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THE ADVISORY COMMISSION ON SERVICES AND SUPPORTS  
FOR PERSONS WITH DEVELOPMENTAL DISABILITIES

**NATIONAL COMMITTEE**

Summary Report of Findings and Conclusions  
Submitted to the Commission  
September 11, 2001

The National Committee of the Advisory Committee on Services and Supports for Persons with Developmental Disabilities was given the charge of completing the tasks outlined below.

- Identify best practice in the field of developmental disabilities and analyze service systems in other states that are representative of these best practices.
- Gather information about how other states define eligibility for developmental disability services.
- Estimate the prevalence of developmental disabilities.

Best Practices

Methodology

The National Committee used several methods to identify best practices in the field of developmental disabilities. These included reviewing recently published documents; speaking with respected experts in the field; and surveying three states, Kansas, Minnesota, Washington which were identified by experts as having various systems components that are based on best practices.

1. Finding

The Guiding Principles and Future Vision, which were developed by the Commission, characterize best practices in the field of developmental disabilities.

Rather than repeating or expanding on each of the Commission's guiding principles, committee members have chosen to refer Commission members to the two documents described below. It is our feeling that they represent a synthesis of best practices in the field and that they are particularly supportive of the concepts articulated in the Commission's principles and vision.

In December 2000, the National Association of State Directors of Developmental Disabilities Services, Inc. (NASDDS) released a report entitled "Person Centered Supports: They're for everyone". This document contains a consensus statement that outlines ten principles and eighteen underlying indicators that are intended to represent essential characteristics of service systems that are both person- and family-centered. Representatives of major stakeholder groups developed the principles and indicators through a process of consensus and review. The

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Commission's guiding principles mirror the NASDDDS (December, 2000) principles and indicators.

In his chapter entitled "The Concept of Quality of Life in 21<sup>st</sup> Century Disability Programmes", Robert Schalock (1997) suggests that services should be based on supports. He describes supports as those resources and strategies that enhance an individual's functioning; enable him or her to access resources and information and build relationships; and result in enhanced independence, productivity, inclusion, and satisfaction (p. 330). Schalock notes that supports typically vary along a continuum of intensity (e.g., intermittent, pervasive) and function (e.g., in-home assistance, employment support) as these characteristics relate to a person's desired outcomes. The intensity of needed support is fluid and will vary from person to person, across situations, and based on life events. This concept of types and intensities of support needed could be useful in determining eligibility of services and level of funding for individuals.

### Conclusion

In addition to the guiding principles, the concepts contained in the documents noted above should guide Commission members as they design Connecticut's system of services and supports for persons with developmental disabilities.

## 2. Finding

Expansion of state eligibility for services does not necessarily lead to increases in funding.

In the three states surveyed, changes in definition and resultant expansion in service eligibility was not accompanied by an increase in funding for services. All of the states reported that there was insufficient funding to support the number of eligible persons. In other words, service eligibility does not equal access to services. As is the case in most states, access to supports in the three surveyed states is limited by fiscal and budgetary realities.

### Conclusion

Any expansion in service eligibility should be accompanied by a detailed plan for funding the services and supports. Commission members should give consideration to the examples below of ways in which funding for new services might be maximized.

- Expansion of or revision to existing home and community based waiver programs under Medicaid.
- Development of new home and community based waiver programs for currently unserved or underserved groups.
- Development of sliding fee scale or mechanisms for a co-pay (e.g., individual and parental contributions).
- Mechanism for rate setting for service providers.
- Mechanism to seek reimbursement from Medicaid, Medicare, and private insurance for services provided.

### 3. Finding

Workforce recruitment, training, and retention were problematic for all three states.

For example, Washington reported that while they require 38 hours of initial training for staff and 12 hours of continuing education per year, they are unable to maintain this standard because the staff turnover is approaching 50%. Kansas also reported high staff turnover. At a recent presentation on workforce issues (May, 2001) Amy Hewitt, Ph.D., University of Minnesota, reported that barriers to workforce growth and sustainability include wages, benefits, training, and a lack of a career path. This in turn leads to high turnover rates and expenditures per hire that range from \$2,500 - \$4,000.

### Conclusion

Commission members should develop a plan that addresses issues of workforce recruitment, training, and retention

- Expand the collaborative work of DMR and Connecticut's Job Bank to support families, individuals, and other agencies in their workforce needs.
- Put systems in place that maximize recruitment at the secondary and post secondary levels.
- Design and implement a comprehensive system of personnel development that is specifically focused on persons with developmental disabilities across the life span.

