

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

STATE-LEVEL COMMITTEE  
INVENTORY OF SERVICES AND SUPPORTS

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

**Methodology**

The State-Level Committee of the Advisory Commission on Services and Supports for Persons with Developmental Disabilities (Commission) was charged with the following tasks.

1. Identifying the state agencies that fund or provide services and supports to persons with developmental disabilities, who do not have mental retardation, as defined in section 1-1g of the general statutes, as amended, and their families.
2. Estimating the numbers of persons with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended.
3. Describing the services and supports funded or provided by state agencies currently available to these individuals and their families.
4. Estimating the cost of and the numbers of persons with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended currently receiving these services and supports.

Committee members found that there was no aggregated data available that described Connecticut's service system for persons with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended. Therefore, they designed, administered, and analyzed an Inventory of Services and Supports (inventory) in an attempt to do so. As a first step in designing this inventory, Committee members developed a list of agreed upon definitions for services and supports (e.g., family support, case management) and critical variables (e.g., ages served, eligibility criteria) See Appendix A for a list of definitions. This was done for the purpose of capturing essential information that could be used across agencies during the process of identifying and analyzing services and supports funded or provided by state agencies. It should be noted that the inventory was not designed to assess the quality of any program or service or to quantify the amount of services that any given state agency may be able to provide to a particular individual or his or her family.

State agency personnel, who participated as members of the Commission, completed the inventory for their respective agencies or worked with people within their agencies to do so. Once the inventories were completed, a set of service matrices were developed and used as a tool for analyzing Connecticut's current system of state funded services and supports for persons with developmental disabilities, who do not have mental retardation. As the inventory responses were summarized, state agency representatives were asked to verify the accuracy of the data.

## Summary of Findings and Conclusions

Below is a summary of findings and conclusions that is intended to represent a snapshot of state-funded services and supports for persons with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended. Information about services and supports for children and youth with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended is presented first. This is followed by a description of services and supports for adults with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended.

### Children and Youth with Developmental Disabilities 3 Through 17 Years of Age Who do not have Mental Retardation

Figure 1 provides a summary of the state agency services (funded or provided) that are available to children and youth with developmental disabilities 3 – 17 years of age, who do not have mental retardation, and their families. Access to these services and supports may be based on or limited by one or more of the following characteristics (a) diagnosis, (b) commitment to DCF, (c) severity of the disability, (d) family income, or (e) agency resources. For example, individual or family income and assets (i.e., a means test) may limit access to certain programs and services (e.g., Medicaid, food stamps). Other services and supports are categorical in nature and access is limited to children with a specific diagnosis (e.g., special health care needs). Lastly, agencies have finite resources (e.g., budgets, personnel) and this serves to limit amount of services that any given agency may be able to provide to a particular person, the numbers of persons an agency may be able to serve, or universal accessibility to funds and services.

### Findings: Children and Youth with Developmental Disabilities 3 Through 17 Years of Age

#### **1. Board of Education Services for the Blind (BESB)**

To receive services from the Board of Education and Services for the Blind (BESB), a child with a developmental disability must also meet the legal definition of visual impairment, legal blindness or deaf-blindness. Education consultants from BESB provide specialized instruction in Braille literacy, access to adaptive technology, and socialization skills training to legally blind and visually impaired children in the 111 towns within the state that are covered by the agency. In addition, BESB provides consultation services to the classroom and the special education teachers of these children. BESB provides specialized services to preschoolers with visual impairments in all towns across the state. The agency maintains a comprehensive lending library of Braille and large print textbooks that can be accessed by school districts for students who meet the statutory definition of visual impairment or legal blindness. Funding can also be accessed by Local Education Agencies (LEAs) to offset some of the costs associated with the vision related services and supports for a student's education. Last year, BESB directly served 576 school age children and supported the vision related educational costs for a total of 507 children in towns not directly served by the agency. Additionally, 241 preschool children across the state also

received services from BESB. Funding for the provision of children's services was approximately \$10.5 million in state appropriations in the past year. While many of the children served through the BESB have secondary disabilities that would meet the definition of developmental disability, there is presently no mechanism within the agency database for sorting out this information.

