



## VIII. Estimated Cost Projections

### *Supporting People with Developmental Disabilities, who do not have Mental Retardation: Controlling Costs and Setting Expectations*

Based on current economic trends, we cannot expect sufficient state dollars to be available to fund all needed services and supports. As noted in our guiding principles and elsewhere in this report, broad partnerships must be developed among individuals, family members, public agencies, and private providers. In addition to active family participation in providing direct and financial supports, we strongly recommend maximization of reimbursement (e.g., private insurance, Medicaid), coordination of existing service resources, and exploration of the utility of establishing a new home and community based waiver (e.g., CMS Independence Plus). Moreover, any new service development should **not** be designed to **supplant existing services** but instead **focus on coordinating and enhancing available resources and**

**designing support systems** that meet the needs of currently unserved populations—individuals with developmental disabilities who do not have mental retardation and their families.

Projecting the cost of funding services and supports for Connecticut citizens with developmental disabilities, who do not have mental retardation was perhaps the biggest challenge Commission members faced. First and as described earlier, we found that 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. Second, the paucity of similar data at the national level compounded the matter. While possible in principle, members 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 range of "cost" for new services. These projections are based on a cost contained non-entitlement waiver model and the state infrastructure needed to support them (i.e., new unit within a lead agency). Several ingredients were used to create this cost model. They include:

- estimated prevalence rate of persons with developmental disabilities without mental retardation,
- consideration of variability in individual need for various levels of support and associated cost patterns,
- estimated overall demand rate for publicly supported services,
- a proposed model for configuring supports and shaping the system,
- a forecast of individual demands for particular services based on a sub-sample of respondents to the Commission survey, and
- the known cost of comparable services in Connecticut.

### ***Estimating the Prevalence Rate for Developmental Disabilities Without Mental Retardation***

Prevalence refers to a "defined characteristic" and the number of "cases" (whether old or new) that are present in a population for a designated time interval or point in time. Therefore, prevalence rates represent the total number of "cases" present in the population relative to the total population. As discussed earlier (Section III), there is no national or state centralized registry or data source for determining the number of persons with developmental disabilities. Moreover, estimates of prevalence are variable, depending on the data source reviewed. Table 3 contains some of these estimates.

Table 3. Selected Prevalence Estimates

	<b>2000 Census</b>	<b>All DD*</b>	<b>MR only</b>	<b>DD not MR**</b>
<i>Percentage</i>	100%	1.65%	1.00%	0.71%
<b>Children</b>	925,702	15,274	9,257	6,572
<b>Adults</b>	2,479,863	40,918	24,799	17,607
<b>Total</b>	3,405,565	56,192	34,056	24,180

*\*Prevalence rate of 1.65% as cited in The Developmental Disabilities Assistance and Bill of Rights Act of 2000, 42 U.S.C. 15001 §101(a)(2)*

*\*\*Prevalence rate of .71% taken from the NHIS-D study (Larson et al., 2000)*

Using the 1.65% prevalence rate cited in the Developmental Disabilities Act of 2000 and 2000 Census Data, we estimate that there are **56,192 people with developmental disabilities residing in Connecticut**. This figure is inclusive of all people with developmental disabilities whether they also have mental retardation or not. We also estimate that approximately **34,056** (using a standard convention of 1%) of individuals living in Connecticut have mental retardation whether they have a developmental disability or not.

Lastly, we examined the **national prevalence rates** from the 1994 – and 1995 National Health Interview Survey’s Disability Supplement (NHIS-D) summarized in the April 2000 MR/DD Data Brief (Larson et al.). These authors provide estimates of the prevalence of mental retardation and/or developmental

disabilities among the non-institutionalized population of the United States. They estimated that the **prevalence rate for non-institutionalized persons with developmental disabilities** (as defined functionally), **who did not have mental retardation** (defined categorically) was **.71%**.

Applying .71% to 2000 Census Data, we estimate that **24,180 people with developmental disabilities who do not have mental retardation reside in Connecticut**. This figure represents a forecast of the **"total potential population"** who could come forward for service and includes everyone who is in the Commission's target population—individuals with developmental disabilities who do not have mental retardation.

***Considering variability in individual need for various levels of support and associated cost patterns***

Estimating needed levels of support on a person-by-person basis and forecasting utilization and cost patterns is a challenging endeavor. First, the need for supports and services are likely to vary along two highly related and individualized dimensions—constancy and intensity (Schalock, 1997).

