Documentation of clinical eligibility for waiver services, and
- Use of checklists and tools to ensure consistent application of evaluation.

To support these efforts, it is recommended that Connecticut leverage the above-mentioned Advisory Group to study work done by the World Health Organization (WHO) and the 11th revision of the International Classification of Diseases and Related Health Problems (ICD-11).[41] This recent work combines intellectual functioning and adaptive behaviors under a new model based on the behavioral indicators framework developed by the WHO and adopted into the clinical version of the ICD-11. The behavior indicators are intended to serve as guidelines for professionals in making an informed clinical decision regarding an individual's level of intellectual functioning and adaptive behavior for the purpose of making a determination about the presence and severity of disorders of intellectual disability. The full tables containing behavioral indicators across the lifespan for intellectual functioning and adaptive behaviors can be found in the Journal of Intellectual Disability Research article available through PubMed.[42]

The Advisory Group could translate literature on behavioral indicators into clear criteria that align with and define the functional needs of individuals with intellectual and developmental disabilities in

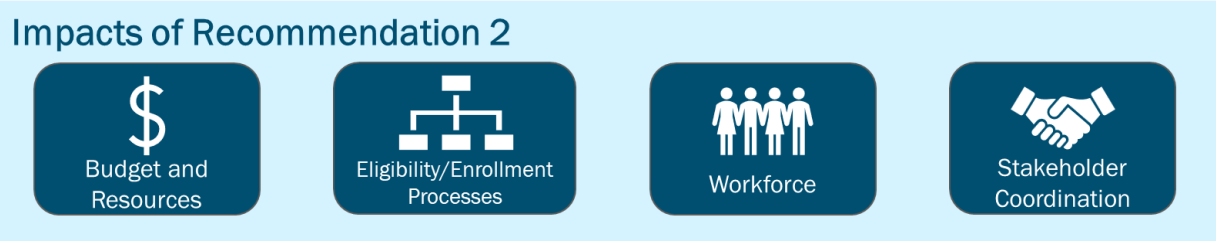
Behavioral Indicators in ICD-11

The ICD-11 provides guidance to clinicians on the use of behavioral indicators noting that a measure of IQ is not an isolated diagnostic requirement to distinguish disorder from normality but should be considered a proxy measure of the "significant limitations in intellectual functioning". The WHO indicates that IQ scores may vary by the conditions or type of test used as well as by a person's development across the lifespan. As a result, the WHO recommends this complementary mixed-method approach to intellectual disability diagnosis, referring clinicians to use the Clinical Descriptions and Diagnostic Requirements for accurate and reliable diagnosis. An interdisciplinary expert panel worked with researchers to construct a series of tables containing behavioral indicators across the lifespan for intellectual functioning and adaptive behaviors. A preliminary study (2022) of the use of behavioral indicators with children ages 5 to 18 years old found excellent inter-rater reliability and good to excellent concurrent validity.

[41] Lemay KR, Kogan CS, Rebello TJ, Keeley JW, Bhargava R, Sharan P, Sharma M, Kommu JVS, Kishore MT, de Jesus Mari J, Ginige P, Buono S, Recupero M, Zingale M, Zagaria T, Cooray S, Roy A, Reed GM. An international field study of the ICD-11 behavioural indicators for disorders of intellectual development. J Intellect Disabil Res. 2022 Apr;66(4):376-391. doi: 10.1111/jir.12924. Epub 2022 Feb 16. PMID: 35170825.

[42] Tassé MJ, Balboni G, Navas P, Luckasson R, Nygren MA, Belacchi C, Bonichini S, Reed GM, Kogan CS. Developing behavioural indicators for intellectual functioning and adaptive behaviour for ICD-11 disorders of intellectual development. J Intellect Disabil Res. 2019 May;63(5):386-407. doi: 10.1111/jir.12582. Epub 2019 Jan 9. PMID: 30628126.

Connecticut. This, in turn, could support clear, objective guidelines for clinical determination and ensure a standardized approach to assessment of individual eligibility for DDS services.



Note: The proposed language for definitions across the options enumerated above would impact eligibility for DDS and DSS services and the HCBS Autism Waiver, the B to 3 program, and public schools. If the definition of intellectual disability is updated based on any of these recommendations, corresponding changes to the definition of autism are also required. Any change in the definition of intellectual disability would likely enable individuals to meet cognitive and adaptive functioning with testing results above Connecticut's current definition of intellectual disability above an IQ score of 70. Suggested language for updated criteria for autism services is as follows:

"To apply to the Waiver for Persons with Autism from the Department of Social Services (DSS) Division of Autism Spectrum Disorder Services, an individual must have:

a. A primary diagnosis of autism spectrum disorder;
b. Residency in the State of Connecticut;
c. Impairment prior to age 22;
d. Impairment expected to continue indefinitely;
e. Cognitive and adaptive functioning above the level of intellectual disability ~~(i.e., IQ equal to or greater than 70)~~; and
f. Substantial functional limitations in two or more of the following areas of major life activity: a) self-care, b) understanding and use of language, c) learning, d) mobility, e) self-direction, f) capacity for independent living."

Recommendation 3. Reevaluate Appropriateness of Current Eligibility and Enrollment Workflows

Concurrent with eligibility change discussions, OPM should determine how potential changes in eligibility and waiver enrollment processes would impact service and administrative activities including whether revisions would ensure fair and equitable distribution of services and supports under existing resources. Specific focal areas for further study include:

- Current eligibility determination processes,
- Waiver enrollment steps conducted by case managers,
- Updates to the Connecticut LON tool, and

- Impacts on service planning.