## **2. Commission on Deaf and Hearing Impaired (CDHI)**

The Commission on Deaf and Hearing-Impaired (CDHI) is charged with advocating, strengthening, and implementing state policies affecting deaf and hearing-impaired individuals and their relationship to the public, industry, health care, and educational opportunity. CDHI serves deaf and hearing-impaired individuals and their family members. While there is no legal definition for deafness or hearing impairment, CDHI has historically used a functional definition. If the hearing loss impacts an individual's quality of life (e.g., ability to function), they are able to access CDHI services, contingent on the availability of staff and other resources. CDHI carries out its statewide responsibilities from a single central office. Last year, the budget was approximately \$1,051,648.00. CDHI collects data on clients and services but does not keep data by age. It is estimated that last year 25% of the services were for children.

## **3. Department of Children and Families (DCF)**

All of Connecticut's children are entitled to protective services under the Department of Children and Families (DCF), whether or not that child has a developmental disability. DCF provides services and supports only to children and youth within their care and/or who have a primary mental health disability (Axis 1). Children become the responsibility of DCF as a result of involvement in the juvenile justice or child welfare systems. In other cases where youngsters are in the care and custody of DCF, provided services include assessment, case management, treatment (both medical and behavioral health), and aftercare. If the child does not have a local education agency of nexus, the department also assumes educational responsibility. As a result of its behavioral mandate, DCF also provides services through its Voluntary Services program to any child or youth in the state who requires such service but has no other options. Last year, DCF served 280 children with developmental disabilities (with and without mental retardation).

## **4. Department of Mental Retardation (DMR)**

To receive services and supports from DMR, children 3 – 17 years of age must have mental retardation as defined in section 1-1g of the Connecticut general statutes, as amended or a medical diagnosis of Prader-Willi syndrome. DMR is also designated as lead agency for autism services. According to section 17a-215 of the Connecticut general statutes, as amended, DMR " . . . shall serve as the lead agency to coordinate, where possible, the functions of the several state agencies which have responsibility for providing services to autistic persons". On the other hand, DMR does not serve persons with autism who do not have mental retardation as defined in section 1-1g of the Connecticut general statutes

## **5. The Department of Public Health (DPH)**

The Department of Public Health (DPH) Children with Special Health Care Needs (CSHCN) Program (Title V) is operated in collaboration with two regional centers, the Connecticut Children's Medical Center (CCMC) located in Hartford and the Yale Center for Children with Special Health Care Needs Center located in New Haven. The CSHCN program coordinates

specialty care services and provides case management and care coordination, advocacy, support, and payment for certain services including, but not limited to adaptive and specialty equipment; specialty medical services including speech, occupational, and physical therapy; specialty pharmacy; and special nutritional formulas. Both CSHCN centers subcontract with community based facilities throughout the state. This is done to increase access for families who do not reside in Hartford or New Haven. The CSHCN centers are also responsible for providing services to children receiving Supplemental Security Income (SSI) benefits who meet program eligibility criteria.

The CSHCN program uses the following medical definition to determine "medical eligibility". "Children who have, or at elevated risk for chronic physical, developmental, behavioral or emotional conditions (biologic or acquired) who also require health and related services (not educational and recreational) of a type and amount not usually required by children of the same age." The program uses the following criteria to determine "financial eligibility": a) families whose income falls at or below 300 percent of the Federal Poverty Level (FPL) (e.g., \$34,830 for a family of two), b) families who are under insured, or c) families whose income exceeds the limits but have high out-of-pocket medical expenses.

Children from birth to 18 years of age who meet both the medical and financial criteria, are eligible for the CSHCN program whether or not they have a developmental disability with or without mental retardation. Care coordination, advocacy, and support are available to all children with special health care needs regardless of enrollment or insurance status. Transition services are also available for eligible children ages 18 to 21 who are enrolled in the program. Currently, there are 927 children enrolled in the CSHCN program. Last year \$1,670,072.00 was expended on this program.

## **6. The Department of Social Services (DSS)**

DSS administers 90 programs. A number of these programs are available to Connecticut families who meet financial means test (i.e., a review of income and assets), whether or not their child has a developmental disability. The means test may vary from program to program, however. Examples of these programs and services include those that protect and promote physical well being (e.g., Temporary Assistance to Needy Families) and those that provide economic support for essential needs (e.g., energy assistance, Medicaid, the HUSKY plan).

Section 17b-606 of the Connecticut general statutes, as amended, designates the Department of Social Services (DSS) “. . . as lead agency for services to persons with physical or mental disabilities.” Of particular note to children with developmental disabilities, who do not have mental retardation and their families, are the programs described below.