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. Figure 10 presents one way of conceptualizing these concepts.

Second, 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. For example, a person with spina bifida will likely have the greatest service costs in the first year or so of life. In this case, the cost pattern starts high and is likely to drop sharply and become relatively stable over time. In contrast, a person with a degenerative condition such as muscular dystrophy will have a relatively low cost pattern at onset, increasing as the disease progresses.

**Figure 10. Conceptualization of levels of support.**

<b>Levels of Support</b>	
<b>Intermittent</b>	Supports are provided on an episodic basis. The person does not always need the support(s). For example, they may be needed during times of lifespan transition such as school to work, work to retirement or during acute medical crisis. The intensity of intermittent supports may be high or low.
<b>Limited</b>	This type of support typically occurs in a single setting (e.g., job support). It involves limited staff and is typically low intensity and low cost.
<b>Extensive--Direct</b>	Extensive supports can be characterized as direct supports that are provided on a regular and ongoing basis (e.g., daily) in one or more environments (at home or work). While long-term, the intensity may vary from high to low across the settings.
<b>Pervasive--Comprehensive</b>	These types of supports are characterized by their constancy and high intensity. Supports are provided in several environments. may be life

Lastly, a person with significant cerebral palsy could have substantial service needs over his or her lifetime and the cost pattern for support would likely remain somewhat constant.

Commission members believe that it is critical for the lead agency to establish sound methodologies for determining an individual’s level of need, assigning resources, and predicting cost patterns. This could be accomplished in part by assessing service needs on an annual basis, using tools that have proved helpful in other states (e.g., Inventory for Client and Agency Planning, North Carolina Support Needs Assessment Profile, Ohio Eligibility Determination Instrument). One example of this type of instrument can be found in Appendix G. Nonetheless, we are acutely aware that we cannot assume that we have captured any phenomena because something is written down, labeled, and put in a box, ideally represented by numbers.

### ***Estimating the Overall Demand Rate for Publicly Supported Services***

Because Connecticut does not currently serve, in any systematic way, people with developmental disabilities who do not have mental retardation, we have no accurate way of predicting who might come forward to request publicly supported services if they were made available. ***Some people who have previously not had access to publicly supported services would choose to access them, others would not, relying instead on informal or private sources of support.***

For example, in the case of people with mental retardation accessing services from DMR, approximately 40% of the estimated total population of people with mental retardation in Connecticut have come forward to request publicly supported services.

Table 4. Sample Benchmarks for Estimating Demand Rate

State	All DD	MR only	DD not MR
CT		40%	
KS	17%	28%	5%

By comparison, Kansas indicated in their survey response that they served approximately 28% of people with mental retardation and 5% of the total potential population of people with developmental disabilities who did not have mental retardation in 2000. The lower Kansas figure may be an artifact of the way the state shaped demand for services by altering or configuring the system. **Using DMR’s experience of 40% as a benchmark, we project that as many as 9,672 people might come forward to request services. A lower demand rate of 20% would result in 4,836 people requesting services.**

Table 5. Estimates of Demand for Publicly Supported Services

<i>Percentage</i>	100%	40%	20%
<b>Children</b>	6,572	2,629	1,314
<b>Adults</b>	17,607	7,043	3,521
<b>Total</b>	24,180	9,672	4,836

### ***Configuring Supports and Shaping the System***

Earlier in this report we characterized Connecticut’s human service system as it relates to individuals with developmental disabilities who do not

have mental retardation and their families (see Section IV). We also portrayed the priority service and support needs of individuals with disabilities and their families as expressed by focus group participants and survey respondents (See Section VI).

In an attempt at more accurately estimating the cost of new service development, service and support matrices (i.e., the menu and current system) were collapsed and reconfigured as shown in Figure 11. This was done to avoid duplicating or supplanting existing service resources and to focus on filling identified service gaps. For example, many survey respondents indicated that they needed one-on-one support in several major areas of life (e.g., at home, on the job, in the community). These categories of potential one-on-one support were collapsed into a single category renamed "direct support specialists".

The reader should also note the conspicuous absence of residential placement and day program options. These support options are not included

in the service configuration because the new service system is focused on a community base of support that does not focus on aggregated care settings (e.g., group homes). National trends and the survey data indicate that the vast majority of the target population would

not want this type of "pre-packaged service". The absence of this option in the menu below would not, however, prevent an eligible person from taking his or her "portable budget" and purchasing this type of service (e.g., group home) from a private provider.