State Eligibility and Enrollment

Workflows for determining eligibility and subsequent enrollment, including who conducts the determination, would require revisions to align with the updated definition of intellectual disability. For instance, a single state psychologist currently reviews all required documentation submitted with eligibility applications. While this is ideal for current clinical determination requirements, additional staff are likely needed to support determinations based on adaptive and functional behaviors. This may require a higher level of effort to review and confirm eligibility. Like Arkansas, Connecticut could consider expanding the team of professionals that conduct clinical reviews. In Arkansas they employ a state psychologist who collaborates with a team of licensed psychologists, as needed, to review various documentation and assessments. Massachusetts offers another innovative approach using their RIET including a licensed doctoral level psychologist, a professional with a master's degree in social work, and department assigned eligibility specialist. As Connecticut considers which recommended definition change to make, they should consider analyzing the potential administrative and fiscal burden for these reviews, evaluate for efficiencies and equity, and consider changes to the eligibility review team and workflow to ensure objective determinations.

While reviewing the eligibility determination workflow for efficiencies, Connecticut could look to Washington's considerations for shifting to a one-step enrollment process for their DDA services. This one-step process would combine existing elements of DDA eligibility determination. Future outreach to the state could help Connecticut learn about best practices in workflow efficiency. Should Connecticut pursue leveraging a different assessment or LON tool, like the interRAI instruments that can support from eligibility determination through enrollment in services and delivery of services, they would need to revise workflow processes to align with implemented applications. There are opportunities to leverage existing workgroups and partnerships to further explore operational business process changes further.

Evaluate and Revise Current Connecticut LON Tool[43]

Updates to the statutory definition may require updates to how adaptive behaviors and functional limitations for individuals with intellectual disability are defined. Connecticut should consider developing a cross walk with the current behavioral and functional elements included in the LON tool to ensure alignment with changes in eligibility requirements. When exploring changes in statutory language, Connecticut should leverage literature on behavioral indicators and other state practices. As Connecticut now allows paid family caregivers as of May 1, 2024, reviewing the LON tool assessment for caregiver supports may be necessary. Connecticut could consider analyzing assessment topics in the LON tool to determine whether revisions to the domains or questions addressing caregiver supports and needs, like the Minnesota MnCHOICES tool and Arkansas' ARIA assessment, could assist in supporting informal caregivers in meeting the needs of individuals with intellectual disability or autism while also understanding their own needs for support, health, and wellness.

Evaluation of current staff roles, responsibilities, and credentials for completing the LON tool is a recommended complementary activity. Minnesota offers years of experience, processes, protocols, and training requirements for ensuring adequate availability of certified assessors to address

[43] Concurrent to this effort to conduct research into the Intellectual Disability definition and the current CT LON tool, there are internal efforts to review and update the Universal Assessment. It is important to note that the Universal Assessment work will be aligned with LON and there is potential in the future to integrate the two, as appropriate.

eligibility and service need. Minnesota has clearly established roles for certified assessors responsible for completing the assessment and developing a person-centered service plan for people in need of long-term services and supports. They require qualified assessors, (detailed above), to complete training on how to use the tool and demonstrate competency to become certified. Arkansas's assessment vendor also employs a rigorous training protocol for onboarding all assessors including online learning systems and monitoring the quality of assessments including remedial training if necessary. Should the approach to evaluating adaptive behaviors change, training staff would ensure appropriate application of the assessment and identification of service needs. Connecticut could also study and determine the potential professional roles across the state that could support the building of a qualified workforce of certified assessors inclusive of state-training and demonstration of appropriate competencies to conduct the revised LON assessment.

Connecticut should approach content and process changes to the LON tool systematically. As demonstrated in Arkansas, Vermont, and Minnesota, implementation of new tools or changes to tools should lean on phased approaches or sample testing to ensure appropriate application.

Assess for Updates to Service Planning Workflows

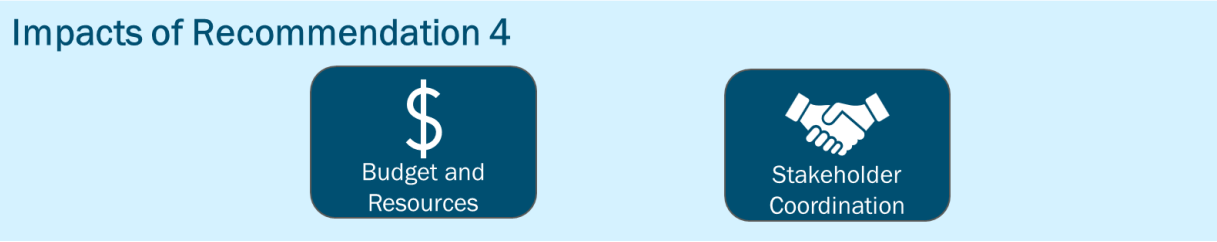
Changes to service planning workflows would require incorporating new approaches to the eligibility process including defining adaptive behaviors and behavioral indicators for individuals with intellectual disability and individuals with autism, as appropriate. It is recommended that the state utilize evidence-based literature on behavioral indicators to ensure that any proposed changes in service planning workflow support the assessment of behaviors. This may include updating language in service descriptions or providing appropriate training to map services to updated behavioral indicators and relevant needs.

In addition to service planning workflows, Connecticut could consider establishing methodologies to support implementation of service tiers that drive the type and amount of support an individual requires. To offset concerns of increased budgets and expenditures for serving a broader population, the development of tiers driven by the LON tool and aligned with program eligibility criteria offers opportunities for standardizing the alignment of a person's functional needs with the level of support Connecticut would expect an individual to receive, by program. These changes would necessitate review of the current LON assessment processes, development of tiering methodology aligned with program eligibility, and testing of any changes to ensure they work as intended, meaning that the methodology results in identification and alignment of individuals they would expect to be served by program and not inadvertently deny or exclude individuals. This is an approach that Arkansas implemented and is continuing to evolve and refine as they learn more about how the current system is meeting both the needs of individuals served as well as the state's capacity to serve individuals within existing budgets. Should Connecticut wish to pursue this option, additional conversation with Arkansas leadership could support appropriate design and implementation based on their lessons learned.