### *Model Waiver (Katie Beckett)*

Children with significant disabilities, who would normally only qualify for Medicaid in an institution under the institutional "deeming" rules may qualify for a Model waiver (also known as the Katie Beckett waiver) through DSS. Services include case management, which is provided through a RN from a home health agency, and all the traditional benefits of Medicaid (payer of last resort). The program currently serves 125 individuals, which is the maximum allowed under State law. Of these, two are adults (there is no age limit on this

waiver). Seventy-seven of the individuals are also served by DMR (i.e., at a minimum they have a DMR case manager). There are 100 children on the waiting list. The unduplicated count for individuals served from January 2000 to December 2001 is 132, at a total cost of \$480, 557.37.

#### *Family Support Grant*

DSS has a small family support grant program available to families of children with developmental disabilities 5 - 18 years of age, who do not have mental retardation. The grant may be used for ongoing expenses such as special equipment or clothing. The child and family must be Connecticut residents and have a gross income that is not greater than 140% of the previous year's median family income for Connecticut. The amount of the benefit is \$250 per month (\$3,000 annually). There are 27 slots available and there are currently 80 families on a waiting list. Last year approximately \$83,250 was spent on this program.

#### *Medicaid (Title XIX) and HUSKY*

In addition to Medicaid (Title XIX), DSS serves children who qualify and enroll for health insurance through HUSKY, the Title XXI state Children's Health Insurance Plan and Husky Plus. These subsidized programs provide free or low-cost health care coverage for Connecticut's children and youth. They are available to families whose income does not exceed 300% FPL and who have no other insurance coverage for their children. There are no premium costs between 185% and 285% of FPL. The premium is \$30.00 per month for one child or \$50.00 for all children in a family with an income of between 235% and 300% FPL. HUSKY Plus was designed as a supplement to HUSKY for middle-income families. It is divided into two programs, HUSKY Plus Behavioral and HUSKY Plus Physical. These plans are intended for children with intensive physical needs and children with intensive behavioral needs that cannot be accommodated within the basic benefit package. Currently, approximately 45,961 children are enrolled in this program.

### **7. State Department of Education (SDE)**

All of Connecticut's children and youth ages 6 to 17 are entitled to public schooling. The State Department of Education (SDE) oversees the services and supports provided through the Local Education Agencies (LEAs) under the Individuals with Disabilities Education Act Amendments of 1997 (IDEA). Children who are eligible under IDEA for special education and related services are eligible to receive free appropriate public education through their local school districts beginning on their third birthday. To receive special education and related services under IDEA, a child must be determined "disabled" under 13 federally identified categories (i.e., diagnosis) of IDEA by the Planning and Placement Team (PPT). Special education and related services are then provided based on the child's individual needs, as delineated in his or her Individualized Education Plan (IEP). This includes the type and intensity of services and where they are provided. While not the rule for every child, IEP services are often provided within the school, during the school day and year. In accordance with IDEA, the term *special education* means specially designed instruction, at no cost to the parents, to meet the unique needs of a child with a disability. *Specially designed instruction* means adapting, as appropriate to the needs of the eligible child, the content, methodology, or delivery of instruction. This is done to 1) address the unique needs of the child that result from the child's disability; and 2) ensure access of the child to the general curriculum, so that he or she can meet the educational standards that apply to all

children. The term *related services* means transportation and developmental, corrective, and other supportive services as are required to assist a child with a disability to benefit from special education. This may include speech-language pathology and audiology services, psychological services, physical and occupational therapy, recreation, including therapeutic recreation, early identification and assessment of disabilities in children, counseling services, including rehabilitation counseling, orientation and mobility services, and medical services for diagnostic or evaluation purposes. The term also includes school health services, social work services in schools, and parent counseling and training.

Summary and Conclusions: Children and Youth with Developmental Disabilities 3 Through 17 Years of Age

1. There are several state agencies that fund or provide services and supports to children and youth with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended, and their families. These include: (a) the Board of Education Services for the Blind (BESB), (b) the Commission on the Deaf and Hearing Impaired (CDHI), (c) the Department of Children and Families (DCF), (d) the Department of Public Health (DPH), (e) the Department of Social Services (DSS), and (f) the State Department of Education (SDE) through the Local Education agencies (LEAs).
2. Connecticut has no principal state agency that is assigned the role of coordinating and delivering services and supports (as delineated in the tables) to children and youth with developmental disabilities, who do not have mental retardation, and their families outside the mandates of IDEA.
3. There are several programs (e.g., MEDICAD, HUSKY) that finance or assist with financing traditional medical care services that are available to all children, whose families meet means test (i.e., income and assets).
4. Children and youth with developmental disabilities, who do not have mental retardation and their families do not have the same routine access to services and supports as those children and youth with mental retardation and their families. For example, schools are the only agency that provides services and supports to children and youth with autism spectrum disorder, who have no other disabilities. These services and supports focus on a child's educational needs and are typically offered during the school day and year.
5. Children and youth with developmental disabilities, who do not have mental retardation and their families, do not have the same routine access to services and supports as those children and youth within the child welfare system.
6. While not always the case, families, whose children may qualify for any of the programs or services (i.e., supports) provided by or through these state agencies, must apply to each

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agency. In other words, there is no single point of entry or formal mechanism for dealing with applying for multiple programs and services or cross agency service coordination.