### 4. Finding

In the states surveyed, services and supports were not available in every part of the state.

Universally accessible supports must be available to people regardless of where they live. The surveyed states have county-based systems of services and supports and are also geographically much larger than Connecticut. Nevertheless, caution should be taken as we design new systems.

### Conclusion

Commission members should develop recommendations that focus on building a local base of services and supports. Recommendations should include ways in which Connecticut's cities and towns can actively support individuals with developmental disabilities across the lifespan.

## Definition of the Population to be Served

### Methodology

"Definitions" for service eligibility used by the principal state agency with authority for persons with mental retardation, developmental disabilities, or other related conditions were gathered from a variety of sources including principal state agency WebPages, email correspondence, and electronic versions of state codes or statutes. A content analysis was done in an effort to examine the variability among service eligibility definitions and identify possible categorization schemes and to estimate the number of states using any particular definition or categories of definitions

1. Finding

Connecticut is one of approximately six states that uses a narrow definition (i.e., mental retardation only) of the population served by the principal state agency with authority for persons with mental retardation, developmental disabilities, or other related conditions.

A preliminary analysis revealed those state definitions and therefore principal state agencies could be roughly grouped into five categories, which are described below. Nearly half (n = 22) of the states could be grouped according to the adoption of a definition of developmental disability that closely mirrors the definition in the Title I, Programs for Individuals with Developmental Disabilities. An example of this would be the definition used by New Jersey's Division of Developmental Disabilities, Department of Human Services (see Table 1).

A second grouping of states (n = 17) have adopted definitions that appear similar to the Title I definition. These state definitions, however, either specifically exclude individuals with physical impairments only or do not specify that individuals with physical impairments only are eligible for services. Additionally, definitions for this grouping of states do not appear to specify that mental retardation is needed for service eligibility. An example of this type of state definition is that used by California's Department of Developmental Services, The California Health and Human Services Agency (see Table I).

Table 1  
Examples of State Definitions

<b>Federal Definitions</b>	<b>Similar to Federal Definition, Excludes Physical Only</b>
<p style="text-align: center;">New Jersey Division of Developmental Disabilities, Department of Human Services</p>	<p style="text-align: center;">California Department of Developmental Services, The California Health and Human Services Agency</p>
<p>Developmental disability means: a. A severe, chronic disability of a person which (1) Is attributable to a mental or physical impairment or combination of mental or physical impairments; (2) Is manifest before age 22; (3) Is likely to continue indefinitely; (4) 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, or economic self-sufficiency; and (5) Reflects the need for a combination and sequence of special, interdisciplinary, or generic care, or other services which are of lifelong or extended duration. b. Other handicapping conditions requiring services and treatment similar to that required by those who meet the criteria defined above. L.1979, c. 105, s. 2, eff. May 31, 1979.</p>	<p>4512. As used in this part: (a) "Developmental disability" means a disability which originates before an individual attains age 18, continues, or can be expected to continue, indefinitely, and constitutes a substantial disability for that individual. As defined by the Director of Developmental Services, in consultation with the Superintendent of Public Instruction, this term shall include mental retardation, cerebral palsy, epilepsy, and autism. This term shall also include disabling conditions found to be closely related to mental retardation or to require treatment similar to that required for individuals with mental retardation, but shall not include other handicapping conditions that are solely physical in nature.</p>

A third grouping includes Colorado and Minnesota. They have definitions that at first glance appear to broaden their definition beyond mental retardation only. Nevertheless, they specify that individuals must have general intellectual functioning or adaptive behavior similar to that of a

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person with mental retardation. The fourth grouping includes Vermont, Maine, and Texas. They appear to have definitions that limit services and supports from the principal agency to individuals with mental retardation and autism. Lastly, six (6) states use definitions that limit the population served by the principal agency only to individuals with mental retardation. Connecticut (see Table 2) would serve as an example of this group. Please note that in some of these apparently more restrictive states (e.g., Texas) there are other agencies that provide some service and supports to persons with developmental disabilities.

Table 2

Excerpts from Connecticut General Statute Regarding the Department of Mental Retardation

Sec. 1-1g. **"Mental retardation", defined.** (a) mental retardation means a significantly subaverage intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period.

