

Report on Service and Support Needs Of Individuals with Developmental Disabilities

**Submitted by the
Individual and Family Supports and Services Committee**

Of the

**Advisory Commission
On Services and Supports for Persons with
Developmental Disabilities**

January 25, 2002

Executive Summary

During the 2000 Connecticut Legislative Session public hearings were held to listen to people with developmental disabilities and their families. The public hearings revealed what many of us already know – many of Connecticut’s citizens with developmental disabilities who do not have mental retardation can not access the services and supports they need to live full, productive lives. Resulting legislation, PA 00-135, established an Advisory Commission on Services and Supports for Persons with Developmental Disabilities to study the needs of persons with developmental disabilities who do not have mental retardation and to advise the General Assembly concerning the needs for services and supports.

The three committees of the Commission conducted extensive studies to determine 1) What are the best practices nationally for serving people with developmental disabilities who do not have mental retardation? 2) What services and supports to people with a variety of disabilities and diagnoses are currently funded by state agencies? and 3) What are the service and support needs of individuals with developmental disabilities and their families?

The Individual and Family Services Committee

The Individual and Family Services Committee (IFSS) was assigned two major tasks: 1) Identify primary service and support needs of individuals who do not have mental retardation and their families; and, 2) Identify the groups who need services and supports based on an analysis of the committee’s findings. The IFSS committee was made up of commission members and additional interested individuals.

There were three primary questions that guided the work of the IFSS Committee. These questions guided the development of a questionnaire and a focus group protocol used to collect information from Connecticut’s citizens with developmental disabilities and their families.

- What services and supports do individuals with developmental disabilities and their families need?
- What are the current experiences of individuals with developmental disabilities and their families?
- What would be the best way to organize, coordinate, and deliver the services to best meet individuals and families needs?

Methods

To answer the questions, the IFSS Committee organized two major research activities: A statewide survey and a statewide series of focus groups. Quantitative data were collected using a detailed questionnaire that was distributed statewide, while qualitative data were collected in several focus groups conducted in cities and towns across Connecticut. The survey activities and the focus group activities are described in detail in the report.

The survey and focus group strategies targeted responses from those individuals with a developmental disability but who do not have a diagnosis of mental retardation. Thirty private service provider agencies and several state agencies assisted with distribution of the survey and recruitment of focus group participants.

Questionnaire responses were entered into Excel spreadsheets by congressional office interns and double-checked by partners to ensure the accuracy of the data entry. Excel spreadsheet data were imported into SPSS (Statistical Program for the Social Sciences) for analysis. Data were

thoroughly examined and analyzed by committee and commission members. Specific analyses were conducted to answer the questions that guided the IFSS activities.

Focus group notes were typed and focus group tapes were partially transcribed for review. All specific statements and notes were coded for topic of statement and then clustered under specific themes. Frequency of comment by topic were calculated and matched to survey results.

Who responded?

Participation in the survey and the focus groups was extensive. In all, 791 usable questionnaires were returned by individuals with developmental disabilities and parents from 124 of Connecticut's cities and towns. Sixty-two individuals with disabilities and family members from 39 different cities and towns participated in the focus groups. Respondents and participants represented a wide variety of disabilities.

Observations and Conclusions

Members of the Committee carefully evaluated the data that were collected through the survey and focus group processes. The committee made observations and conclusions, which are listed throughout the report, on which they based their recommendations to the Advisory Commission.

Conclusions based on survey and focus group participants

People in Eastern CT and people in rural areas are not being identified, are not being served, do not have access to services to the same degree that people in urban and suburban areas do. Statewide support groups do not appear to be finding people in the rural areas, Eastern regions.

There are many people who do not meet the federal definition for developmental disabilities by the book, but have disabilities and have service and supports needs nonetheless.

People are shifted around based on distinct diagnoses but the one diagnosis/one agency mentality doesn't work. People have multiple diagnoses that result in their being eligible or ineligible for services from specific agencies and many of these people experience being shifted from agency to agency.

Conclusions concerning service and support needs

Service needs and service configurations are largely individual. Many services that may not be needed by a large number of people are still critical for a small number of people. Survey results should not be used to make a conclusion that some services are not needed.

Education is a key player in helping children and families access services and supports. However, many of the needed services and supports do not fall under the purview of special education. Further, some children with developmental disabilities, primarily those with physical disabilities who do meet eligibility criteria, do not qualify for special education. The question remains, should education's role be expanded? or should a "third party" should be developed to coordinate the array of services and supports needed by children and families. In all likelihood, education cannot accomplish adequate service delivery alone.

No state agency has services and supports to children with disabilities and their families as part of its mission.

Individuals over age 18 experience a similar issue. Bureau of Rehabilitation Services is the key player for adult services but most needs on the list don't fall under the purview of BRS. Who will pick up the slack to coordinate the non-vocational services?

Case management/service coordination is critical to effective planning and accessing services, yet case management is missing from the current system.

The transition from school to adult life is a critical time for young people with developmental disabilities. In general, the system is not working here. The lack of service coordination, limited collaboration between education and adult service agencies, poorly developed curriculum, and shortage of family education and counseling regarding the transition result in slow and unsuccessful transitions for many young people with developmental disabilities.

Conclusions concerning experiences of individuals and families in the current service system

The survey and focus group data strongly support the notion that people with developmental disabilities are not getting the services and supports necessary for them to lead independent and productive lives in the community.

Family supports and services are underdeveloped and often non-existent.

Families are actively providing financial support whether they want to or not. Families and individuals are currently paying for a number of their services or supplementing their service plans with self-purchased services and supports. The ability and willingness of families and individuals to pay for services varies from family to family. Some families pay because they have no choice but truly are not able to do so, other families are able to pay and do so willingly. Still more families cannot pay for services and so their family members go without needed services.

There are a number of systems issues related to people purchasing their own services: economic issues, service availability issues (case management), systems won't contract with individuals.

The funding system lacks flexibility – both in terms of accessing funds, purchasing services.