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*Figure 1. A depiction of eligibility limitations for state agencies providing or funding services and supports to children and youth with developmental disabilities 3 through 17 years of age, who do not have mental retardation and their families.*

Service Category	Agency or Bureau							
	BESB <sup>1</sup>	BRS <sup>2</sup>	CDHI <sup>3</sup>	DCF <sup>4</sup>	DMR <sup>5,6</sup>	DPH <sup>7</sup>	DSS	SDE <sup>8</sup>
Access (sign language interpreter, Braille)	D		DR	C+D				D
Assessment	D			C or D		ID		D
Assistive Technology	D			C+D		ID	I	D
Case Management	D		DR	C or D		ID	I	
Child Protection				A				
Education (related services, transition)	D			C or D				D
Education & Training: Families/Caregivers	D			C or D		ID		D
Financial Subsidy (cash)							I	
Residential Service (out-of-home)	D <sup>9</sup>			C or D				D
Family Support (respite, cash subsidy)				C or D		ID <sup>10</sup>	IDSR <sup>11</sup>	
Juvenile Justice Services <sup>12</sup>				C				
Health Care Financial Support	D <sup>13</sup>					ID	I	
Health Care Service				C or D		ID		DI
Mental Health Financial Support							I	
Mental Health Service	D		DR	C or D				D
Transportation Services				C or D				D
Recreation Support	D			C or D				D

**Key:**

**D** = Diagnostic or categorical limitations  
**S** = Severity of disability limits service  
**C** = Within the care of the department

**R** = Resource limits accessibility (e.g., state agency budget, waiting lists)  
**I** = Income limitation (financial means test)  
**A** = All

<sup>1</sup> Must be blind or visually impaired.

<sup>2</sup> Rehabilitation services are sometimes available for 16- and 17-year olds who have left school.

<sup>3</sup> Must be deaf or hearing-impaired.

<sup>4</sup> DCF provides services and supports only to children and youth within their care and/or who have a primary mental health disability (Axis 1).

<sup>5</sup> Section 17a-215 of the Connecticut general statutes as amended designates DMR as lead agency to coordinate state agencies that have responsibility for providing services to autistic persons.

<sup>6</sup> DMR provides services and supports only to children and youth who have mental retardation or Prader Willi.

<sup>7</sup> Must meet requirements for Children with Special Health Care Needs.

<sup>8</sup> SDE oversees the services and supports provided through local boards of education. Children and youth must determined "disabled" by the Planning and Placement Team (PPT) under 13 federally identified categories of IDEA. Services are based on the child's needs as delineated in the IEP and are most often provided within the school, during the school day.

<sup>9</sup> As part of an out school district placement as delineated in the IEP.

<sup>10</sup> Up to \$500.00 per year is available for respite on a first comes first serve basis.

<sup>11</sup> To be eligible, children cannot have mental retardation and must be between 5 and 18 years of age. There are currently 27 slots, which are full.

<sup>12</sup> No juvenile justice commitments after 16 years of age.

<sup>13</sup> As they relate to vision services.

Adults with Developmental Disabilities 21 Through 64 Years of Age  
Who do not have Mental Retardation

Figure 2 provides a summary of the state agencies that fund or provide services and supports to adults with developmental disabilities 21 through 64 years of age, who do not have mental retardation as defined in section 1-1g of the general statutes, as amended, and their families. Many of the agencies and programs described below fund or provide services that are designed to reach people with a variety of disabilities and needs. In other words, the programs are not specifically designed to meet the needs of adults with developmental disabilities. As described earlier, access to services and supports funded or provided by state agencies may be based on or limited by a number of characteristics or combination of characteristics. These may include (a) diagnosis, (b) severity of the disability, (c) income, or (d) agency resources (e.g., budget, personnel). For example, there are programs that are categorical in nature and access is limited to those adults with a specific diagnosis (e.g., acquired brain injury). Individual or family income and assets (i.e., a means test) limit access to other programs. Lastly, agency resources (e.g., budget, personnel) may limit the amount of services that any given agency may be able to provide to a particular person, the numbers of persons an agency may be able to serve, or universal accessibility.