Recommendation 4. Establish Comprehensive Coordination Approach

The state should consider the downstream impacts of making a change to the definition for intellectual disability and the high level of effort it would require ensuring broad coordination and attention to multiple areas of policy and procedure. State strategies proven most successful include leveraging internal workgroups, dedicating staff, and external operational support when possible. For instance, coordination can take the form of regular meetings and frequent communication to monitor progress on implementation, in-person strategy discussions where the state staff and key partners roll up their sleeves, talk about specific policy needs, and work through the necessary changes to internal processes, workflows, vendor contracts, partnership with payers and providers, system changes, or structural changes across departments, and quality assurance, among other things. Connecticut currently has numerous committees and workgroups that are engaged in establishing these recommendations and could be vital platforms for these conversations to support efforts going forward.

Connecticut's coordination approach should involve external stakeholders such as intellectual disability service providers, state psychologists, school-based program staff, advocacy groups including and representing individuals with lived experience, and other entities or departments in the state to ensure a comprehensive lens is brought to understanding possible impacts and to support planning and implementation of potential changes. For example, coordinating with state psychologists would help ensure all approaches are clinically updated and aligned with proposed changes. Overall, establishing a coordination approach that intentionally involves essential internal and external entities would allow Connecticut to implement changes effectively while assessing all impacted programs and policies, ensuring nothing is left unaddressed as changes are made. While this recommendation does not require statutory or regulatory changes, coordination is paramount for success.



Recommendation 5. Develop Comprehensive Communication Strategy

A comprehensive communication strategy is essential at all stages of planning and implementation of potential changes. Given the many steps that these changes would involve, Connecticut's communication strategy would require a phased approach, as suggested at a high level in **Figure 8**.

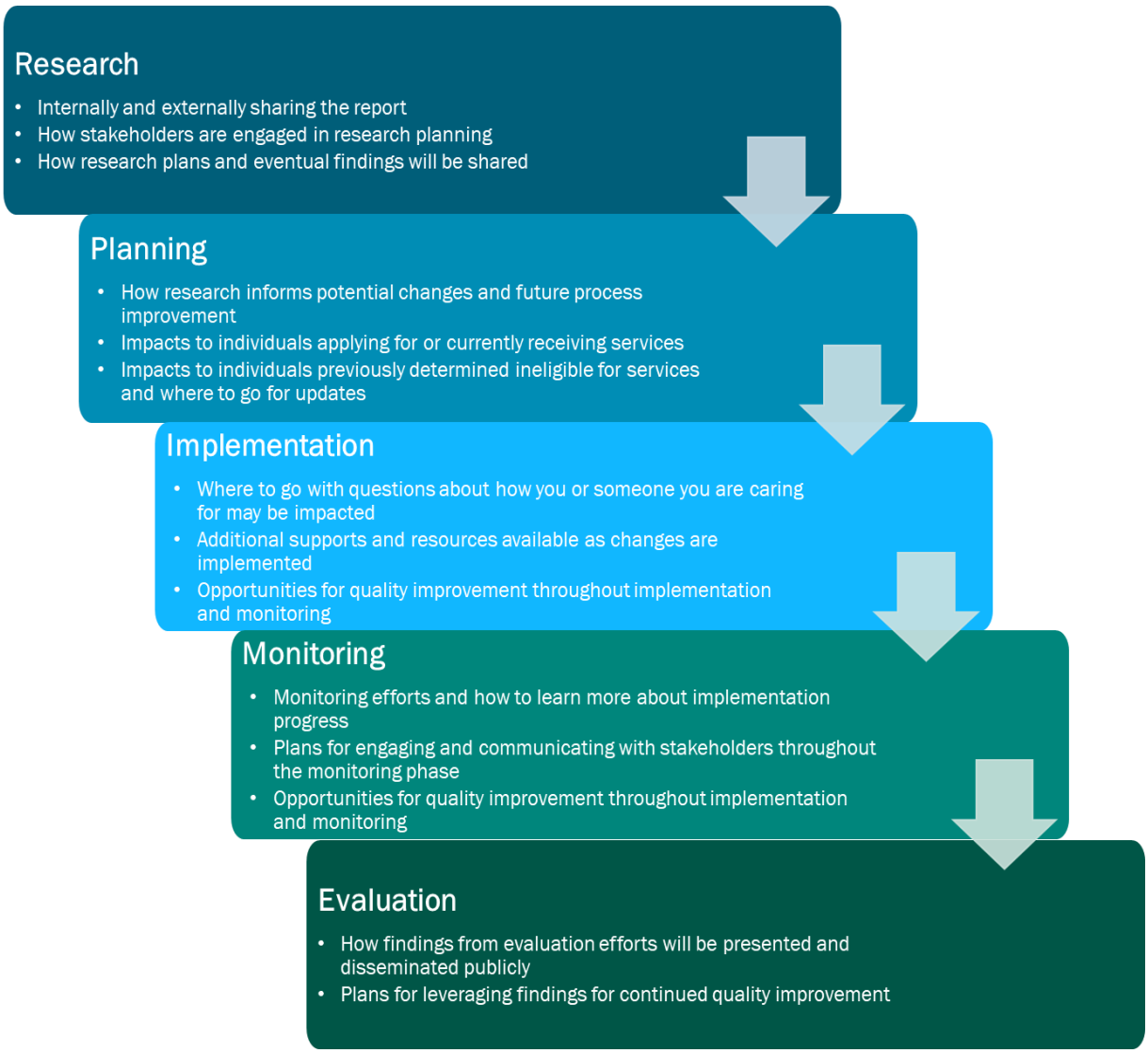
The state should consider collaborating with community partners and existing committees and workgroups to develop a plan to communicate the proposed changes and strategies in response to the legislative mandate and the public calls to act. As noted above, there has been public attention around the reliance on IQ scores within the definition of intellectual disability and the resulting eligibility determination that would persist through implementation of any changes, or any efforts taken to evaluate potential changes. Connecticut should develop a comprehensive plan to not only communicate proposed and approved changes in advance of implementation but also engage