**Figure 11. A depiction of an interagency service and support matrix for individuals with developmental disabilities and their families based on the development of new services and the coordination and enhancement of existing services.**

<p align="center"><b>New Service Development: Lead Agency Funds (payer of last resort)</b></p>	<p align="center"><b>Existing Services Coordination and Enhancement: Lead Agency Assists Responsible Agencies (non-supplanting)</b></p>
<p><b>Service Coordination</b>—assistance with, understanding and securing benefits and locating services and supports (i.e., service broker or benefits counselor).</p>	<p><b>“Case Managers” Multiple Agencies</b> <i>DSS, DPH, BRS, etc.</i></p>
<p><b>“Direct Support Specialists”</b>—persons who are employed by the individual, family, or through an agency to provide direct assistance to the individual with a disability (adult or child). The support could include assistance:</p> <ul style="list-style-type: none"> <li>• with access to and participation in community activities</li> <li>• on the job</li> <li>• for leisure and recreation activities</li> <li>• with independent living or in the family home</li> </ul>	<p><b>PCA Waiver</b>—provides personal care assistance services only for adults with physical disabilities, who require hands-on help with at least two of these activities of daily living—bathing, dressing, eating, transferring, or toileting <i>DSS</i></p> <p><b>Life Skills Training</b>—education and training in basic life skills <i>SDE—LEA</i></p>
<p><b>Family Support</b>—supports provided directly to the family or other caregiver, including:</p> <ul style="list-style-type: none"> <li>• Money to purchase necessary and non-reimbursable equipment or services</li> <li>• Parent to parent support</li> <li>• Support groups or networks</li> <li>• Family Counseling</li> <li>• Information, education, training</li> <li>• In-home respite</li> </ul>	<p><b>Family Support Grant</b>—children with developmental disabilities 5 - 18 years of age, who do not have mental retardation, ongoing expenses such as special equipment or clothing <i>DSS</i></p>
<p><b>Social Skills Training/Behavior Management</b>—specialized behavior and social skills training services, including collaborative staff development, technical assistance and training activities.</p>	<p align="center"><i>SDE—LEA, DCF</i></p>

<p align="center"><b>New Service Development: Lead Agency Funds</b> (payer of last resort)</p>	<p align="center"><b>Existing Services Coordination and Enhancement: Lead Agency Assists Responsible Agencies</b> (non-supplanting)</p>
<p><b>Out of home Respite Care</b>— include persons with comprehensive support needs in pool of eligible candidates for use of the DMR center-based respite care program. Expand by one additional center.</p>	
<p><b>Assessment Fund</b>—provide limited funds for specialized assessment that are not covered through other sources of support.</p>	<p><b>Assessment Services</b>—specialized evaluations or assessments <i>DSS (Medicaid to the Disabled, Medicaid, HUSKY, etc.)</i></p>
<p><b>Assistive Technology Fund</b>— provide limited funds for specialized equipment, vehicle modifications, and adaptations to the home that are not covered through other sources of support.</p>	<p><b>Assistive Technology</b>—specialized equipment, vehicle modifications, and adaptations to the home <i>DSS (Medicaid to the Disabled, Medicaid, HUSKY etc.)</i></p>
	<p><b>Education</b>—school-based education <i>SDE—LEA</i></p>
	<p><b>School to Work Transition Support</b>—assistance moving from high school to employment <i>SDE—LEA, BRS</i></p>
	<p><b>Job Training and Placement</b>—assistance with finding a job and learning to do a job (competitive employment) <i>BRS</i></p>
	<p><b>Housing Assistance</b>—subsidy, financing, modification, locator services <i>DSS—Section 8, HUD, RAP, etc.</i></p>
	<p><b>Transportation Services</b>—individualized and adapted transportation <i>DOT</i></p>
	<p><b>Medical and Health Care</b>—direct service health care and/or funding or subsidy) <i>DSS—Medicaid to the Disabled, Medicaid, HUSKY, etc.</i> <i>DPH—CSHCN</i></p>
	<p><b>Mental Health Care</b>—direct mental health care and/or funding or subsidy <i>DSS—Medicaid to the Disabled, Medicaid, HUSKY</i></p>
	<p><b>Financial Subsidy</b>—cash payments from government agencies directly to individual <i>DSS—SSI, SSDI, etc</i></p>
	<p><b>Welfare Services</b>—provide temporary housing, food, clothing <i>DSS</i></p>

***Forecasting Individual Demand for Supports for People with Developmental Disabilities who do not have Mental Retardation***

While a particular proportion of the total population of people with developmental disabilities who do not have mental retardation might request services, **not all people will want or need the same services or all of the services all of the time.** Moreover and as described earlier, the level of intensity and constancy of any particular support will likely vary across the lifespan, from person to person, and across categories of disabilities.