Findings: Adults with Developmental Disabilities 21 Through 64 Years of Age

**1. Board of Education Services for the Blind (BESB)**

The Board of Education and Services for the Blind (BESB) is a consumer oriented, comprehensive community-based service delivery agency providing a continuum of individualized, educational, rehabilitation, social services and adaptive technology services to adults who are legally blind. Last year, BESB provided services to approximately 3,200 adults through the combined efforts of the Adult Services Division for Independent Living, Vocational Rehabilitation, Industries, and Business Enterprises. Total funding for these programs was approximately \$15.2 million from all sources in the past year. There presently is not a waiting list for services. BESB is considered the sole state agency to provide vocational rehabilitation services to eligible consumers who are legally blind, including people who may have secondary disabilities such as developmental disabilities. The scope of services available to these consumers mirror those provided by the Bureau of Rehabilitation Services for consumers who are not legally blind. While the agency does collect data on secondary disabilities, it is not differentiated based upon the definition of developmental disability.

**2. Bureau of Rehabilitation Services (BRS), Department of Social Services (DSS)**

The Bureau of Rehabilitation Services (BRS), Department of Social Services (DSS) services are specifically focused on assisting individuals with disabilities, either physical or mental, to prepare for, find, or keep a job. To be eligible, a person's disability must present a substantial barrier to employment and he or she must require services to prepare for find and succeed in employment with a priority on a paid job in the competitive labor force. When resources are limited, the law requires that BRS first provide services to persons with significant disabilities (order of selection). These services are time limited and must relate to employment. Persons, who are in a priority group that BRS is currently serving under their order of selection, work

with their counselor to develop an individualized Employment Plan. These plans are tailored to meet each person's unique needs and will vary from person to person. Services and supports provided through BRS might include any of the following (a) vocational counseling, (b) benefits counseling, (c) job search assistance, (d) skill training or career preparation, (e) on the job training, (f) assistive technology, (g) vehicle and home modifications, (f) job coaching and supported employment, (g) physical or mental restoration services, and (i) other services needed to achieve job goal. Last year (SFY 200), BRS served 10,136 individuals with significant disabilities at the cost of \$22,749,000. There is no waiting list for people with significant disabilities.

### **3. Commission on Deaf and Hearing Impaired (CDHI)**

As stated above, the Commission on Deaf and Hearing-Impaired (CDHI) serves deaf and hearing-impaired individuals and their family members. CDHI has historically used a functional definition for deafness or hearing impairment. If the hearing loss impacts an individual's quality of life (e.g., ability to function), they are able to access CDHI services, contingent on the availability of staff and other resources. The services and supports provided include information and referral, personal and family counseling, sign language interpreting services, and job development and placement for adults. The counseling services, including job development and placement are free to residents of Connecticut. Individuals who are deaf are not billed for interpreting services with the exception of weddings, family parties, for example. Federal, state, private agencies and private companies are responsible for reimbursement of interpreting services. CDHI has no funds to contract out for services nor do they provide or fund hearing aids or assistive technology. Last year, the CDHI budget was \$1,051,648.00. CDHI keeps statistics by two categories, clients and services. They do not, however, keep statistics by age. It is estimated that approximately 75% of the services are dedicated to adults. CDHI does not collect data that differentiates between program participants who have developmental disabilities with or without mental retardation and those who do not.

### **4. Department of Mental Health and Addiction Services (DMHAS)**

The Department of Mental Health and Addiction Services (DMHAS) is the single state agency for providing comprehensive mental health and substance abuse services throughout Connecticut. While the DMHAS's prevention services serve all Connecticut citizens, its primary treatment clients are adults (over 18 years of age) with psychiatric or substance use disorders, or both, who lack the financial means to obtain such services. DMHAS provides services to persons with developmental disabilities only if there is a concomitant psychiatric disorder.

Throughout each of the five human service regions in Connecticut, DMHAS has in place 18 Local Mental Health Authorities (LMHAs), nine of which are state-operated and nine are private non-profit. The LMHAs have the authority and responsibility for planning, delivering and managing a vast array of DMHAS-funded community mental health services including case management, outpatient, residential, social rehabilitation, vocational, and Assertive Community Treatment (ACT). Crisis intervention services are also available in each region, 24-hours a day, seven days a week. As the state's lead agency for the prevention and treatment of alcohol and other drug abuse, DMHAS provides direct services through state-operated programs and funds and monitors private community-based programs located throughout the state. In addition,

DMHAS operates inpatient hospitals and facilities for persons with severe addiction and/or psychiatric problems.

