



STATE OF CONNECTICUT
Advisory Commission On Services and Supports
For Persons With Developmental Disabilities
Who Do Not Have Mental Retardation

Supporting Connecticut's Citizens with Developmental Disabilities

Final Report from the Advisory Commission on
Services and Supports for Persons with
Developmental Disabilities who do not have
Mental Retardation

Executive Summary

July 2002

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EXECUTIVE SUMMARY

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The Commission. The Advisory Commission was established by P.A. 00-135 Section 19 in response to concern about uneven and limited access to supports and services in Connecticut for citizens with developmental disabilities other than mental retardation. Commission members represented a broad cross section of potential stakeholders and include individuals with developmental disabilities, family members, private provider agencies serving people with developmental disabilities, and state agencies involved in the provision of support to persons with disabilities. The Commission began meeting in November of 2000 and immediately established a process to gather information that would assist in the development of formal recommendations to address the requirements of the P.A. 00-135-19(b):

1. Define the population of people with a developmental disability in Connecticut;
2. Identify the types of services and supports they need;
3. Identify how such services and supports can be best delivered; and,
4. Identify the costs of providing these services and supports.

Three Commission work groups focused on the careful study and analysis of: (a) national practices, (b) existing services in Connecticut, and (c) consumer and family needs and preferences for support. Detailed work group reports were developed¹ and utilized by the Commission to formulate a series of recommendations for guiding the further development of public policy.

Developmental Disability. A developmental disability - in a very general sense - is a disability that occurs during the early developmental stages of life (before adulthood) that requires the provision of special and ongoing supports in order for the individual to lead a normal life and participate in all the natural activities of their community, consistent with their age and culture. The definition of developmental disability recommended by the Commission for use in setting public policy in Connecticut includes the following major components:

1. The disability is due to a mental or physical impairment
2. The disability is chronic in nature, *i.e.*, it is expected to continue indefinitely
3. The disability is present before the age of 22-yrs.
4. The disability results in substantial limitations in 3 or more major life activities:
 - Self-care
 - Receptive or expressive language

¹ A copy of the full report can be obtained on the DMR WebPages: www.dmr.state.ct.us.

- Learning
- Mobility
- Self-direction
- Independent living
- Economic self-sufficiency

Use of such a “functional definition,” which is consistent with the majority of states and federal regulations, eliminates reliance on diagnostic labels as the basis for eligibility for support, and instead establishes age of onset and actual need for support as the basis for receiving state-sponsored services.²

Using this definition, the Commission estimates that there are approximately 56,000 citizens in Connecticut with a developmental disability (including those with mental retardation).

Major Findings. While there is no uniform or standard approach across the country to providing services to individuals with a developmental disability, the vast majority of states have established one state agency as the lead or responsible entity for coordinating and providing services to the population of citizens with a developmental disability. Connecticut is one of only six states in the U.S. that have a state agency serving only persons with mental retardation.³

The absence of a single state agency in Connecticut – or other method of integrating and coordinating services – has resulted in a complex, confusing, and fragmented system of support for persons with developmental disabilities. No less than seven separate state agencies/divisions have established eligibility criteria based on diagnostic labels, income limitations, and discrete functional needs. This has led to uneven access to state sponsored services that often denies critical support to citizens with substantial need for assistance,⁴ resulting in significant frustration and hardship for individuals and families, and fostering the utilization of inappropriate – and more expensive – systems of care (e.g., acute care hospitals or long term care facilities). It also results in a waste of human talent and diminution of quality of life for a large group of Connecticut citizens and families.

² Individuals with mental retardation, autism spectrum disorders, cerebral palsy, spina bifida, severe hearing or visual disorders, and many other clinical conditions would be considered to have a developmental disability if they have a need for ongoing support due to significant limitations in their ability to conduct major life activities.

³ About 40 of the 50 states have moved toward the establishment of a single state agency that serves people with developmental disabilities beyond just those with mental retardation. Only Connecticut, Massachusetts, Pennsylvania, Virginia, Alabama and Mississippi have a state agency that only serves people with mental retardation.

⁴ For example, an individual with an autism spectrum disorder who has significant need for support in activities of daily living can receive relatively comprehensive services from DMR if his/her IQ is less than 70; but may be only eligible for time-limited vocational support from BRS if his/her IQ is a few points higher.