For the purposes of estimating the potential need for any particular service and the costs, we looked at levels of self-identified needs on Question # 7 in the survey. This question asked respondents to indicate, on a four-point scale, their need for support in nine areas of major life activities. Of the 638 individuals in the survey sample, 37.9% (n = 242) indicated that they had a level of need for **direct assistance** (i.e., 3) or **comprehensive support** (i.e., 4) in **three or more** major life activities.

Given this intensity of self-identified need in three or more areas of life, one could infer that this sub-sample of survey respondents (n = 241) would likely meet the Federal definition of developmental disability and be eligible for services. Of the sub-sample of 241 individuals who would likely meet the Federal definition of developmental disability, 77% (n = 186) were children and youth birth through 18 years of age and 23% (n = 55) were adults 19 years of age or older.

To forecast the potential demand for services, we then looked at this sub-sample of respondents and identified their priority needs (i.e., moderate or great need for a listed support) for the services listed in Question #9 of the survey. We used these figures as benchmarks for representing potential demand for specific types of support (See Figures 12 and 13 respectively.).

**Figure 12. A depiction of the potential demand rates for select services—children birth - 18 years of age.**

Support Category	% Requesting (Q # 9 survey)
Service Coordination	72.4%
Family Support	72.8%
“Direct Support Specialists”	87.7%
Respite - Out of Home	40.8%
Behavior Management Social Skills	82.4%

**Figure 13. A depiction of the potential demand rates for select services—adults 19 years of age and older.**

Support Category	% Requesting (Q # 9 survey)
Service Coordination	76.0%
Family Support	46.8%
“Direct Support Specialists”	83.7%
Respite - Out of Home	38.3%
Behavior Management Social Skills	52.0%
Assistive Technology/ Assessment Services	32.2%

***Using Known Costs for Comparable Services to Estimate New Services Costs***

Using what we know about the cost of existing programs and waiver services (e.g., BRS, DMR, PCA Waiver), we estimated average costs for the new services listed in Figure 11. We also

used these experiences to predict potential utilization (e.g., average hours or times per year). Figures 14 and 15 depict the estimated annual cost of select services for children and adults respectively.

**Figure 14. Average annual cost per person for select services for children.**

Support Category	Cost Basis	Annual Cost Av. Est.
Service Coordination	Average 1/40	\$ 3,500
Family Support	DMR annual av.	\$ 3,000
Direct Support Specialists	av. 2 hrs/wk X \$15	\$ 1,560
Respite - Out of Home	14 days/year	\$ 2,800
Behavior Management Social Skills	50 hrs/yr X \$40.00	\$ 2,000

**Figure 15. Average annual per person cost for select services for adults.**

Support Category	Cost Basis	Annual Cost Av. Est.
Service Coordination	Average 1/40	\$ 3,500
Family Support	DMR annual av.	\$ 3,000
Direct Support Specialists	av. 20 hrs/wk X \$15	\$ 15,600
Respite - Out of Home	14 days/year	\$ 2,800
Behavior Management Social Skills	50 hrs/yr X \$40.00	\$ 2,000
Assistive Technology/ Assessment Services	1 time annual av.	\$ 2,000

***Cost of State Infrastructure to Coordinate and Develop the System***

Using what we know about the cost of existing state infrastructure that support units within state agencies (e.g., Connecticut’s Birth to Three System),

we estimated an average annual cost for a new state-level developmental disabilities unit and regional infrastructure. The additional cost for establishing a state infrastructure is estimated to be **\$2,416,605**. Figure 16 depicts the estimated annual cost for this infrastructure.