Lastly, DMHAS operates a pilot program--Special Populations Program-- for a select group of individuals who present unique risks to public safety and who have been clients of DCF. A very small group of individuals with autism, who also have extremely challenging behaviors that pose a risk to others, are served in this pilot program. DMHAS does not collect data that differentiates between program participants who have developmental disabilities with or without mental retardation and those who do not.

### **5. Department of Mental Retardation (DMR)**

As previously noted, section 17a-215 of the Connecticut general statutes, as amended, designates DMR as lead agency for coordinating, where possible, the functions of state agencies that have responsibility for providing services to persons with autism. At the time of this writing, there are no state agencies that have programs or services that are specifically designated for adults with autism spectrum disorder. Lastly, as described earlier to receive services and supports from DMR, individuals must have mental retardation as defined in section 1-1g of the Connecticut general statutes, as amended or a medical diagnosis of Prader-Willi syndrome.

### **6. Department of Social Services (DSS)**

DSS administers 90 programs and a number of them are available to Connecticut citizens who meet financial means test (i.e., a review of income and assets), the amount of which may vary from program to program. Examples of these programs include services that protect and promote physical well being, (e.g., Temporary Assistance to Needy Families) and those that provide economic support for essential needs (e.g., energy assistance, Medicaid). As noted earlier, section 17b-606 of the Connecticut general statutes, as amended, designates the DSS “. . . as lead agency for services to persons with physical or mental disabilities.” whether or not an individual has a developmental disability, without mental retardation. The DSS programs described below are designed to meet the needs of persons with a variety of disabilities and individuals with developmental disabilities would be included in this group. DSS does not collect data that differentiates between program participants who have developmental disabilities and those who do not.

#### *Personal Care Assistance Services Waiver (PCA)*

The PCA waiver provides personal care assistance services 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. The program has the capacity to serve up to 409 adults ages 18 through 64. A person’s monthly income may not exceed \$1,590.00 per month. Total assets may not exceed \$1,600.00. Individuals, who are employed, may also meet financial eligibility for this program, if they qualify for Medicaid through the Medicaid for the Employed Disabled coverage group. Under PCA waiver, the adult with a disability is the employer of the personal care assistant. They are responsible for hiring, training, supervising, paying and if necessary firing their assistants. Wages are negotiated between the individual and his or her assistant. The program currently has about 280 persons enrolled, leaving 129 slots available. Last year, \$5,059,193 was expended on this program.

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*Acquired Brain Injury Waiver (ABI)*

To be eligible for ABI waiver services a person must be 1) between the ages of 18 and 64; 2) have an acquired brain injury (not a degenerative disorder or a developmental disability); 3) meet the DSS "level of care" requirement for this waiver; 4) be able to participate in the development of a service plan; 5) and meet all of the technical, financial, and procedural financial requirements for Medicaid (i.e., means test). This ABI waiver provides a range of non-medical behavioral and support services to adults. The capacity of the waiver program is capped at 500 persons. Currently, 103 people are enrolled in the program and there are 160 individuals in the process of being assessed. Last year, \$4,138,095 was expended on this program.

*Medicaid for the Employed Disabled*

DSS implements the Federal "Ticket to Work" initiative that enables adults with disabilities 18 through 64 to earn up to \$75,000 and continue to qualify for Medicaid benefits. The program allows persons with a disability to engage in employment without jeopardizing needed medical services through the Medicaid program. It also allows certain individuals to retain other necessary services enabling those individuals to remain actively employed. These services include those typically funded under Medicaid. At the present time (7/01), 1,418 persons are enrolled in this program. There is no waiting list for this program.

*Community-Based Services*

This State-funded program is designed to augment services that an individual may be receiving from Medicaid's home health benefits. The program serves approximately 1,600 individuals each month and provides homemaker, companion, and personal care assistance. At the present time, 1,607 persons are enrolled in this program and there is no waiting list. Last year, \$7,500,000 was spent on this program.