individuals receiving or waiting for services and their families in a fully transparent change management process.

Stakeholder input should be solicited as part of the current evaluation project prior to finalizing any recommendations. Multiple workgroups could convene to review and provide input on the recommendations, including but not limited to the appropriateness of suggested changes and what may be missing or need to be changed before the recommendation is moved forward. These workgroups could incorporate perspectives from multiple state agencies and individuals who would be impacted by changes, including the Connecticut Council on Developmental Disabilities and the Autism Advisory Council. As reports and recommendations are submitted to legislators, these stakeholders should continue to be informed of progress. Ongoing communication would support community-level buy-in and strengthen advocacy for any additional legislative needs by ensuring transparency, clearly demonstrating actions taken in response to public calls and advocacy across the state.

Part of this communication should focus on ensuring that individuals with intellectual disability, individuals with autism, and their families fully understand these changes and how it may or may not impact their pathway to services. For instance, communications directed to individuals currently receiving waiver services should not only describe the changes but also note how it would have minor impact on the supports they might be receiving. Communications to individuals on the waitlist for DDS services or the HCBS Autism Waiver would need to note how these changes could impact their eligibility determination and whether a different waiver may be more appropriate for them and their needs. Broad communications to the public should also describe the changes and offer support to answer questions about their potential eligibility resulting from a shift in definition. These communications could be distributed in various materials, culturally appropriate and sensitive formats, plain language, webinars, or direct outreach, as determined most appropriate by the state.

Figure 8. High-Level Phased Approach for Connecticut's Communication Strategy



In other states, specific eligibility determination materials have proven to be effective communication tools. For example, Washington State developed "Applying for DDA Eligibility Services" Workflow material to assist families and help communicate what they can do to support their family members. While this material is outdated regarding their current procedures, it can serve as an example to Connecticut. Alternatively, the state could keep this effort internal but leverage the Connecticut Council on Developmental Disabilities to support the creation of clear communication and information-sharing tools. Similarly, if not exactly the same relationship, the State of Minnesota partnered with advocates at The Arc Minnesota to connect individuals with disabilities to key resources on government benefits.

This work could lean on community partners, academic entities, and advocacy organizations across the state to drive effective communication strategies. Another valuable partnership option

Connecticut could consider is with the University of Connecticut's University Center for Excellence in Developmental Disabilities (UCEDD). The State of Iowa partnered with the University of Iowa Health Care Center and their Iowa Compass to develop a tool that connects individuals with disabilities to services and supports in their communities. Advocacy organizations across states are also instrumental in sharing information with the public about the application process, what people need to know, and what they should expect when going through eligibility determination and the next steps. For instance, Moms in Motion in Virginia has dedicated sites to share information on Developmental Disability Waivers in the state. In Arkansas, the state engaged in regional information sessions across all impacted populations, inviting community-based organizations, advocacy groups, participants, families, and caregivers to learn about the intended system changes around the implementation of a single comprehensive assessment and movement toward the use of tiers to drive the determination of services and supports. Feedback was cataloged and considered as the state made final decisions on implementation strategies.

Impact of Changes

There could be positive, negative, and neutral impacts on the waiver program, waitlists, individuals with intellectual disability or autism, and their family members, providers, and community support when the state revisit

s long-standing statutes and makes required updates to related program documentation and eligibility and enrollment workflows. DDS and DSS offer six (6) waivers for individuals with intellectual disability or autism; however, three (3) waivers could see an appreciable impact should the IQ eligibility criteria be changed or removed, and additional persons qualify for services and support. These three waivers, the Comprehensive Supports (Comp) Waiver, the Employment and Day Supports Waiver, and the Home and Community Supports Waiver for Persons with Autism, are described in additional detail in Appendix A.

Should the definition change, Connecticut's eligibility determination and processes could consider a broader range of factors, such as adaptive functioning, medical history, and overall well-being, rather than solely relying on IQ scores. This approach allows for a more individualized evaluation in the context of the person's environment, available support, and ability for self-care. A more holistic approach to eligibility can promote inclusion by recognizing that intellectual disability is multifaceted. It acknowledges that individuals can face significant limitations even if their IQ falls within the "normal" range. Lastly, changing the way IQ scores are used to determine eligibility may reduce the stigma associated with intellectual disability. People with borderline intellectual functioning or other challenges may still qualify for support without being labeled solely based on their IQ score. But these changes would have significant impact on the state's budget, eligibility workflows and enrollment processes, workforce, and need for additional coordination.

Further description and details about the potential impacts referenced for each proposed

recommendation is outlined below. This information reflects what could be predicted based on research conducted for this report into other state approaches to intellectual disability services and detailed understanding of Connecticut's current policies and workflows to determine eligibility and provide services to individuals with intellectual disability or autism.