Employment is a real problem for people with developmental disabilities – unemployment, under employment, transportation, job training, job supports, job searching/placement, short term services with minimal employment as the goal, public attitudes, discrimination, earnings put benefits at risk, lack of ongoing services. The unemployment rate of people with disabilities is rising despite many efforts. BRS mandates and priorities don't serve the needs of the people. BRS appears to be under-funded to serve the number of people who need services

The bureaucratic maze is frustrating and inefficient. Many people who need services do not have the systems savvy to navigate the maze. Others feel that the maze is set up specifically to prevent them from accessing needed services.

Recommendations

The Individual and Family Services and Supports Committee submitted the following recommendations to the Advisory Commission. Our recommendations are based on our thorough review of the data we have collected. Our hope is that we have accurately reflected the concerns and ideas of the many people who took the time to share their thoughts with us.

Eligibility

- Use functional assessment and not the diagnoses and age cut off as a way of determining whether or not someone is eligible for services.

System Access

- Set up a central entry point that people can access regardless of diagnosis.
- Every person who enters the system should leave with either a service plan or a referral.
- Set up a central location to make information readily available.
- Ensure local access.

Service Coordination and Service Planning

- Case management/service coordination must be a key component of whatever system we design. Individualized service planning is essential in the revised system.
- Service development must involve more comprehensive thinking about the range of needs, not just focused on vocational needs. The coordination of the variety of services people need is very important.
- Funding and ability to purchase services should be part of the service planning discussion.
- Each person should have an individualized service plan developed from a 'menu' of services.
- Case manager/service broker who can assess, determine eligibility, advocate, develop service plan, secure services, problem solve is an important position in the new system.

Service Quality

- Establish cross agency communication and information sharing.
- Build a statewide database of individual and service information that is available to all state agencies.
- Create a system that is easy to navigate.
- Develop an appeals process with regard to eligibility determination.
- Train workers in the field to take a customer service mentality of responsiveness and respect.

Systems Improvements

- There must be a major review of the system for children with developmental disabilities and their families to develop partnerships, services, and system.
- Use Birth-to-Three model as a basis for designing a new system. The Birth-to-Three model's strengths include: single point of entry, comprehensive individualized services, service coordination, zero-reject entry, and local access.
- Focus efforts on major improvements and redesign of the service system around young people in transition
- The whole notion of employment of people with disabilities needs to be revisited. We need a public policy shift with all levels of government highly involved.
- Build a working transportation system regulated at state level.
- Develop assisted living, in-home supports, respite services.
- Make major improvements to PCA (Personal Care Assistant) system.

Funding

1. Promote flexible funding.
2. Authorize flexible income caps based on individual assessment.
3. Develop a voucher/credit card to pay for services and equipment maintenance
4. Develop a system of sliding scales and to support individual/family contributions.

Inclusion

- Individuals with disabilities must be directly and actively involved in efforts to design and revise the service system.
- Include individuals with disabilities as leaders in the developing system and invest in the development of future leaders through mentor ships, internships and other development activities.
- Design and develop ways for high school and college students with disabilities to learn and practice leadership.

Healthcare

- Train and develop sufficient, knowledgeable medical personnel.
- Create a “Husky” type healthcare plan for adults to improve coverage

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Advisory Commission on Services and Supports for Persons with Developmental Disabilities

Individual and Family Supports and Services Committee

Report on Service and Support Needs of Individuals with Developmental Disabilities

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Introduction

During the 2000 Connecticut Legislative Session public hearings were held to listen to people with developmental disabilities and their families. The public hearings revealed what many of us already know – many of Connecticut’s citizens with developmental disabilities who do not have mental retardation can not access the services and supports they need to live full, productive lives. Resulting legislation, PA 00-135, established an Advisory Commission on Services and Supports for Persons with Developmental Disabilities to study the needs of persons with developmental disabilities who do not have mental retardation and to advise the General Assembly concerning the needs for services and supports.

The three committees of the Commission conducted extensive studies to determine 1) What are the best practices nationally for serving people with developmental disabilities who do not have mental retardation? 2) What services and supports to people with a variety of disabilities and diagnoses are currently funded by state agencies? and 3) What are the service and support needs of individuals with developmental disabilities and their families?

The Individual and Family Services Committee

The Individual and Family Services Committee (IFSS) was assigned two major tasks: 1) Identify primary service and support needs of individuals who do not have mental retardation and their families; and, 2) Identify the groups who need services and supports based on an analysis of the committee’s findings.

The IFSS committee was made up of commission members and additional interested individuals. The committee built its membership beyond commission members to gain representation of culturally diverse groups as well as of individuals with disabilities and parents of individuals with disabilities. A complete list of committee members is published in Appendix B.

The IFSS Committee was not provided any funding through the legislation which created the Commission to fund the many facets of the project: print surveys, make extensive phone contacts, conduct large-scale mailings, enter and analyze data, as well as conduct focus groups requiring facilitators, refreshments, locations, etc. The Council on Developmental Disabilities generously offered the Committee a grant to cover such costs, for which the CT Autism Spectrum Resource Center, Inc. agreed to be the fiduciary agent. The grant was submitted, approved, and distributed, and a budget maintained.

Questions

There were three primary questions that guided the work of the IFSS Committee. These questions guided the development of a questionnaire and a focus group protocol used to collect information from Connecticut's citizens with developmental disabilities and their families.

- What services and supports do individuals with developmental disabilities and their families need?
- What are the current experiences of individuals with developmental disabilities and their families?
- To what degree are individuals with developmental disabilities and their families able to access and receive those services that they need?
- To what degree are they finding and paying for their own services and supports?
- What are the barriers to individuals and their families being able to access or receive the services and supports they need?
- What would be the best way to organize, coordinate, and deliver the services to best meet individuals and families needs?

Methods

To answer the questions, the IFSS Committee organized two major research activities: A statewide survey and a statewide series of focus groups. Quantitative data were collected using a detailed questionnaire that was distributed statewide, while qualitative data were collected in several focus groups conducted in cities and towns across Connecticut. The survey activities and the focus group activities are described in detail in the next sections.

The Survey

The Individual and Family Services and Support Committee developed the extensive survey strategy with the help of research specialists who were assigned to the commission. A questionnaire (see Appendix C) was developed, piloted and revised, and then distributed across the state with the help of a large number of disability advocacy and support groups. A Spanish version of the questionnaire has been developed and will be distributed to Spanish-speaking individuals with disabilities and their families in the near future. In addition, focus groups are being planned to gather information from Spanish-speaking families.