Summary and Conclusions: Adults with Developmental Disabilities 21 Through 64 Years of Age

1. Connecticut has no principal state agency assigned the role of coordinating and delivering services and supports for adults with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the Connecticut general statutes, as amended.
2. Individuals with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the Connecticut general statutes, as amended do not have the same access to services and supports as those individuals who have mental retardation or a medical diagnosis of Prader-Willi syndrome.
3. Within budgetary constraints, BRS provides services on a time limited basis and as they relate to employment to individuals with developmental disabilities, who do not have mental retardation as defined in section 1-1g of the Connecticut general statutes, as amended.
4. DSS is designated as the lead agency for services to persons with physical or mental disabilities whether or not they have a developmental disability. Of note, are the DSS home and community based Medicaid waiver programs (e.g., ABI, PCA).

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**Figure 2.** A depiction of eligibility limitations for state agencies providing or funding services and supports to adults with developmental disabilities 21 through 64 years of age, who do not have mental retardation.

Service Category	Agency or Bureau and Eligibility and Access Limitation						
	BESB <sup>14</sup>	BRS <sup>15</sup>	CDHI	DMHAS <sup>16</sup>	DMR <sup>17 18</sup>	DPH	DSS
Access (sign language interpreter, Braille)	D	ESR	DR				
Assessment	D	ESR <sup>19</sup>		ID			ISD
Assistive Technology	D	ESR					ISD
Case Management	D	ESR	DR	ID			ID
Education & Training for Individual	D	ESR		ID			
Education & Training for Families/Caregivers	D						
Economic and Cash Subsidy				ID			I
Residential Service (in-home and out-of-home)				ID			ISD
Family Support (respite, in-home support, cash subsidy)				ID			ISD
Health Care Financial Support							ISD
Health Care Service	DE			ID <sup>20</sup>			
Mental Health Financial Support	DE			ID			ID
Mental Health Service	D		DR	ID			
Transportation Services	DE <sup>21</sup>	ESR					ID
Recreation Support							
Vocational	DE	ESR					

**Key:**

**D** = Diagnostic/categorical limitations

**S** = Severity of disability limits service

**E** = Employment and vocational rehabilitation related

**R** = Resource limits accessibility (e.g., state agency budget, waiting lists, order of selection)

**I** = Income limitation (financial means test)

<sup>14</sup> BESB provides services and supports to persons who are legally blind.

<sup>15</sup> BRS provides vocational rehabilitation services to individuals with the most severe disabilities.

<sup>16</sup> DMHAS provides services to persons with developmental disabilities only if there is a concomitant psychiatric disorder.

<sup>17</sup> DMR provides services and supports to persons who have mental retardation or Prader Willi.

<sup>18</sup> Section 17a-215 of the Connecticut general statutes as amended designates DMR as lead agency to coordinate, where possible, the functions of the several state agencies that have responsibility for providing services to autistic persons.

<sup>19</sup> BRS provides assessments services only as they relate to the vocational rehabilitation program.

<sup>20</sup> Available only on an inpatient basis as part of DMHAS state hospital system.

<sup>21</sup> Short term.

Conclusions: Persons with Developmental Disabilities Across the Lifespan

Programs are designed based on when state agency responsibility begins and ends and this in turn creates artificial barriers to accessing needed services and supports. For example, an individual's age may lead to a change in department of responsibility and this brings with it different rules. This change is likely to occur during critical life transition such as entering or leaving school, for example.

In general, services and supports funded or provided by state agencies focus on eligibility requirements, "programs" or funding streams rather than on the individual, the types of supports an individual might want or need, or where the individual chooses to live and work.

**Appendix A**  
**Inventory of Services and Supports**  
**Definitions**

**Access Services** - These types of services help to ensure that individuals and their families have access to other needed services and supports. They include, but are not limited to sign language interpreters, translation services, readers for the blind, and so on.

**Assessment Services** - This category of services may be defined as diagnostic and evaluative. Assessments usually involve professional determination regarding the etiology, diagnosis, functioning, or capabilities of the individual with a developmental disability. It may also include determination of a family's concerns and consideration of the strengths and weaknesses of the individual and his or her family environment. Assessments may be conducted to determine eligibility for a particular program and/or to develop a plan of services to be provided. These may be conducted for a single program or in a multi-program environment.

**Assistive Technology** - Sometimes called adaptive equipment, the category of assistive technology services includes evaluation and assessment of need for items or pieces of (re) habilitation equipment, or product systems used to increase, maintain, or improve functional capabilities of individuals with disabilities. The agency may also provide funding either directly to the person with a disability/family or through contracts with vendors that allows the individual to purchase or lease devices. Examples of such devices are orthotics, wheelchairs, and adaptive seating.