**Figure 16. Estimated state infrastructure costs for developmental disabilities unit, including central office (CO) and regional staff.**

<u>Title/Position</u>	<u>FTE's</u>	<u>Entry Level Salary &amp;Fringe</u>
Director--CO	1	112,000
Clinical Psychologist--Eligibility	1	84,605
Data System Personnel--CO	1	110,000
Associate Accountant--CO	1	85,000
Training Staff--CO	2	150,000
Secretary--CO	2	90,000
Regional Managers	5	625,000
Regional Secretaries	5	225,000
Regional Fiscal Administrative Officers	5	500,000
<b>Total FTE's, Salaries and Fringe</b>	<b>23</b>	<b>1,981,605</b>
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<u>Unit--Administrative Costs</u>		
Other (e.g., technology, office supplies)		170,000
Training		150,000
Public Awareness		75,000
Council		40,000
<b>Total Administrative Costs</b>		<b>435,000</b>
<b>Total Estimated Cost for State Infrastructure</b>		<b>2,416,605</b>

Figures 17 and 18, contain comparisons of estimates for annual costs of services projected at 40% and 20% of the estimated population for children and adults respectively. Using the 40% benchmark, it is estimated that services

for children in the target population, would cost up to **\$ 19,003,779**, exclusive of infrastructure costs. Similarly, services for adults are estimated to cost between **\$ 128,137,525 and 79,302,075**.

**Figure 17. A comparison of estimates for annual costs of services for children with developmental disabilities who do not have mental retardation, with projections at 40% and 20% of the estimated population respectively.**

Category of Service*	Av. Est. Cost (annual)	Cost Basis	40% Population	Est. % Requesting (from survey)	Est. No. Requesting	Estimated Annual Cost for 40% of Pop.	20% Population	Est. No. Requesting	Estimated Annual Cost for 20% of Pop.
Service Coordination	\$ 3,500	Average 1/40	2,629	72.4%	1903	\$ 6,661,886	1,314	951	\$ 3,329,676
Family Support	\$ 3,000	DMR annual av.	2,629	72.8%	1914	\$ 5,741,736	1,314	957	\$ 2,869,776
Direct Support Specialist	\$1,560	av. 2 hrs/wk * \$15	2,629	87.7%	2306	\$ 3,596,787	1,314	1152	\$ 1,797,710
Respite - Out of Home	\$ 2,800	14 days/year	2,629	40.8%	1073	\$ 3,003,370	1,314	536	\$ 1,501,114
Behavior Management Social Skills	\$ 2,000	50 hrs/yr * \$40.00	2,629	82.4%	2166	\$ 4,332,592	1,314	1083	\$ 2,165,472
						<b>\$ 19,003,779</b>			<b>\$ 9,498,275</b>

\* Assistive Technology and Assessment Services were not included because they should be provided as part of a child's IEP.

**Figure 18. A comparison of estimates for annual costs of services for adults with developmental disabilities and who do not have mental retardation, with projections at 40 % and 20% of the estimated population respectively.**

Category of Service	Av. Est. Cost (annual)	Cost Basis	40% Population	Est. % Requesting (from survey)	Est. No. Requesting	Estimated Annual Cost for 40% of Pop.	20% Population	Est. No. Requesting	Estimated Annual Cost for 20% of Pop.
Service Coordination	\$ 3,500	Average 1/40	7,043	76.0%	5353	\$ 18,734,380	3,521	2676	\$ 9,365,860
Family Support	\$ 3,000	DMR annual av.	7,043	46.8%	3296	\$ 9,888,372	3,521	1648	\$ 20,185,893
Direct Support Specialist	\$15,600	av. 20 hrs/wk * \$15	7,043	83.7%	5895	\$ 91,961,860	3,521	2947	\$ 45,974,401
Respite - Out of Home	\$ 2,800	14 days/year	7,043	38.3%	2697	\$ 7,552,913	3,521	1349	\$ 3,775,920
Behavior Management Social Skills	\$ 2,000	50 hrs/yr * \$40.00	7,043	52.0%	3662	\$ 7,324,720	3,521	1831	\$ 3,661,840
Assistive Technology/ Assessment Services	\$ 2,000	1 time annual av.	7,043	62.5%	4402	\$ 8,803,750	3,521	2201	\$ 4,401,250
						<b>\$ 128,137,525</b>			<b>\$ 79,302,075</b>

Therefore, we project that the annual cost for serving an estimated **40% of projected population** of people with developmental disabilities who do not have mental retardation. is approximately **\$ 149,557,908.68**.