The survey strategy targeted responses from those individuals with a developmental disability but who do not have a diagnosis of mental retardation. The questionnaire could be completed either by the individual with a developmental disability, by a parent or other family member, or by a regular caregiver. The method of distribution and strategies for obtaining a good response rate were discussed by the committee. The committee decided to contact all support groups and organization - statewide, regional, and local - we believed would have lists of individuals who met the respondent specifications. Karen Charest from U.S. Representative Christopher Shays (R – 4th District) office, offered interns to assist in the development of a comprehensive listing, using a variety of sources, including a widespread search of the internet. IFSS Committee members made personal phone contact with as many of groups as possible to enlist their assistance in distribution of the questionnaire. Postage for large mailings, as well as other survey expenses, were funded through a grant from the Council on Developmental Disabilities of Connecticut. In addition, Cummings and Lockwood, a Hartford law firm, posted 1000 questionnaires.

Here is a list of the organizations and groups that assisted with distribution of the questionnaires:

CT Parent Advocacy Center, Niantic	ACES (Area Cooperative Education Services), New Haven County (7 separate sites)
Park City Office for Persons with Disabilities, Bridgeport	SPALD, Inc., Tolland
Autism Project, Greenwich	Intensive Education Academy, W. Hartford
Chapel Haven, New Haven	Jobs and More, New Britain
St Vincent's Special Needs Care, Trumbull	Dept of Psychiatry, Trinity College, Hartford
United Cerebral Palsy of Eastern CT, New London	DATAHR, Brookfield
Center for Disability Rights, Bridgeport	Brain Injury Association of CT, Rocky Hill
CACLD (Children and Adults Center for Learning Disabilities), Norwalk	Atypical PDD/Asperger Support Group, Fairfield
Epilepsy Foundation of CT, Middletown	PDD NETWORK newsletter, Shelton
Multiple Sclerosis Society of CT, Norwalk	CT Autism Spectrum Resource Center, Inc., New Haven
Easter Seals Wellness and Rehab Center, Meriden	Kennedy Center, Trumbull
Parents Available to Help, Trumbull	Department of Social Services, New Canaan
Easter Seals Employment Agency, Waterbury	Brain Injury Association of CT, Norwalk
Farmington Valley Asperger's Network, Simsbury	Learning Disabilities Association, Hartford
	Disability Resource Center of Fairfield County
	Disabilities Network of Eastern Connecticut

In addition to mailing questionnaires, the questionnaire was posted on the websites of the Atypical PDD/Asperger Support Group of Fairfield, The CT Autism Spectrum Resource Center, Inc. and the CT Parent Advocacy Center (CPAC). Those who visited the site could print a copy of the questionnaire, fill it out, and mail it.

Aside from direct work with the target list of organizations listed above, at least one survey was sent out to each listed individual or group appearing on the comprehensive listing. These surveys were accompanied by a letter of introduction, explanation of the project along with an invitation to copy and distribute the survey as desired, or if additional copies were needed, a name and phone number to contact. The mailing list included:

- All state agencies except DMR
- All DSS offices
- All Child and Family Services offices
- All community action agencies
- All DCF branches
- All Birth-To-Three branches
- Bureau of Rehabilitation Services
- Transition service/independent living agencies
- Private schools serving children with developmental disabilities
- All Regional Education Service Centers (i.e. CES, ACES, etc.)
- Students with Disabilities' offices at colleges and universities

Each member of the Commission also received at least one copy of the survey, and were offered as many as they needed for their constituency groups.

In all, 8000 questionnaires were distributed to individuals and organizations. Our estimate is that 6500 questionnaires reached individuals. As of the deadline return date of July 30, 2001, 791 questionnaires were completed and returned to the committee for analysis, a 12% return rate.

Focus groups

While the survey strategy was designed to obtain broad-based data that could be aggregated to reveal trends in service needs and service access, a focus group strategy was designed to collect individual stories, personal accounts, and detailed information concerning the service and support needs of individuals with disabilities and their families. The IFSS committee, with the help of research specialists, created a format for the focus group sessions and a strategy for reaching as many diverse constituents as possible.

We wanted to ensure that focus groups included individuals with disabilities as well as their family members. Also, we wanted to make sure that the groups included individuals with different developmental disabilities and from diverse ethnic groups. Further, we wanted to be sure that the groups were accessible to individuals living in urban, suburban, and rural parts of Connecticut. And finally, we wanted comparable representation of the needs of adults with developmental disabilities as well as children.

The following table shows the actual selection of focus group locations:

Table 1. Focus group types and locations

Group type	Location Type	City/town
Family over 21	Rural/suburban	New Milford
Family over 21	Urban	New Haven
Family over 21	Urban/suburban	Stamford
Family over 21	Suburban	Enfield
Family under 21	Urban	Hartford
Family under 21	Suburban	Middletown
Family under 21	Urban/suburban	Norwalk
Family under 21	Urban	Waterbury
Family under 21	Urban/suburban	New London
Individual	Urban	New Britain
Individual	Urban/rural	Willimantic
individual	Suburban	Old Saybrook
individual	Urban	Bridgeport

To recruit focus group participants who represented a variety of developmental disabilities, we contacted local disability services, support groups, and advocacy groups.

Focus groups were facilitated by volunteers from state and private agencies as well as committee members. Focus group facilitators were trained and given extensive materials to ensure that each of the focus groups were conducted consistently. Each focus group was set up and supported by a focus group coordinator, most often an IFSS committee member.

The focus group format (see Appendix D) walked participants through a group discussion that centered around their current service and support needs, their current experiences within the service system, and their ideas about how to improve the system. The guiding questions were:

- What services and supports do you currently need?

Individual and Family Services and Supports Committee

- To what degree are you receiving or accessing those services?
- To what degree are you finding and paying for your own services and supports?
- What do you think are the barriers to your being able to access or receive the services and supports you need?
- What would be the best way to organize, coordinate, and deliver the services you need?

Participants were led through a two-hour group discussion based on the questions. Each focus group sessions was recorded in writing and on tape to facilitate analysis of focus group data.