Note for All Potential Impacts: Beyond the specific criteria for waiver enrollment, eligibility determination workflows and pathways, service needs and availability, waitlists for services, overall state budget, and the current workforce may require changes and some additional consideration for support due to changes. However, further research is necessary to accurately depict a quantifiable shift in population, workforce need, and budget changes. The true impact of changes on the following aspects of care delivery and service accessibility is difficult to confirm. Future studies and analysis could support a clearer picture, but it is also important to frame all these impacts as evolving. In addition to conducting research, coordination with a broad range of internal and external entities to understand the potential downstream impacts of changes is essential, as described above in Recommendation 4. As changes are made and implemented, and Connecticut leans on continuous quality improvement processes to evaluate and mitigate challenges, the impacts may continue to shift. The following information summarizes potential impacts that should be considered when planning for any change to eligibility.

Impact to Resources and Budget

Connecticut anticipates increases in the number of individuals who would be determined eligible should IQ scores be removed from the definition of intellectual disability and eligibility criteria for DDS and DSS services. This may include individuals who were previously determined ineligible and individuals who never sought services with the understanding that IQ would preclude them from eligibility. The increase in eligible individuals would compound the existing concern over individuals on waitlists for services and the need to assess the potential lack of waiver slots. Connecticut is acutely aware of the concerns around service accessibility due to lack of availability. Specifically, residential support remains a consistent challenge across the state, with many people waiting for services. Should the population of eligible individuals increase, the accessibility challenge may be exacerbated. The potential increases in the eligible population may require an additional budget to ensure the availability of services. To assess a more accurate quantifiable impact of waiver enrollment and service waitlists, the state of Connecticut would need to conduct data analysis on the total population potentially eligible for intellectual disability and autism services. This assessment would focus on understanding the potential increase in population and resulting increases in the budget to ensure service accessibility.

At this time, the various state agencies regularly monitor individuals enrolled in waivers and receiving services and track those that are on waitlists for services based on a tiered system of need. This data does not include individuals who may become eligible, as noted above. Applying lessons learned from other states, however, can help Connecticut to predict potential impact to the population that may be eligible. As recommended above, quantitative analyses such as those Washington and Arkansas conducted when making changes, would support Connecticut in understanding a more accurate estimate of the increase to the eligible population. Similar to other efforts the state is taking to assess how new changes would impact individuals with regard to acuity and quality rates, this analysis would support preparation for any action taken or change made.

However, since there is already an existing waitlist for several services, it is expected that the state would see an increase in the number of people on a waitlist should the total population of eligible individuals increase. While it is difficult to accurately identify how many people on waitlists are

actually going without services because they may have met their care needs in alternative ways since being on the waitlist, public opinion in Connecticut has clearly identified the need to minimize these waitlists and improve access. While the state is exploring these changes and proposing revisions to statutory language to the legislature, it would be important to continue transparent communication with the governor and state legislature to build support for increased investment in HCBS services to ensure that waitlist concerns are not exacerbated by actions taken to revise statutory definitions to promote inclusivity and access for individuals in need. Connecticut could also study the impacts of and public receptiveness to implementation of stratification or prioritization of waitlists to ensure those most in need are served first.

Lastly, while discussed in more detail in the next sections, it would be important to note that changes to the workforce that supports eligibility determination would have an impact on budget as well. Increasing the number of people qualified to conduct determinations may increase the fiscal requirement to support this process.

Impact to Eligibility Determination

Changes to the definition could impact current eligibility determination workflows across DDS and DSS service eligibility determination. Further, diagnostic clarity may shift as the definition changes. IQ tests are intended to objectively measure cognitive ability. If not adequately addressed, removing this criterion may introduce more subjectivity into the assessment process. Further, without clear guidelines, diagnosing intellectual disability may become less straightforward, leading to variability in decisions. Therefore, with the implementation of changes, the state should anticipate the need to review and refine eligibility determination workflows, including providing clear guidance for professional psychologists and other clinicians engaged in the determination of intellectual disability and autism. Based on the option chosen for updating the definition language, impacts could require the development of guidelines for in-depth training on behavioral indicators.

As referenced above, the recommendation to look at addressing the increase in the level of effort to conduct reviews that do not leverage IQ would require the state to consider updating the team of professionals employed or contracted to conduct reviews. Additional staff may be needed to support the process to avoid long wait times for determination. Naturally, this would have budget implications for the state and should be weighed against the risk of the increase in wait time for determination. Future analyses could support a better understanding of the administrative burden and the necessary staff support needed to conduct reviews in a timely and appropriate manner.

Additionally, when changing eligibility criteria, individuals currently eligible and receiving services or waiting for services could be impacted, and eligibility could be redetermined at specific age milestones. The state would need to review and confirm redetermination processes and the implications for individuals who are already eligible when implementing changes to the definition, LON tool, and service planning policies and procedures. This would require internal expertise and coordination across multiple agencies to ensure workflows align with changes. While this may not necessarily have a budget impact, it would impact implementation timelines.

Impact to Workforce

Impacts on the number of individuals eligible for services would create additional needs in the community, further complicating existing direct support workforce shortages and strain. Investment into expanding the availability of services would require corresponding investment in the workforce, including recruitment, retention, skill development, and worker satisfaction elements. Investment in the internal workforce for eligibility and enrollment may impact investment in service delivery in the

community, diverting resources from direct care and service providers to assessment workflows.

Changes to the eligibility determination policy may impact the pool of professionals able to conduct determination. This could broaden the number of individuals able to assess eligibility, but it may further strain the professional health and human service workforce and require additional fiscal support necessary for eligibility determination and enrollment processes. Additionally, it may lead to increased responsibilities across the intellectual disability and autism service provider workforce and require updated state policies to outline staff roles. It may also necessitate detailed training for current staff, as well as seeking additional staff to support the caseloads on the processes and workflows associated with eligibility determination and enrollment in services.