**Case Management Services** - Sometimes called service coordination, this category of services includes assistance to the individual with developmental disabilities and/or his or her family in implementing his or her service plan, and the on-going assurance of effective coordination, communication and cooperation among all sources of support and services. The activities may include coordination of multiple services and providers, development and implementation of individual service and support plans, and documentation of service provision. Case managers also assist in identifying, locating, and gaining access to economic, social, medical, recreational, educational, and other types of needed services and supports. Case managers may be employed by the agency or by their contractors.

**Child Protective and Family Services** - This category of services and supports are provided to children and their families to protect children and strengthen and support the families. Supportive services, such as prevention and protective supervision, assist the child to remain within the home. If the family is so stressed that it cannot remain intact, substitute services (e.g., foster care) may be provided. Respite care may be considered a child welfare service or a mental health service, depending on the level of focus of the service provided.

**Economic Assistance and Cash Subsidy** - The category of economic assistance includes the provision of funds to persons with developmental disabilities and/or their families so they can procure essential goods and various services and supports for themselves or their family members. This assistance includes direct cash payments, cash reimbursements, voucher systems, food stamps, Social Security Disability Income, and so on. It may also include cash payments to the individual with a disability to purchase staff support (personal care assistance) from individuals who become their employees.

**Education and Training for Families or other Caregivers** - This category of services enables parents and family members to better understand, support, care, plan, or advocate for their family member with a developmental disability.

**Education and Training Services for Individuals** - This category of services includes training in ADL skills or the provision of staff who are available to provide specialized training in functional life skills (i.e., non-academic) and social competence. It may include day programs that are focused on enabling the person with a developmental disability to attain or maintain his or her maximum functioning. For school age children and youth, the agency provides for pays/contracts for the development and implementation of a special education program for a child with a disability (under IDEA).

**Family Support (respite, cash subsidy)** - This category of services and supports are focused on families of persons with developmental disabilities. The aim is to support and strengthen family functioning. This category includes cash payments to families of persons with disabilities to help defray extraordinary costs of maintaining the family member with a disability at home. It also includes respite funds that are provided directly to a family that allow the family to gain free time from daily care and supervision responsibilities for their family member with a developmental disability. These payments to families may be used to purchase in-home or out-of-home respite support, summer camp or other supports that provide relief from caregiving responsibilities.

**Health Care Financial Support** – Funding for health care services, includes MEDICAID, HUSKY, Medicare, Conn Pace.

**Health Care Services** - This category of services includes various types of health-related services provided by individuals or agencies. The activities typically involve detection and treatment of physical impairments or damage to the body. Included are routine physical examinations and follow-up care as well as prenatal and postnatal care and treatment of sexually transmitted diseases.

**Juvenile Justice Services** - This category of supports includes a range of service options available to youth in the juvenile justice system. The services may include diversionary and nonresidential.

**Mental Health Financial Support** – Funding for mental health services, includes MEDICAID, HUSKY, and Medicare.

**Mental Health Services** - This category of services encompasses a broad range of residential and nonresidential programs and services directed toward treating and resolving individuals' and family members' mental illness. Mental health services can be divided into several major categories: (1) early identification and intervention, (2) community-based therapeutic services, (3) emergency or crisis services, (4) independent residential services, (5) therapeutic residential services, and (6) inpatient hospitalization.

**Recreational Services** - This category of services includes supports that encourage participation in age-appropriate formal and informal interactions or amusement activities with peers. Recreational or leisure activities might include those for individuals and/or their families (e.g., individual or team sports, special interest clubs or groups, camps and special events).

**Residential Services (in-home and out of home)** - This category of services includes supported living, foster care, group homes, and other types of living arrangements. The focus of the service is on the individual and where he or she lives. The agency provides staff or pays/contracts with private agencies to provide staff who work with an individual with a disability who is living in his or her family home. The focus of the staff support is on the individual and can include direct care and assistance in completing activities of daily living, training and skill development, recreational and leisure time activities (in or out of home), transportation to activities, and so on.

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APPENDIX C

This does not include in-home staff support designed primarily to provide temporary relief for the family (respite).

**Transportation Services** - The category of transportation services includes services to enable individuals with developmental disabilities and/or their families to travel to and from needed services and activities. The transportation may be to and from work (day program), community activities (recreation), or medical appointments.

**Vocational** - This category of services includes those designed to assist individuals and their families to move from education to employment or to acquire and maintain employment. These services may include individualized assessment of vocational readiness, skills, and/or preferences; development of skills in career selection, job finding, job retention, and specific technical skills needed for job accomplishment.