Data analysis

Questionnaire responses were entered into Excel spreadsheets by congressional office interns and double-checked by partners to ensure the accuracy of the data entry. Excel spreadsheet data were imported into SPSS (Statistical Program for the Social Sciences) for analysis. Data were thoroughly examined and analyzed by committee and commission members. Specific analyses were conducted to answer the questions that guided the IFSS activities.

Focus group notes were typed and focus group tapes were partially transcribed for review. All specific statements and notes were coded for topic of statement and then clustered under specific themes. Frequency of comment by topic were calculated and matched to survey results.

Who responded?

Participation in the survey and the focus groups was extensive. We have developed information for this report to describe specifically who responded to the survey and who participated in the focus groups.

The survey respondents

The following bullet points help describe the 791 people who filled out and returned questionnaires:

- Responded from 182 zip codes representing 124 of Connecticut's cities and towns. (See Appendix E for complete list of cities and towns from which surveys were returned.)
- 22% filled out by individuals with disabilities, 67% filled out by parents of individuals with disabilities, 5% by other family members, 4.5% by other caregivers.
- 4% of surveys focused on individuals with disabilities age 0-3, 57% on individuals age 4 – 18 yrs., 6% on individuals age 19-22 yrs., 33% on individuals age 23 yrs. or older.
- Overall, 60% of those who responded were under 18 years and 40% were individuals who were over 18 years. These age groupings were used to better understand the different needs of children and adults.
- 74% of those who responded lived with their families. Of the 74%, 69% received no in-home support. 19% of those who responded lived in their own homes or apartments, half of whom received no in-home support.
- 85% of those who responded were diagnosed with a developmental disability before age 22.
- Perhaps most striking was the fact that many individuals who responded were diagnosed with multiple disabilities. Of the 21 disability diagnoses listed 521 individuals checked two diagnoses, 317 individuals checked three diagnoses, 188 individuals checked four, and 111 individuals checked five or more diagnoses. Given the overlapping diagnoses, the following table lists the number of respondents who checked the diagnosis listed.

Table 2. Diagnostic categories of survey respondents

Acquired brain injury	67	Muscular dystrophy	14
Attention deficit disorder	166	Neurological impairment	156
Autism spectrum disorder	256	Orthopedic impairment	50
Asperger syndrome	98	Pervasive developmental disorder	172
Cerebral palsy	63	Social/emotional disorder	89
Epilepsy	108	Speech impairment	86
Health impairment	72	Spina bifida	6
Hearing impairment	38	Tourette's syndrome	6
Learning disability	248	Visual impairment	45
Mental retardation	19	Other	155

The focus group participants

The following bullet points describe the 67 people who participated in the focus groups.

5. Focus group sessions were attended by 30 individuals with disabilities, 36 parents of individuals with developmental disabilities, and one sister of a man with developmental disabilities.
6. Twenty-one participants represented children with developmental disabilities (age 0-18). Adults with disabilities (age 19 and older) were represented by 46 focus group participants, 30 of whom were the individuals themselves.
7. Focus group participants lived in the 39 different cities and towns listed below.

Bridgeport	Madison	Pomfret Center
Bristol	Manchester	South Windsor
Brookfield	Mansfield Center	Southington
Brooklyn	Middletown	Storrs
Cheshire	New Britain	Trumbull
Clinton	New Canaan	West Haven
Cromwell	New Haven	Weston
East Granby	New London	Westport
East Haddam	New Milford	Wethersfield
East Hartford	North Haven	Willimantic
East Haven	Old Greenwich	Wilton
Hamden	Old Lyme	Windsor
Hartford	Plantville	

8. Nineteen focus group participants lived in urban settings (e.g., Hartford, New Haven, Bridgeport, Willimantic, Waterbury), and 44 participants lived in suburban settings. Rural areas were seriously under-represented in our focus group efforts, which included only four individuals from rural towns.
9. Fifty-one focus group participants were white, 9 were African-American, 3 were Hispanic, 1 was Native American, and 1 was multi-racial. The ethnicity of two focus group participants was unknown.
10. Focus group participants or those they represented, like survey respondents, often had multiple diagnoses. The following table lists the disability/diagnoses represented by focus group participants.

Table 3: Diagnostic categories of focus group participants

Acquired brain injury	4	Stroke	1
Attention deficit disorder	19	Neurological impairment	7
Autism spectrum disorder	17	Orthopedic impairment	4
Asperger syndrome	9	Pervasive developmental disorder	2
Cerebral palsy	12	Social/emotional disorder	8
Epilepsy	6	Speech impairment	9
Hydrocephalus	1	Spina bifida	6
Hearing impairment	1	Agoraphobia	1
Learning disability	24	Visual impairment	5
Depression	1	Cystic fibrosis	1
Spinal cord injury	1	Diabetes	2
Tourette's syndrome	2	Kallman's syndrome	1
Panic/anxiety disorder	1	Spina bifida	1
Rheumatoid arthritis	1		

Observations concerning survey and focus group participants

The Individual and Family Supports and Services Committee members made the following observations about survey and focus group participants.

- Low representation of Eastern part of the state and people from rural areas was troubling. While the committee made an extensive effort to find people living in rural areas, we were unable to find them and unable find services to connect us to people (from local level services to statewide networks)
- 15% of the survey participants did not meet the “diagnosis by 22” requirement of the federal definition of developmental disabilities. We assume that the developmental disability the person is currently experiencing manifested itself prior to age 22 for most of the respondents. Further, in terms of diagnoses, many identified diagnoses are not traditionally classified as developmental disabilities.
- Many participants had multiple diagnoses that resulted in them not fitting in to any distinct service agency.
- We don't have real demographic data on survey participants.
- Ethnic group representation among focus group participants was good. Questions still remain about whether or not the needs of ethnic groups are significantly different.
- Preliminary analyses showed that people with multiple diagnoses were less likely to be independent in learning, self-direction, employment, and healthcare. They were also less likely to have the information they needed to plan and secure services, feel welcome in the community, and to have friends that help them participate in community.

Conclusions

People in Eastern CT and people in rural areas are not being identified, are not being served, do not have access to services to the same degree that people in urban and suburban areas do. Statewide support groups do not appear to be finding people in the rural areas, Eastern regions.