Connecticut is currently exploring data on the workforce to identify potential opportunities to incentivize providers to respond to growing needs in the intellectual disability and autism space. This type of investigation would be extremely important for any proposed budget changes or necessary support from the legislature. As this information is gathered, the anticipated impacts can be updated within this report and leveraged further to support future proposals to the legislature. As part of the legislation that brought forth this research effort, Connecticut was also charged to evaluate the human services career pipeline and assess the workforce across the state. There is a separate draft report going through the internal development processes concurrently to this report. The outcomes of that evaluation should be aligned with the recommendations from this report, coordinating to move forward with any next steps to amplify efforts and avoid any duplication.

Impact to Interagency and Stakeholder Coordination

Making substantial changes in any program area would have impacts across the state governing body. As noted above, changes to the eligibility criteria would result in changes to determination workflows and processes, which would, in turn, have a downstream impact on inter-agency coordination to ensure that as children transition to adulthood, their care planning can be seamlessly transferred across state agencies, follow a clear pathway, and avoid disruption in services. These changes and the associated review and updating of policies and practices would require additional coordination to implement new procedures. Furthermore, policy changes would necessitate communication strategies for all impacted individuals and stakeholders. This may require investment in an inter-agency workgroup, to support the operationalization of the broad changes.

Conclusion

Through this report, OPM presents, for legislative consideration, potential recommendations for new statutory definitions for intellectual disability. Further, actions to address updates to state processes and approaches for implementing changes within intellectual disability and related programs based on updated eligibility definitions and requirements are included. These recommendations were driven by research to evaluate the use of IQ scores for eligibility for Connecticut's programs and services supporting individuals with intellectual disability or autism and refined through iterative state feedback and input from multiple Advisory Groups. As indicated in this report, all recommendations should be considered for implementation after appropriate steps are taken to assess for potential impact and implement an intentional change management process, outlined in the Introduction and Background section.

Appendix A: Connecticut Waivers

Currently, DSS and DDS offer six (6) waivers serving individuals with intellectual disability. This report focused on the evaluation and impact assessment of a change to the regulatory language and additional persons to be eligible for enrollment for three (3) waivers: Comprehensive Supports (Comp) Waiver, Employment and Day Supports Waiver, and the Home and Community Supports Waiver for Persons with Autism.

The DDS Comprehensive Supports (COMP) Waiver supports individuals who live in licensed community living arrangements, community companion homes, or assisted living facilities. It provides services to individuals with developmental disabilities ages 18 or older and individuals with intellectual disability ages three or older who meet level of care criteria. To be eligible for services under this waiver, individuals must be deemed eligible for DDS services, need an ICF/IID level of care, be willing or have the desire to live in a community setting, and be within designated income and asset limits. The Comp Waiver offers a range of services, including licensed residential services, residential and family support services, vocational and day services, and specialized support services.

The DSS Home and Community Supports Waiver for Persons with Autism provides services to individuals with autism ages three (3) or older who do not have an intellectual disability according to the State's definition. This includes individuals with cognitive and adaptive functioning above the level of intellectual disability (i.e., a full IQ score of 70 or higher). Individuals qualify for services under this waiver if they have substantial limitations in two or more of the following major life activities: 1) self-care, 2) understanding and use of language, 3) learning, 4) mobility, 5) self-direction, or 6) capacity for independent living. Functional impairments must have been diagnosed before age 22 and be expected to continue indefinitely. Under this waiver, services and support are capped at $50,000 annually per recipient.[44,45,46]

The DDS Employment and Day Supports Waiver offers services, including respite, supported employment, assistive technology, and more, to individuals aged 18 or older with developmental disabilities and those aged 3 or older with intellectual disability. DDS helps people with disabilities find jobs based on their interests, skills, and abilities. Supported employment includes real jobs with real wages, building relationships with coworkers, transitioning from a school setting to day services, setting up settings at home and in the community, and ongoing support and supervision. Day services help individuals or their family members spend supervised, productive time outside of their home. Day services might incorporate social activities and recreation, life skills training, transportation, meal preparation, and health and medical services.

Four additional home and community-based services waivers in Connecticut that serve individuals with IDD are described below. These waivers should be monitored for potential impact from changes to regulatory language; however, at this time, there is a lower likelihood of immediate impact.

The DSS Katie Beckett Waiver provides home and community-based services to individuals 21 years and younger who have a physical disability and may or may not have a co-occurring developmental disability, and who do not qualify for Medicaid due to family income. These are individuals who prefer

[44] CT Home and Community Supports Waiver for Persons with Autism. Available online: https://www.joingivers.com/programs/ct-hcbs-persons-with-autism
[45] DSS Autism Waiver Service Descriptions. Available online: https://portal.ct.gov/-/media/departments-and-agencies/dss/health-and-home-care/autism-spectrum-disorder/dss-autism-waiver-service-descriptions.pdf
[46] Autism Spectrum Disorder – ASD. Available online: https://portal.ct.gov/dss/health-and-home-care/autism-spectrum-disorder---asd/autism-spectrum-disorder---asd

to reside in their homes or the community instead of in an institutional setting. They are provided case management by a home health agency in addition to other Medicaid services such as therapy services, physician services, home health services, and hospital inpatient and outpatient services.

The DSS Personal Care Assistance Waiver assists eligible adults in need of assistance to remain in their homes. The program enables individuals to have greater independence in the community. Based on an assessment of "Activities of Daily Living," individuals can receive essential day-to-day assistance: bathing, dressing, toileting, incontinence, eating, and transferring.