(b) As used in subsection (a) "general intellectual functioning" means the results obtained by assessment with one or more if the individually administered intelligence tests developed for that purpose and standardized on a significantly adequate population and administered by a person formally trained in test administration: significantly subaverage" means an intelligence quotient more than two standard deviations below the mean for the test: "adaptive behavior means the effectiveness or degree with which an individual meet the standards of personal independence and social responsibility expected for the individual's age and cultural group; and "developmental period" means the period of time between birth and the eighteenth birthday.

Sec. 17a-210. **Department and Commissioner of Mental Retardation.** . . . (a) There shall be a Department of Mental Retardation. The Department of Mental Retardation, with the Advice of a Council on Mental Retardation, shall be responsible for the planning, development and administration of complete, comprehensive and integrated state-wide services for persons with mental retardation and persons medically diagnosed as having Prader-Willi syndrome. . . .

Sec. 17a-215. **Department designated lead agency for autism services.** The Department of Mental Retardation shall serve as the lead agency to coordinate, where possible, the functions of several state agencies which have the responsibility for providing services to autistic persons.

Conclusion

Commission members should give consideration to broadening the definition of the population to be served beyond Connecticut's current definition of mental retardation as defined in section 1-1g of the general statutes, as amended. This would bring Connecticut in line with other states and the national trends.

Prevalence of Developmental Disabilities

Methodology

Committee members reviewed developmental disabilities prevalence data from a number of reputable sources including WebPages (e.g., Center for Disease Control, National Information Center for Children and Youth with Disabilities), scholarly books (e.g., Batshaw, 1997; Capute & Accardo, 1996), and other recent publications (e.g., Research and Training Center on Community Living and the Institute on Community Integration, 1999).

1. Finding

There is no national or centralized registry or data source in the U.S. for determining the number of persons with developmental disabilities.

Prevalence refers to the number of people with the defined characteristic. Incidence refers to the number of new cases each year. As a nation, we do not systematically collect data on the prevalence of developmental disabilities. Estimates on prevalence are variable, depending on the data source reviewed. Moreover, when one examines estimates of prevalence for specific categorical disabilities (e.g., epilepsy, learning disability) the available information rarely describes prevalence in regard to level of disability (e.g., relative cognitive deficits, functional limitations). Lastly, the states surveyed did not have a systematic way of collecting this type of information.

The Developmental Disabilities Act of 2000 states " . . . recent studies indicate that individuals with developmental disabilities comprise between 1.2 and 1.65 percent of the United States population." (Public Law 106-402, DD Act and Bill of Rights Act of 2000, Sect.101(a)(1)). In Connecticut, using 2000 Census Data that means it is estimated there are between 40,867 and 56,192 people with developmental disabilities.

According to Ed Preneta, Director of the Connecticut Council on Developmental Disabilities (personal communication, September 5, 2001) the Council, for the purposes of their State Plan, has historically used 1.1% of the Connecticut general population, to reflect their emphasis on people with the most severe and multiple disabilities regardless of disability label. Therefore, they estimate that there are 37,461 people with developmental disabilities in Connecticut.

Table 3 presents a summary of data on selected developmental disabilities. This was taken from the MR/DD Data Brief April 2000 Research and Training Center on Community Living—Institute in Community Integration (UAP). This brief summarizes data from 1994 –and 1995 National Health Interview Survey’s Disability Supplement (NHIS-D) and provides estimates the prevalence of mental retardation and/or developmental disabilities among non-institutionalized population of the United States.

Table 3.  
Estimated Prevalence of Selected Conditions in Non-Institutionalized U.S. Population

<b>Condition</b>	<b>Est.N</b>	<b>Prev.</b>	<b>RSE</b>
Developmental Disabilities	2,942,068	11.28	2.2%
Mental Retardation	2,033,710	7.80	2.7%
Cerebral Palsy	1,049,322	4.02	3.7%
Spina Bifida	161,866	.62	9.7%
Autism	105,464	.40	11.4%

Est. N = Estimated number of people in the U.S. population  
 Prev = Number of people per 1,000 in the US non-institutionalized population  
 RSE = Relative Standard Error (SE/N\*100)

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Conclusion

While our nation does not systematically collect data on the prevalence of developmental disabilities, there are several reliable sources the Commission may draw from in regard to estimating the numbers of Connecticut citizens who may have a developmental disability without mental retardation. The estimates contained in the MR/DD Data Brief April 2000 Research and Training Center on Community Living—Institute in Community Integration (UAP) would be particularly helpful to that end.

Commission members should give serious consideration to recommending that Connecticut develop a linked data system. This system should be designed to track, among other things, information about prevalence of developmental disabilities. This information would be of great benefit in regard to future planning.

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