There are many people who do not meet the federal definition for developmental disabilities by the book, but have disabilities and have service and supports needs nonetheless.

People are shifted around based on distinct diagnoses but the one diagnosis/one agency mentality doesn't work. People have multiple diagnoses that result in their being eligible or ineligible for services from specific agencies and many of these people experience being shifted from agency to agency.

Results

The results section of this report is organized by the questions that the IFSS Committee set out to answer.

Question 1: What services and supports do individuals with developmental disabilities and their families need?

The following list of service and supports were published in the questionnaire and presented to the focus groups as a comprehensive list of possible service needs. Survey respondents were asked to rate each of the services by the degree to which they currently needed the service and the degree to which the service, were they receiving it, currently meets their needs. Focus group participants were asked review the list when they were discussing their most pressing service needs as a way of ensuring that no need was left out of the discussion.

Table 4: Service and support needs and their descriptions

<ul style="list-style-type: none">▪ Assessment Services (specialized evaluations and assessments)▪ Assistive Technology (equipment, vehicle modifications, and adaptations)▪ Personal Assistant (employed by person to provide direct service/support)▪ Community Inclusion Services (assistance to access/participate in community activities)▪ Education (school-based education for all age groups)▪ Life Skills Training (education and training in basic life skills)▪ Case Management or Service Coordination (assistance with locating and securing benefits/programs)▪ Financial (Cash) Subsidy (payments from govt agencies directly to individual)▪ Welfare Services (provide temporary housing, food, clothing)▪ Housing Assistance (subsidy, financing, modifications, finding affordable and accessible housing)▪ Residential Support in Home (independent living support or support in family home)▪ Placement in a Residential Program (includes residential school, group home, etc.)▪ Transition Support: School to Work (assistance moving from high school to employment)▪ Job Placement/Job Training (assistance with finding a job and learning to do a job)▪ On-the-job Support (assistance on current job from support provider agency)▪ Day Program (specialized day program that does not have job focus)▪ Transportation Services (individualized and adapted transportation)▪ Legal Services (consultation and legal representation)▪ Medical and Health Care (direct service health care and/or funding or subsidy)▪ Mental Health Care (direct mental health care and/or funding or subsidy)▪ Social Skills Training/Behavior Management (specialized behavior and social skills training services)▪ Recreation Services (supports or services for leisure and recreation activities)▪ Family/Caregiver Education and Training (special information or training for parents or caregivers)▪ Family Counseling or Support Group (counseling services or parent/peer networks)▪ Respite care : out of home (overnight or weekend care at a center or program)▪ Respite care: in-home (in-home caregiver to provide temporary relief/assistance)▪ Funding to purchase support services for family (direct funds to family for purchase of necessary services/equipment)

Service and support need data were examined for three groups: 1) children with developmental disabilities (age 0-17), adults with developmental disabilities (age 18 and older), and young people with developmental disabilities who are in the transition from school to adult life (age 18 – 24). The data were analyzed in groups because initial analyses showed marked differences in service needs among the three groups.

Service and Support Needs for Children with Developmental Disabilities

“I’m a single parent. We live in low income housing, which is a Godsend. I mean, we wouldn’t have a place to live. We receive partial disability and partial welfare so I’m able to stay home with her and take care of her and get her treatments done. Her condition is more physical, though she was diagnosed at 2 ½ months old, so it really did slow down her speech, her motor skills, we were working with Birth-to-Three for a while, and really I don’t know what we’d do without the insurance (Husky Plan) we get. With her preexisting condition, even if I was able to go out and work, who (insurance) would pick her up? I just don’t know where I’d be without the help I’ve received. I might not know enough about her disease, she’s my first child, and when she was diagnosed it was a lot to take in, there was a lot to learn. I felt like the doctors were just kind of cramming it...and maybe educational programs on different disabilities (would be needed)...I have family who know how to take care of her and how to give her her treatments and her medications. If I need them they’re there, everybody works full time, and they’re very busy and I hardly see them, but they pitch in when I need them.”

The following table lists the top 14 service and support needs (of the 27 listed above) for children with developmental disabilities, according to their parents. Please refer to the preceding table for more extensive descriptions of the service need areas. The service needs are ordered by the mean score for the degree of need of the service. Each service need is followed by the data on the number of people who reported “No need” for the service, “Small need”, “Moderate need”, and “Extensive need”. The number of focus group comments concerning each need is posted in the next column followed by an example of the type of comment made.

Table 5: Service and support needs of individuals under 18 years of age (n = 454)

Needs (Under 18 years)	Mean	No Need	Small Need	Moderate Need	Extensive Need	Number Focus group comments	Example comment
Education	3.42	43 (9%)	23 (5%)	73 (15%)	292 (61%)	43	One of the things I feel strongly about is that the school is only 6 hours out of 16 waking hours a day, and it’s less than half, considerably less than half. And it’s only 183 days out of 365, which is exactly half. So school is about 20% or less of my son’s waking hours, and he really needs school to teach him <u>all</u> the time.
Assessment	2.95	57 (13%)	53 (12%)	147 (32%)	157 (35%)	20	
Social skills	2.93	98 (22%)	35 (8%)	78 (17%)	218 (48%)	5	Social skills training is currently unavailable from any source, even private providers, including 1-1 coaching and small group work. School time that is currently set aside for this is not adequate for the complexity of these skills.
Life skills	2.82	101	46	94	185	3	

training		(22%)	(10%)	(21%)	(41%)		
Recreation	2.75	126 (27%)	44 (9%)	97 (20%)	185 (41%)	19	There are no activities after school, no sports or summer camps for kids with disabilities in my town.
Family Counseling	2.65	100 (22%)	76 (17%)	104 (23%)	149 (33%)	4	
Family Education	2.61	109 (24%)	63 (14%)	122 (27%)	135 (30%)	10	I needed training on my child's disability.
Case management/service coordination	2.45	174 (37%)	52 (11%)	84 (18%)	149 (31%)	45	I need a service broker who Would act as an advocate to obtain services we need and to cut through red tape.
Community inclusion	2.29	178 (39%)	55 (12%)	79 (17%)	115 (25%)	8	
Medical and health care	2.19	205 (45%)	37 (8%)	84 (19%)	100 (22%)	11	“The health insurance company was uncooperative for providing OT, speech/language, and PT. Most parents I know pay for these through private providers. My daughter's lifetime cap was reached at age 11.
Mental health care	2.03	231 (51%)	34 (7%)	73 (16%)	87 (19%)	4	
Family financial subsidy	1.97	240 (53%)	49 (11%)	56 (12%)	88 (19%)	24	I know a family with a child with cystic fibrosis and they really could have used some financial help with medication, but because they were on this fine line, like a thousand dollars over, they wouldn't help...
In home respite care	1.96	263 (55%)	40 (8%)	55 (12%)	95 (20%)	6	The supply of babysitters and respite providers is not there, and the responsibility falls to the family members.
Financial assistance	1.92	260 (57%)	29 (6%)	63 (14%)	81 (18%)	11	We need help with financial planning and guardianship coordination.