The annual cost of serving **20%** of this population is estimated to be **\$ 91,216,954.68** (See Figures 19 and 20 below.).

**Figure 19. Total estimated annual cost for serving 40% of projected population of people with developmental disabilities who do not have mental retardation.**

Total Estimated Cost for State Infrastructure	2,416,604.80
Estimated Annual Cost for 40% of Pop. of Children with DD not MR	19,003,779.08
Estimated Annual Cost for 40% of Pop. of Adults with DD not MR	128,137,524.80
<b>Total Estimated Annual Cost for 40% of Pop.</b>	<b>149,557,908.68</b>

**Figure 20. Total estimated annual cost for serving 20% of projected population of people with developmental disabilities who do not have mental retardation.**

Total Estimated Cost for State Infrastructure	2,416,604.80
Estimated Annual Cost for 20% of Pop. of Children with DD not MR	9,498,275.28
Estimated Annual Cost for 20% of Pop. of Adults with DD not MR	79,302,074.60
<b>Total Estimated Annual Cost for 20% of Pop.</b>	<b>91,216,954.68</b>

These cost estimates reflect a service and support system based upon all of the commissions recommendations. It should be noted that any planning associated with implementation would need to consider three additional concepts.

1. **Age range for the target population.** Currently, Connecticut serves infants and toddlers birth through two years of age with disabilities and their families through the Connecticut Birth to Three System under Part C of the Individuals with Disabilities Education Act (IDEA). Most of the systems and supports (e.g., service coordination, respite) described here are available through that system and DMR. At the other end of the lifespan, are services for people 64 years of age and older. Here again systems are in place that meet many of expressed needs for the target population. Serious consideration will need to be given to how, if at all, to include these upper and lower age ranges.

2. **Incremental development.** Any expansion of services would need to be gradually phased in over time due to economic and operational needs. Infrastructure must be established and provider capacity developed before the roll out of direct supports. At a minimum, an implementation plan would need to cover a three to five year period.
3. **Federal reimbursement.** A large portion of the estimated cost for infrastructures and services would be eligible for federal reimbursement to the state of Connecticut. The Commission strongly recommends that any developmental disability services be provided via a Medicaid Home and Community-Based Services (HCSB) Waiver. As this would substantially reduce the net state liability.

In sum, estimating the cost of serving people with developmental disabilities who do not have mental retardation is a multi-faceted and complex task. Several ingredients were used to create this cost

model and forecast presented in this section. They include:

- estimated prevalence rate of persons with developmental disabilities without mental retardation,
- consideration of variability in individual need for various levels of support and associated cost patterns,
- estimated overall demand rate for publicly supported services,
- a proposed model for configuring supports and shaping the system,
- a forecast of individual demands for particular services based on a sub-sample of respondents to the Commission survey, and
- the known cost of comparable services in Connecticut.

### ***Incremental Development and Revenue Enhancement***

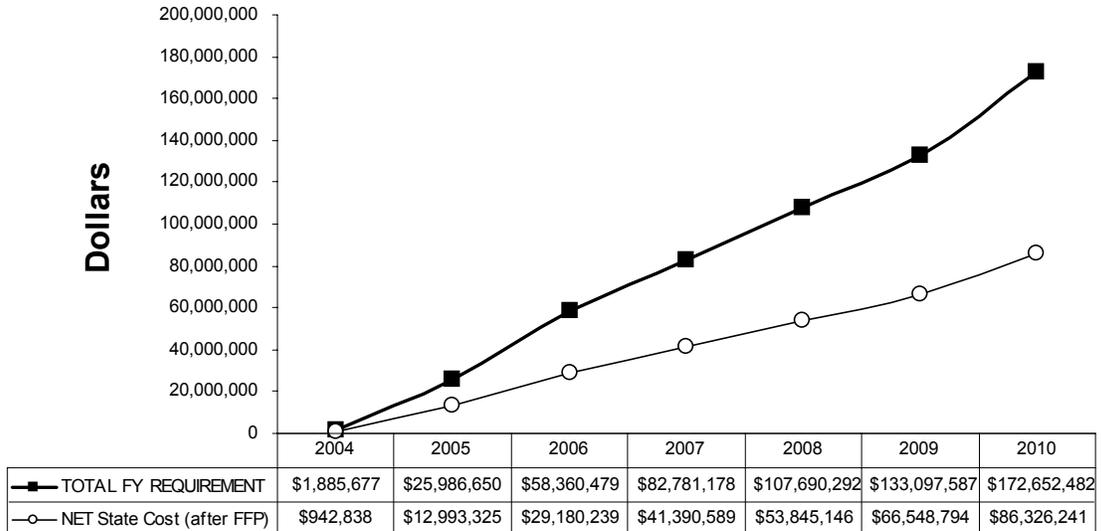
Both economic and practical considerations preclude the instantaneous development of a full

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.