Important and essential service and support needs of persons with developmental disabilities other than mental retardation were identified from survey results obtained from almost 800 individuals with disabilities and their families and were combined with direct feedback derived from 13 focus groups. Analysis of consumer and family feedback suggests that:

1. The actual configuration of needed supports is highly individualized, suggesting the importance of making available a “menu” of services and supports.
2. A comprehensive educational plan provided by the school is the most critical need for children.
3. Individuals with disabilities and their families see service coordination as a vital service to assure effective planning and access to supports.
4. The profile of supports and services that individuals and families appear to desire is substantially different than those of persons currently served by DMR.
5. Expressed needs and existing problems encountered by individuals and families are extremely similar to findings of other legislated and non-mandated committees, workgroups, and contracted studies over the past two decades.

Unfortunately, despite the fact that the gaps in service have been studied again and again, the need to support Connecticut citizens with developmental disabilities continues to exist.

Principles to Guide Future Development. The Commission has established a set of guiding principles that it believes can serve as a framework for designing a future comprehensive system of services and supports. These principles reflect best practices around the country and are fully consistent with the wishes and desires of the vast majority of consumers and families who informed the Commission’s work. The principles stress the:

- Central role of individuals and families
- Need for partnership and collaboration
- Creation of a simple and easy to use system
- Services that reflect quality and are comprehensive in nature
- Working in partnership with local communities
- Active development of and support for employees and support personnel.

Commission Recommendations. After careful deliberation and review, the Commission strongly recommends that the State of Connecticut develop and implement a statewide coordinated interagency system of services and supports for persons with developmental disabilities and their families. The current array of services is too complicated, fragmented, and confusing to consumers and agency staff; and it leads to uneven access and substantial frustration for Connecticut’s citizens who have developmental disabilities and their families.

In order to achieve a system of support that is fair, much easier to use, and that can offer a comprehensive array of specialized services and supports that address priority needs of people with developmental disabilities, the Commission further recommends that the system embrace 11 key components:

1. Adopt the federal definition of developmental disabilities as the basis for service eligibility.
2. Designate DMR as the responsible lead agency for coordinating existing services and developing new services for persons with developmental disabilities and their families.
3. Establish an independent Council to advise the lead agency in system design, implementation, and quality enhancement.
4. Adopt of the Commission's Guiding Principles and Future Vision as the framework for the new system.
5. Develop a comprehensive and coordinated process for accessing information, resources, supports, and services.
6. Provide for the development and provision of individualized services and supports.
7. Establish procedural safeguards and consumer assurances.
8. Establish an interagency data and information management system.
9. Develop a competent and adequate workforce.
10. Design and implement a comprehensive system of quality enhancement and improvement.
11. Secure sufficient resources to fund new services and supports.

The Commission recommends that all 11 components be included in any redesign of the system of services, but recognizes that such a major shift in Connecticut's public policy will require substantial new resources and will need to be phased-in over time.

Cost Projections. Projecting the cost of funding services and supports for Connecticut citizens with developmental disabilities who do not have mental retardation presented a major challenge to Commission members. Unfortunately, Connecticut neither keeps statistics on the prevalence of developmental disabilities nor do we aggregate data that quantify the numbers of persons with a developmental disability who receive services. The paucity of similar data at the national level compounded the problem.

The Commission also found it extraordinarily difficult to "forecast" with any certainty the patterns of service use, the multiple and complex variations on individual level of need, and the cost of supporting individuals with developmental disabilities who do not have mental retardation. Nonetheless, Commission members have attempted to capture the phenomena and project a potential range of "cost" for new services and supports. These projections are based on a cost contained waiver model and the state infrastructure needed to support them (i.e., new unit within a lead agency). Basic ingredients in the cost projection model include:

1. Estimated prevalence rate of persons with developmental disabilities without mental retardation,
2. Estimated overall demand rate for publicly supported services,
3. Variability in individual need for various levels of support and associated cost patterns,
4. Proposed model for configuring supports and shaping the system to avoid duplicative services,
5. Forecast of individual demands for particular services based on a sub-sample of respondents to the Commission survey, and
6. Known costs of comparable services in Connecticut.