Mean: 1 = no need, 2 = small need, 3 = moderate need, 4 = extensive need.

As the table shows, the largest percentages appear under the category ‘No need (for the service)’ and ‘Extensive need’. The difference between the top priority need and the lowest priority need seems to be the number of people who have an extensive need for the service. Of note, even the lowest priority need on the list was highly needed by 95 individuals and their families.

Focus Group Comments

The focus groups’ comments help to clarify and define the service needs that emerged from the survey data.

A parent talks about respite care:

“In the past, my elder son will watch his little brother...Right now he’s the best thing I have close to a babysitter.... Mostly my immediate family, my kids and I, are all we have. I tell them, the three of us are

in a situation where we only have each other, and we have to support each other. Other than that we're lost."

A parent talks about the need for social skills training:

"What David needs the most is social skills training; it's the key thing that he needs. That, I can't seem to get for him from any source, even being willing to pay, and we've been through screenings at several private places...I think that he needs it now, as he's becoming 14, but it would have been much more effective had it started early on, so I would really advocate for starting in early elementary school, first or second grade, beginning social training for children who have autism or other types of disabilities, they need that...."

Service and Support Needs for Adults with Developmental Disabilities

The following table lists the top 16 service and support needs (of the 27 listed above) for children with developmental disabilities, according to their parents. Please refer to the preceding table for more extensive descriptions of the service need areas. The service needs are ordered by the mean score for the degree of need of the service. Each service need is followed by the data on the number of people who reported "No need" for the service, "Small need", "Moderate need", and "Extensive need". The number of focus group comments concerning each need is posted in the next column followed by an example of the type of comment made.

Table 6: Service and support needs of individuals 18 years of age and older (n = 330)

Needs (18 years and older)	Mean	No Need	Small Need	Moderate Need	Extensive Need	Number Focus group comments	Example comment
Medical and health care	2.57	95 (29%)	32 (10%)	64 (20%)	93 (25%)	17	Medical needs are neglected if no Medicaid. Health and dental services – especially dental – Medicaid doesn't cover all adult needs (prescriptions, dental)
Case management Service coordination	2.38	109 (33%)	45 (14%)	57 (17%)	82 (25%)	71	Adults with disabilities don't know what is available or how to access them. Services are being underused. Don't know how to navigate the system, it is "not user friendly". There is no one to "connect" the individual to the appropriate agency, and they don't give people precise information on where to go. Parents are left hanging in obtaining services. There are many loopholes within and across agencies. No info on how to access services. Phone contact over months was unsuccessful.
Financial assistance	2.34	123 (37%)	35 (11%)	46 (14%)	84 (25%)	45	Disability expenses need to be taken into account – deduct the cost of personal assistance, transportation, assistive technology, etc. "I am not poor enough (to get financial assistance) or rich enough (to buy what I need)".

Recreation	2.32	118 (36%)	35 (11%)	58 (18%)	78 (24%)	11	
Transportation	2.30	139 (42%)	26 (8%)	30 (9%)	101 (31%)	17	Transportation is a big issue – the cost of accessible transportation is very high - the arrangements are very complicated Transportation is only available by appointment and there is a long wait.
Community inclusion	2.12	140 (42%)	45 (14%)	46 (14%)	64 (16%)	20	
Job placement and training	2.10	165 (50%)	23 (7%)	31 (9%)	84 (26%)	48	They need job coaching long-term – changes in routine happen and needs management. Jobs need flexibility. The job coach needs to be a “gatekeeper”. There is a problem with employer understanding - there is still discrimination out there. I’d like to be able to work and earn some decent money – the job market and the resources for employment are limited for people with disabilities.
Assistive technology	2.05	164 (50%)	27 (8%)	37 (11%)	67 (20%)	5	If I need a walker I have to pay out of pocket and wait and wait – or BRS might help purchase the equipment but you have to pay for maintenance.
Assessment services	2.00	133 (40%)	53 (16%)	57 (17%)	42 (13%)	19	It’s important to get the right diagnosis early so you can develop the right plan.
Personal assistant	1.96	140 (47%)	45 (14%)	46 (14%)	64 (19%)	5	He has PCA waiver but the supply of PCA’s is poor – aides have serious issues, money is not great, the pool of people is not great
In-home assistance/support	1.93	170 (52%)	35 (11%)	37 (11%)	56 (17%)	6	
Family financial subsidy	1.89	179 (54%)	19 (6%)	34 (10%)	56 (17%)	11	
Family counseling	1.85	164 (50%)	47 (14%)	35 (11%)	40 (12%)		Parents’ health and mental state is stressed while child is at home, and this is a problem. System education - learning how the system works and how to get things done in the system
Housing	1.84	188 (57%)	22 (7%)	37 (11%)	57 (15%)	11	Housing is needed for higher functioning adults. They are not compatible with lower functioning individuals in their needs. An apartment with supported or assisted living would be good.
Life skills training	1.82	173 (52%)	37 (11%)	43 (13%)	42 (13%)		Learning independent living skills – education, daily reminders, money management, social skills Transition services (high school to independent living)
Legal services	1.82	175 (53%)	48 (15%)	40 (12%)	38 (12%)	5	There are not a lot of advocates and you don’t get help paying for legal fees.

Mean: 1 = no need, 2 = small need, 3 = moderate need, 4 = extensive need.