The DDS Individual and Family Supports Waiver supports individuals who live in their own homes and do not need the extensive services provided on the Comprehensive Waiver. This waiver provides individuals with a variety of services such as the following: adult day health, behavioral support, companion supports, community companion homes, continuous residential support, group day support, individual supported employment, live-in companion, respite, groups supported employment, health care coordination, transportation, and vehicle modifications, among other supports.

Appendix B: Waiver Eligibility and Enrollment Process

Application

To apply for services under the DDS Comprehensive Supports (Comp) Waiver and the Employment and Day Supports Waiver, an individual must be a resident of Connecticut, have an intellectual disability (per Connecticut General Statutes Section 1-1g, intellectual disability is defined as a significant limitation in intellectual functioning and deficits in adaptive behavior that originated during the developmental period before 18 years of age) or have a medical diagnosis of Prader-Willi Syndrome (a neurobehavioral genetic disorder that a physician must diagnose). These waivers also serve individuals with developmental disabilities who currently reside in general nursing facilities, but who have been shown, because of the Pre-Admission Screening and Annual Resident Review process mandated by P.L. 100-203 to require active treatment at the level of an ICF/IID. Additional target groups include children with significant medical needs who would require institutionalization without waiver services such as respite, adults who reside in their family home, or adults who do not require 24/7 services to remain in their own homes. These individuals have significant natural supports, generic community services, and state plan services in addition to the services available under this waiver.

To apply for services under the DSS Home and Community Supports Waiver for Persons with Autism an individual must be a resident of Connecticut and have a primary diagnosis of autism, impairment before the age of 22 and expected to continue indefinitely, a cognitive and adaptive functioning above the level of intellectual disability (i.e., IQ equal to or greater than 70) and lastly substantial functional limitations in two or more of the following areas of major life activity: a) self-care, b) understanding and use of language, c) learning, d) mobility, e) self-direction, or f) capacity for independent living.

The eligibility application packet, which is streamlined across these waivers, requires several supportive attachment documents including the following: a completed two-page eligibility application, Psychological and Educational Testing performed through the age of seventeen (17), Intelligence/Cognitive tests, Adaptive skills tests, autism diagnostic testing (if applicable), Medical History and Most Recent Physical Examination, HIPAA Acknowledgement Form, Guardianship or Conservatorship Forms, Proof of Connecticut Residence, and copies of their birth certificate, social security card, health insurance card, and Medicaid card (if applicable), and educational information. Educational information includes the last three (3) years of Individualized Education Programs (IEPs), standardized test scores, and triennial evaluations. For individuals under 3 years of age, the application requires submission of a copy of the Individual Family Support Plan (IFSP).

Eligibility Determination and Initial Enrollment

Once eligibility is determined for DDS services, individuals are assigned a case manager in one of the three regions (North, South, and West). Their region is determined by the town in which the individual resides. This case manager supports the individual in next steps, including enrollment in HUSKY C coverage and conducting a LON assessment to move toward building out an individual service plan and enrolling in services.

If the individual is applying for the HCBS Autism waiver, the process is slightly different. The application and required testing documentation is still reviewed by the state psychologist for determination. However, once determined eligible, the individual is placed on a waitlist for the waiver. When they reach the top of that waitlist, a DSS case manager processes the case, including

enrolling the individual in HUSKY C, conducting the LON assessment, and working with the individual to develop their service plan.

HUSKY C (also known as Medicaid for the Aged/Blind/Disabled includes long-term services and supports and Medicaid for Employees with Disabilities) is a comprehensive health care benefits package for residents of Connecticut 65 years of age or older and/or who are blind or disabled. Under this program, income and asset eligibility vary, depending on which part of HUSKY C individuals qualify for. Enrollment in HUSKY C is mandatory for the enrollment in DDS waivers and provision of waiver services.

Connecticut Level of Need Assessment

DDS case managers with the Individual Support Team work with the individual and their family to complete the LON assessment[47] and enroll in HUSKY C to take the required initial steps of connecting individuals to services.

Each domain listed in **Exhibit 1** is scored based on an individual's strengths and weaknesses relative to each area, ranging from 0-8.

- A zero (0) score represents the greatest skill level in an area.
- Each increase in score represents an increased need for support in that domain.
- The Composite Score on the Connecticut LON is used to validate the participants' Level of Care.
- Individuals with a Composite score of one (1) or greater qualify for an ICF/IID Level of Care.

Key Domains Assessed on Connecticut LON Tool

- Health and Medical
- Personal Independent Care Activities (PICA)
- Behavior
- Mental Health
- Criminal/Sexual Issues
- Seizure
- Mobility
- Safety
- Comprehension and Understanding
- Social Life
- Communication
- Personal Care
- Daily Living

The LON does not replace other assessments (e.g., Residential living skills, vocational, nursing, occupational therapy, physical therapy, dietary, communication, etc.). The results from these evaluations should be used when completing the LON and when developing the individual plan.

Service Planning – Individual Plan

All individuals who receive supports and services from DDS have an individual plan, coordinated by their case manager, and based on the supports and services they receive. The individual plan is the document that guides all department supports and services provided to the individual. The plan identifies supports and services across multiple areas of services that will address the individual's needs and maps out strategies to obtain services. Individual plans are developed on a yearly basis following the LON assessment. The Connecticut LON can be conducted annually or as needed to update service plans, contingent on any significant changes in a person's life, or to identify and document concerns that may be a possible health and safety risk to the client. As noted, those who have individual plans will go through a review of those plans and an updated LON assessment

[47] DDS: Connecticut Level of Need Assessment and Screening Tool Manual. Available online: https://portal.ct.gov/dds/-/media/dds/lon/lon_manual_version_9_march_2022_pdf.pdf

annually before the planning meeting designed to update the individual plan.[48] However, plans may be updated when any changes to circumstances require it.[49]

Redetermination

According to DDS, once an adult is determined eligible for DDS services based on intellectual disability, there is no systematic reevaluation of that determination, although the department may request reevaluations in exceptional cases. However, DDS outlines stipulations for reevaluation requirements for individuals in specified age ranges and provides for reevaluation of individuals of any age when there is documentation. DDS also reserves the right to reevaluate any individual based on clinical opinion, new information, or any other relevant basis that brings into question continued eligibility.