Prevalence. The Commission projects that there are approximately 24,180 people with developmental disabilities and who do not have mental retardation who reside in Connecticut. This figure represents a projection of the "total potential population" that theoretically could step forward for service.

Demand. A more accurate projection of the potential number of people who would seek state sponsored support must take into consideration the estimated "demand rate."⁵ Using the Connecticut DMR experience of a 40% demand rate, the Commission projects that upwards of 9,672 Connecticut citizens might come forward to request DD services. A lower demand rate of 20% – substantially higher than but based on the experience of other states (e.g., Kansas) - would result in 4,836 people requesting services. Therefore, expansion of eligibility to all individuals with a developmental disability would most likely lead to no more than 5,000 to 10,000 persons who do not have mental retardation requesting services and supports. It should be noted, however, that a sizeable percentage of this group are already receiving some sort of state sponsored support (e.g., from Birth to Three, BRS, DSS, DCF, LEAs) and would not require new funding for a full "package" of services.

Individual Need. The need for supports and services are likely to vary along two highly related and individualized dimensions—constancy and intensity. Constancy can be thought of as the relative persistence of the need for support and may range from intermittent to continuous. Intensity relates to the quantity or amount of support that may be needed and may range from low to high. In addition, just as the level of need for support may vary significantly within in an individual's lifetime and from one person with a disability to another, service cost patterns and utilization may vary to reflect the nature and dynamics of differing disabling conditions and etiologies. Absent a historical base to project service utilization, the Commission has estimated "average" usage patterns across both the intensity and constancy dimensions.

⁵ Demand rate represents the proportion of individuals from any given population who actually seek services. For example, in Connecticut only about 40% of all citizens with mental retardation are clients of the DMR. More than half of the total MR population does not seek state services. In a similar fashion, the State of Kansas estimates that only about 5% of all its citizens with a developmental disability who do not have mental retardation seek DD services. Thus, the demand rate, which is always lower than the prevalence rate, is a more valid indicator of potential cost since it represents who will seek services, not all those who would be eligible.

System Configuration. The proposed system includes the establishment of a special unit within the Department of Mental Retardation. Projections used the current Birth to Three model to estimate infrastructure costs. Table 1 below summarizes the major expense categories for this infrastructure.

Table 1
Estimated Costs for DMR Infrastructure

Expense Category	No. FTE	Annual Cost
Personnel	23	\$ 1,981,605
Operating		\$ 170,000
Training		\$ 150,000
Public Educ		\$ 75,000
Council/Misc		\$ 40,000
Total		\$ 2,416,605

Personnel costs include salary and fringe benefits.

The actual costs associated with services and supports will be dependent upon the ability of the lead agency to establish sound methodologies for determining an individual’s level of need, assigning resources, and predicting cost patterns due to the highly individualized nature of service need. The Commission believes the lead agency will need to develop and implement formal protocols for assessing level of need that are directly related to funding “bands” or limits. This will not only lead to an objective and fair process for assigning resources, but will allow the state to exercise increased control over costs and utilization.

It is equally important that substantial efforts be directed toward identifying what existing services and supports are already available and, in fact, are being used by the target population. As previously mentioned, Connecticut does not have any objective data to differentiate service usage by persons with developmental disabilities. Consequently, cost projections may overestimate new costs, since there is the potential for either shifting current resources or reducing lead agency activities based on existing receipt of support.

Forecasting Individual Support Needs. Not all people will want or need the same services or all of the services all of the time. To estimate potential patterns of usage the Commission extrapolated data from the consumer and family survey and identified clusters of priority needs and associated services. These priority services, and the relative percentage of Connecticut citizens with a developmental disability and their families who are projected to need them, are presented below in Table 2 for both children and youth and adults.

Table 2
Estimated Rates of Request for Services
Based on Consumer and Family Survey Responses

Service or Support	Percentage Requesting: <u>Children</u>	Percentage Requesting: <u>Adults</u>
Service Coordination	72.4%	76.0%
Family Support	72.8%	46.8%
Direct Support Specialists*	87.7%	83.7%
Respite – Out of Home	40.8%	38.3%
Behavior Management/Social Skills	82.4%	52.0%
Specialized Assessment - Assistive Technology		32.2%

*Term developed to replace Personal Care Assistant or Direct Care Worker

Comparable Costs. The Commission gathered information from a wide variety of sources (e.g., DMR, BRS, PCA Waiver, private provider survey) to calculate a cost per unit and average rate of use for each of the major services categories identified above. The results of this analysis are presented in Table 3.