The picture painted by these data is more varied than that painted for children with developmental disabilities. For most of the top 16 needs the percentage of people who do not need the service is larger than any other category. The data indicate that extensive needs are individualized. The data suggest that service plans must be individualized and that it is inefficient to deliver a full array of services to many adults.

Focus Group Comments

The focus groups' comments help to clarify and define the service needs that emerged from the survey data.

Betty speaks about employment:

“There are plenty of people with disabilities who want to work, but employers cannot see us. They don't want to see us. And that is very discouraging. So between the discrimination and the social security disincentives, it is very difficult, and I feel a lot of talent is going to waste.”

Karen speaks about housing:

“The other concern that I have within the cities is affordable safe housing for people - that's not segregated, by the way - that's in the community. That people have an opportunity to pick and choose where they live, not to live in a building that happens to have Section 8 certificates attached to it and you can live for 30% of your income but you're stuck living in that building, but that you have a certificate or voucher in your hand and you can find an affordable, safe place to live should you not, unfortunately, be employed and need financial supports with your housing. This has been an ongoing issue and concern.”

Dorothy speaks about transportation:

“How can the state of CT let a man that just walked out of the hospital off a dialysis machine that also has depression, high blood pressure, heart problems, sleep apnea, going through a series of eye surgeries every month to keep his sight, be dismissed off the machine and told, ‘well, you have to get home from Norwalk to Bridgeport the best way you can, because we don't have your name down (on the transportation list).”

An individual with a developmental disability speaks about the service system:

“You see, it's a catch-22 with social security, you can make enough to lose your benefits, but not enough to live on, and people at BRS can't understand that, they can't, and a part of the problem there is I think that BRS needs to be more of an advocacy agency because the federal government, the Rehab Services Administration, measures the success of BRS's work according to statistics – how many people they place. Pressuring someone to take a part-time job fills up the statistics, but it doesn't equal a job that the person can make a living on and pay all their expenses. And so naturally people are reluctant to take part-time jobs, lose their benefits, and yet not be able to live. It's a no win situation.”

An individual with a developmental disability speaks about medical care:

There are physical health concerns that aren't taken care of. Many of the psychiatric medications cause different problems if you take them for a number of years – diabetes, heart problems, kidney problems - and somehow a lot of these conditions just fall through the cracks, and people just don't get the physical health care they need. When people don't have the money, or sometimes their income is a little too high so they can't get Medicaid, that means if they need new glasses, they can't get new glasses. Here, you're

getting into the ‘you’re not poor enough’, but the person doesn’t have enough money to purchase it on his or her own, and it ends up ‘do without’.

Service and Support Needs for Young Adults with Developmental Disabilities in Transition

The following table lists the top service and support needs (of the 27 listed above) for young adults (age 18-24) with developmental disabilities. The service needs are ordered by the mean score for the degree of need of the service. Please refer to the Service Needs (Table 5) for more extensive descriptions of the service need areas. Focus group comments could not be attributed to this very specific age group.

Table 7: Service and support needs of individuals between 18 and 24 years of age (n = 76)

Needs (18-24 yrs)	Mean	No Need	Small Need	Moderate Need	Extensive Need
Job placement and training	2.71	24 (32%)	5 (7%)	6 (8%)	43 (33%)
Transportation	2.55	28 (37%)	5 (7%)	6 (8%)	30 (40%)
Medical and health care	2.52	22 (29%)	11 (15%)	16 (21%)	21 (28%)
Recreation	2.51	22 (29%)	11 (15%)	19 (25%)	17 (22%)
Case management/service coordination	2.45	22 (29%)	11 (15%)	19 (25%)	17 (22%)
Transition support	2.36	32 (42%)	4 (5%)	9 (12%)	24 (32%)
Social skills training	2.35	22 (29%)	11 (14%)	16 (21%)	21 (28%)
Financial subsidy	2.35	28 (37%)	8 (11%)	12 (16%)	20 (26%)
Life skills training	2.34	25 (33%)	12 (16%)	15 (20%)	14 (18%)
Community inclusion	2.31	24 (32%)	14 (18%)	15 (20%)	14 (18%)
Assessment services	2.25	26 (34%)	12 (16%)	15 (20%)	14 (18%)
On the job support	2.18	31 (41%)	9 (12%)	7 (9%)	18 (24%)
Mental health care	2.10	32 (42%)	11 (15%)	13 (17%)	13 (17%)
Housing assistance	2.06	38 (50%)	3 (4%)	16 (21%)	13 (17%)
In-home residential support	2.01	41 (54%)	5 (7%)	8 (11%)	17 (22%)
Funding to purchase family supports	1.94	42 (55%)	5 (7%)	10 (13%)	14 (18%)

Mean: 1 = no need, 2 = small need, 3 = moderate need, 4 = extensive need.

Of note, the mean 'need' scores for the list of service needs of individuals between 18 and 24 years are significantly higher than the mean 'need' scores for all adults with developmental disabilities. The data indicate that the needs of young people in the transition period are more extensive than at any other time in their lives.

Focus group themes concerning service and support needs

Focus group comments were coded and sorted by themes to provide a better sense of the key issues associated with services and supports. The following themes emerged from the focus group data.

- Service needs, configurations, and amounts vary from person to person. No two service plans would look exactly alike. This seems to be true for individuals with minimal support needs as well as great support needs.
- Eligibility should be determined based on functional limitations and functional needs, not diagnosis, labels, or test scores such as IQ.
- People want to work in meaningful, challenging jobs that take advantage of their skills and talents.
- People need access to long-term supports. People need to be determined eligible and know that their eligibility opens access to services they may need throughout their lives rather than determinations for short-term services such as BRS provides.
- Professionals do not seem well-prepared or well-trained to meet individual needs - teachers, doctors, employers, state workers, BRS workers.
- Service quality, particularly responsiveness, in the current service system is poor.
- There is a great need for advocacy services.
- There is a great need for service coordination assistance.
- Social acceptance and community acceptance is missing and this seriously affects quality of life for individuals with developmental disabilities.