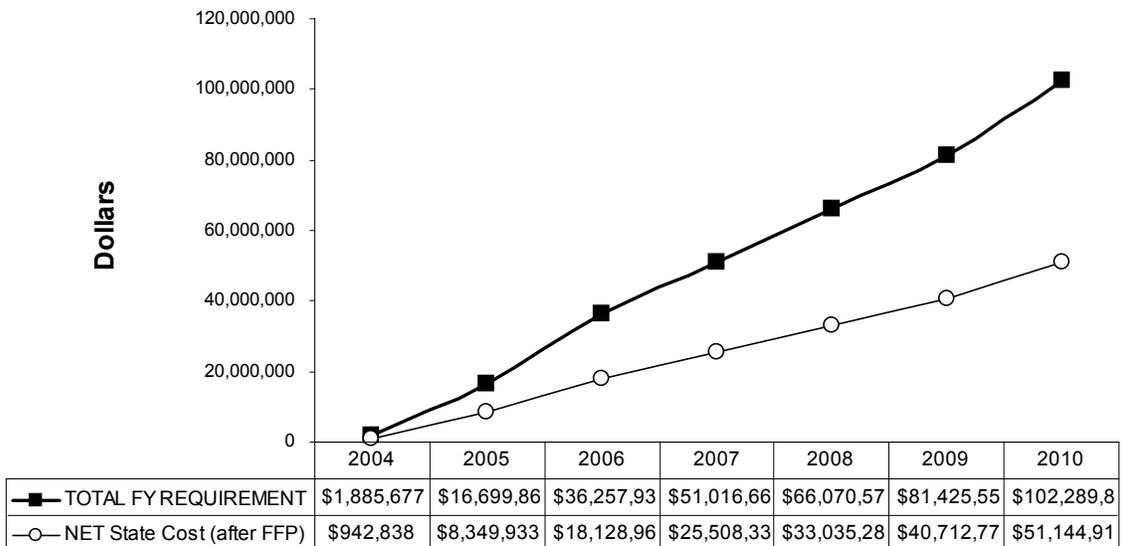
It is also strongly recommended that the system be designed consistent with federal Medicaid Waiver options to reduce the net state funding requirements over time.

Projections of the total and net fiscal requirements, for the higher estimated demand (40%) and the lower (20%) are summarized in Figures 21 and 22 respectively.

**Figure 21. Projected fiscal requirements for serving children and adults with developmental disabilities using a demand rate of 40%.**



**Figure 22. Projected fiscal requirements for serving children and adults with developmental disabilities using a demand rate of 20%.**



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.

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. It will not serve persons with developmental disabilities well if the existing resource

base is expected to serve even more people. The experience of other states as well as common sense strongly suggests that such an approach creates waiting lists and simply does not work.



## IX. Summary

The DD Advisory Commission is pleased to present this final report. We believe it is consistent with all of the requirements of PA 00-135 19(b). The report represents over 19 months of careful study and deliberation by an extremely dedicated and talented group of individuals, brought together by a common desire to find solutions that can address the substantial – and unmet – needs of children and adults in our state who have a developmental disability.

The Commission has established a set of important principles, provided a vision of how a future service system could be structured that is consistent with those principles, and projected potential costs for new services and supports.

The Commission recognizes that ***Special Act No. 02-14 Sec. (1)*** (Appendix H) ***requires DMR and DSS to jointly prepare a plan for addressing the Commission’s recommendations by October 1,***

***2002,*** and we stand ready to assist in this effort.

Although the Commission has completed its formal work, many of its members remain fully committed to seeing Connecticut move forward in establishing a system of support that will enhance the opportunities and quality of life of its citizens with developmental disabilities.

Disability is a natural part of the human experience that does not diminish the rights of people with developmental disabilities to live independently, to exert choice and control over their lives, and to fully participate in and contribute to their communities, through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of Connecticut.