Table 3
Estimated Per Person Annual Cost for Service Clusters⁶

Service or Support	Average Annual Cost Per Person: <u>Children</u>	Average Annual Cost Per Person: <u>Adults</u>
Service Coordination	\$ 3,500	\$ 3,500
Family Support	\$ 3,000	\$ 3,000
Direct Support Specialists*	\$ 1,560	\$ 15,600
Respite – Out of Home	\$ 2,800	\$ 2,800
Behavior Management/Social Skills	\$ 2,000	\$ 2,000
Specialized Assessment - Assistive Technology	(usually covered by LEA)	\$ 2,000

⁶ More detailed information regarding the basis for assigning costs and rates of use is contained in the full report.

Estimated Costs. Using the information outlined above, a simple formula was developed to project the potential cost of providing priority services and supports to Connecticut citizens with developmental disabilities other than mental retardation. This basic formula states:

$$\text{Annual Cost} = (\text{Sum of the Estimated Prevalence}) \times (\text{Demand Rate [High and Low]}) \times (\text{Estimated Percentage Needing a Service}) \times (\text{Estimated Average Annual Cost for the service}).$$

This formula was utilized for both children and adults to generate a range of total potential cost for implementing the Commission's recommendations. Using the 40% estimate of demand, it is estimated that services for children in the target population, would cost about \$19,000,000 (higher estimate), exclusive of infrastructure costs. If the demand were 20% (lower estimate), such services would cost approximately \$9,500,000. In a similar fashion, the cost of services for adults is estimated to range between \$128,000,000 and about \$79,000,000.

Incremental Development and Revenue Enhancement. Both economic and practical considerations preclude the instantaneous development of a full array of services and supports for all eligible persons with a developmental disability. Therefore, it is recommended that development proceed in an incremental fashion, beginning with infrastructure development and proceeding, over the course of five years, toward full roll-out of services. Using this approach not only mitigates the immediacy of the funding requirements, but recognizes the importance of establishing a foundation of competent and committed providers and effective information, planning and referral mechanisms.

It is also strongly recommended that the system be designed consistent with federal Medicaid Waiver options to reduce the net state funding requirements over time.

Projections of the total and net fiscal requirements, for the higher estimated demand (40%) and the lower (20%) are summarized below in Figures 1 and 2.

Figure 1
Projected Fiscal Requirements for Serving Children and Adults with
Developmental Disabilities Using a Demand Rate of 40% (High)