Services & Programs

DDS offers many services to ensure individuals with intellectual disability enjoy a healthy life in their community. DDS provides specialized support to individuals so they can thrive in their homes, form relationships, make decisions, and develop essential skills. Each individual's service plan is based on their needs and annual LON assessment information.

At the core of DDS's work is **STEP: Supporting Transformation to Empower People,** a program with seven person-centered pillars focusing on autonomy and integrating individuals with intellectual disability into the community. Key programs and services available to individuals with intellectual disability and autism include:

- **Individualized Home Support** is a program whereby a staff member supports individuals living in a home of their choosing.
- **Supportive Housing,** combines assistance from a qualified provider and apartment rental subsidization, ensuring individuals live in a safe and affordable place of their choice.
- **Community Companion Homes (CCH)** carefully matches people with intellectual disability to a DDS-licensed family setting, enabling them to live in a nurturing home when situations make living with their own families impractical.
- **Self-Direction Supports** allow individuals to use their allocated budget to direct their support and services how they want; they become the employer and the boss.
- **Assistive Technology** provides equipment, software, or products to perpetuate the client's ability to live more autonomous lives.
- **Remote Supports** provide considerable autonomy through technology utilization to connect individuals with a staff person or caregiver not on location.
- **Employment Services** offered by DDS include several options:
    - *Individualized Supported Employment (ISE)* helps individuals work with a job coach who finds a viable job and gives support and training until the job is understood. The coach then follows along to ensure the individual's continuous success.

[48] For individuals receiving minimal services from DDS, the individual plan may be updated every three years at minimum.
[49] Connecticut Developmental Services. Individual Plan. Available here: https://portal.ct.gov/dds/searchable-archive/family/ip/individual-plan?language=en_US

- *Customized Employment (CE)* finds employment that matches the client's strengths, skills, and abilities with employers. Support is there to help individuals achieve their employment goals. The coach then follows along to ensure the individual's continuous success.
- *Employment Transition Services (ETS)* are community-based services that support individuals as they learn job skills, how to manage their money, find out what type of job they want, and how to network to facilitate them getting a job.
- *Group Supported Employment* provides community-based employment for a small group of individuals with disabilities to work at a local business while being supported by a job coach and a provider. These supports also include career planning that matches individuals with employers if they want to move to an independent position.
- *Project Search* is a nine-month high school internship business training program for students close to school graduation who require additional concentrated employment skills training.

In addition to the STEP program, DDS has **Community Living Arrangements (CLA)**, or private residential homes licensed by DDS that provide care, treatment, and rooms allowing individuals to remain in their own community. These homes are typically smaller and house a maximum of six (6) people. Some homes are also certified as ICF/IID. DDS provides another alternative community living situation, **Continuous Residential Supports (CRS).** CRS is a living arrangement whereby a few individuals share a house or apartment, and before moving into a CRS living situation, DDS checks to ensure certain standards are met.

Like the STEP supports, DDS has an **Employment and Day Services Division** to support individuals with disabilities in preparing for a job, finding a job with real wages, building relationships with coworkers, transitioning from a school setting to day services, transportation, employment at home or in the community and ongoing support and supervision in a position.

Recent Service Changes

Effective July 1, 2023, DDS began the establishment of the **Transitional Life Skills College program.** This program provides transitional tools and life skills development for persons who are at least 22 years of age who have an intellectual disability or other developmental disabilities and are transitioning from (1) kindergarten through the grade twelve education system, or (2) living with parents or guardians and moving to live independently or quasi-independently through a residential program administered by DDS.[50]

DDS implemented the **Paid Family Caregivers** program on May 1, 2024, which enables parents of school-aged children to be paid for two types of services: **Individualized Home Support** and **Personal Support.** In some cases where the child and parent do not live in the same home, parents may be paid **Respite Care.** In cases of guardians that support adults with intellectual disability, they can be paid for four types of services: **Individualized Home Support**, **Individualized Day Support**, **Senior**

[50] Connecticut Substitute House Bill No. 5001, Public Act No. 23-137. AN ACT CONCERNING RESOURCES AND SUPPORT SERVICES FOR PERSONS WITH AN INTELLECTUAL OR DEVELOPMENTAL DISABILITY. Available here: https://www.cga.ct.gov/2023/act/pa/pdf/2023PA-00137-R00HB-05001-PA.pdf

Support, and **Personal Support.**

The 2024 legislative session revised and recently enacted the **Supportive Housing Assistance Program,** a grant program for providers of supportive housing for people with an intellectual disability or other developmental disabilities, including autism. The new law (1) shifts primary responsibility for the program from DDS to the Department of Housing; (2) expands the types of entities eligible for program grants to include not just nonprofits but other eligible developers, such as housing construction businesses meeting certain requirements or municipal developers; and (3) adds the condition that the developer have partnered with a DDS-qualified provider or a provider approved to provide services supporting people receiving services under DSS's Autism Waiver program (PA 24-122, § 3, effective October 1, 2024).[51]

[51] Connecticut office of Legislative Research Special Report. (July 2024). 2024 Acts Affecting People with Disabilities. Available here: https://www.cga.ct.gov/2024/rpt/pdf/2024-R-0102.pdf