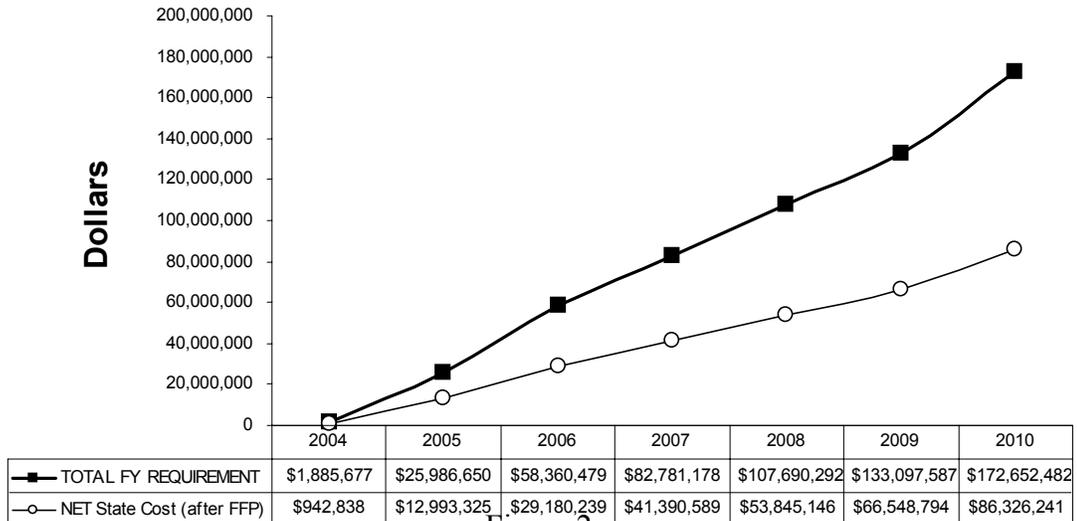
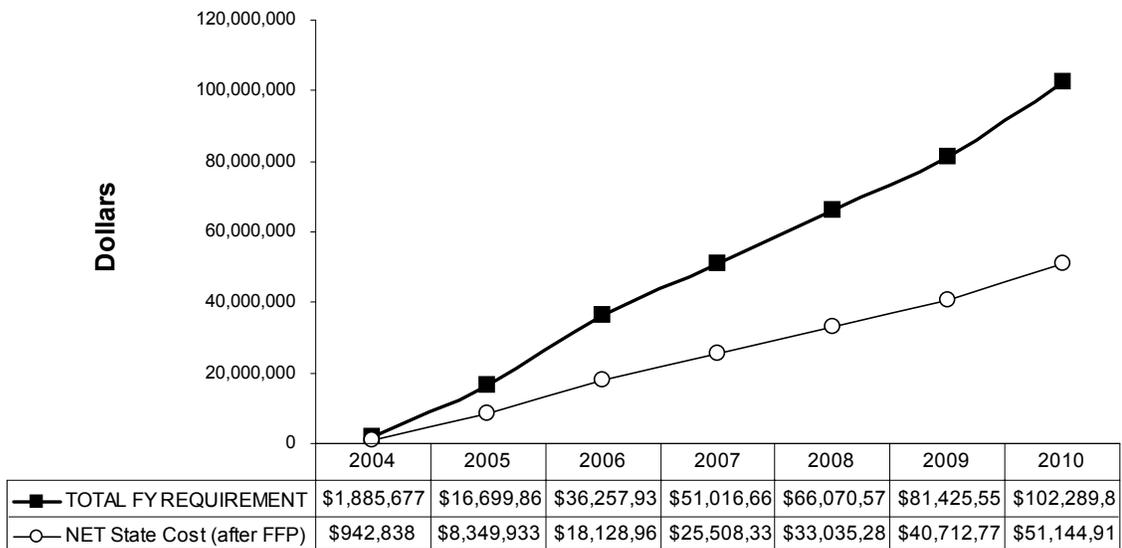


Figure 2
Projected Fiscal Requirements for Serving Children and Adults with
Developmental Disabilities Using a Demand Rate of 20% (Low)



Estimated costs at low end of projected demand range using current census statistics. Cost adjusted for inflation and assume an incremental roll-out of services over a 5 year time period. Net State Cost assumes federal reimbursement of 50% (Waiver services).

As noted, there are a wide variety of unknown factors that could influence the actual costs that would be incurred by the State of Connecticut if eligibility for services and supports are expanded to citizens with developmental disabilities other than mental retardation. How the actual system is structured (e.g., public v private service coordination, private provider v self directed supports), efforts to avoid duplication (e.g., Birth to Three, LEA, other state agency services), schedules for phasing-in services, cost containment strategies (e.g., capping of services based on level of need determination, age and/or financial eligibility criteria), and a whole host of other variables will ultimately determine the funding requirements that will follow adoption of the Commission's recommendations.⁷

Whatever strategies are ultimately embraced, it is essential that both executive and legislative leadership act in a responsible fashion by providing additional resources commensurate with the mandate to increase the number of citizens that are to be served. DMR is currently struggling with a significant Waiting List, made up of over 1,500 individuals with mental retardation who have requested residential services, and for whom additional resources are clearly needed. It will not serve these individuals well nor will it assist those persons with other types of developmental disabilities if the same resource base is expected to serve even more people. The experience of other states as well as common sense strongly suggest that such an approach will not work.

⁷ It should be noted that costs for out-of-home residential placement or formal provider-based day programs are not included in these cost projections. The use of Direct Support Specialists (aka Personal Care Attendant) provides increased flexibility for providing residential living and vocational support, and will address the needs of the vast majority of individuals. Nonetheless, there may be a small group of persons who will require 24-hr out-of-home residential service. The Commission recommends that the DMR average rate be utilized to project these service costs.