Observations concerning the service and support needs of individuals with developmental disabilities

- Even the lowest priority services are still needed extensively by a number of people. Items on the service and supports that were marked 'not needed' by a large number of respondents were marked 'needed extensively' by a small number of people. This observation leads us to conclude that all services and supports listed should be part of the available array. Further, while some individuals and families have a relatively small number of service needs, others have large numbers.
- The needs for the Under 18 group are a blend of child supports and family supports. For the Over 18 group, the needs are much more focused on the individual.

- For individuals under 18, education is the ‘hub’ for services for children. Many of the services are extensively needed by large numbers of children and their families. There is a lot of concern about what is and is not happening at the education level. Inconsistencies across LEA’s mean that where you live determines what you get.
- Further, many of the priority needs for individuals under 18 do not fall under the purview of special education – respite, in-home support, family counseling, family subsidies. Families report that there is no place to go for these services. The family support system is nonexistent.
- Physical and material wellbeing are the key concerns for adults with developmental disabilities. Many of the priority services for adults are primarily contributing to physical and material wellbeing – medical care, transportation, job training, etc.
- The need for case management is consistently high across all age groups.
- The transition group (18-24 years) has the highest level of needs. The pressures and challenges of the transition from school to adult life result in a large number of service and support needs, many focused on preparation for the imminent move to work, college, and independent living. Further, the transition period is characterized by a lack of coordination between education and adult system, no case management, anxiety for individuals and families, poor planning, and questionable accountability.

Conclusions

- Service needs and service configurations are largely individual. Many services that may not be needed by a large number of people are still critical for a small number of people. Survey results should not be used to make a conclusion that some services are not needed.
- Education is a key player in helping children and families access services and supports. However, many of the needed services and supports do not fall under the purview of special education. Further, some children with developmental disabilities, primarily those with physical disabilities who do meet eligibility criteria, do not qualify for special education. The question remains, should education’s role be expanded? or should a “third party” should be developed to coordinate the array of services and supports needed by children and families. In all likelihood, education can not accomplish adequate service delivery alone.
- No state agency has services and supports to children with disabilities and their families as part of its mission.
- Individuals over age 18 experience a similar issue. Bureau of Rehabilitation Services is the key player for adult services but most needs on the list don’t fall under the purview of BRS. Who will pick up the slack to coordinate the non-vocational services?
- Case management/service coordination is critical to effective planning and accessing services, yet case management is missing from the current system.
- The transition from school to adult life is a critical time for young people with developmental disabilities. In general, the system is not working here. The lack of service coordination, limited collaboration between education and adult service agencies, poorly developed curriculum, and

shortage of family education and counseling regarding the transition result in slow and unsuccessful transitions for many young people with developmental disabilities.

The findings of the IFSS Committee are similar to the findings of several other groups such as the children’s services task force, CT initiatives, CT Family Support Council, OSEP Self-Assessment, and the Olmstead Plan

Question 2: What are the current experiences of individuals with developmental Disabilities and their families?

To what degree are individuals with developmental disabilities and their families able to access and receive those services that they need?

Table 8: Top Needs for Under 18 group (n = 454); A comparison of the number of people needing services to the number of people receiving them.

Service Need	Number who reported they need the service	Number receiving service (Mean*)
• Education	376	353 (3.0)
• Assessment	357	302 (1.9)
• Social skills training	331	243 (2.1)
• Life skills training	325	244 (2.3)
• Recreation	313	209 (1.8)
• Family Counseling	325	223 (2.0)
• Family Education	320	219 (1.9)
• Case management/service coordination	272	182 (2.0)
• Community inclusion	249	171 (1.9)
• Medical and health care	217	197 (2.4)
• Mental health care	194	178 (2.2)
• Family financial subsidy	193	147 (1.3)
• In home respite care	187	139 (1.4)
• Financial assistance	173	142 (1.6)

*Mean: To what degree is the service meeting your needs?
 1 = not at all, 2 = to a small extent, 3 = to a moderate extent, 4 = completely

The number of people receiving the service is always significantly lower than the number who need the service. Those who receive the service say that services, with the exception of education, are meeting their needs only to a small extent. Education is meeting needs to a moderate extent (Mean = 3.0).

Table 9: Top Needs for Over 18 group (n = 330); A comparison of the number of people needing services to the number of people receiving them.

Service Need	Number who reported they need the service	Number receiving service (Mean*)
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• Medical and health care	189	148 (3.0)
• Case management/service coordination	184	117 (2.4)
• Financial assistance	165	129 (2.3)
• Recreation	171	109 (2.2)
• Transportation	157	110 (2.5)
• Community inclusion	155	106 (2.1)
• Job placement and training	138	93 (2.0)
• Assistive technology	141	113 (2.6)
• Assessment services	152	119 (2.6)
• Personal assistant	123	114 (2.5)
• In-home assistance/support	128	95 (2.3)
• Family financial subsidy	109	79 (1.7)
• Family counseling	122	75(1.7)
• Housing	110	84 (2.1)
• Life skills training	122	93 (2.2)
• Legal services	126	84 (1.9)

*Mean: To what degree is the service meeting your needs?

1 = not at all, 2 = to a small extent, 3 = to a moderate extent, 4 = completely

The number of people receiving the service is always significantly lower than the number who need the service. Those who receive the service say that that services are meeting their needs to a small to moderate extent. Services to families of adults with developmental disabilities seem to be the least developed.

To what degree are individuals or their parents finding and paying for their own services and supports?

The following table shows the percentages of people responding to the survey who pay for their own services and supports. Each percentage indicates the percentage of the entire number of people responding who checked off that they pay for the service.

Table 10: Degree to which individuals and families are paying for services

	All (n = 791)	Under 18 (n = 454)	Over 18 (n = 330)	18-24 years (n = 76)
Are you paying for services?				
Yes.	349 (42%)	204 (45%)	115 (35%)	30 (40%)
In part	304 (37%)	154 (34%)	121 (37%)	29 (38%)
No	171 (21%)	84 (18%)	74 (22%)	13 (17%)
Assistive technology	86 (11%)	47 (10%)	32 (10%)	7 (9%)
Personal assistance	85 (11%)	45 (10%)	34 (10%)	6 (8%)
Education and training	211 (27%)	137 (30%)	48 (15%)	26 (34%)
Transportation	189 (24%)	49 (11%)	112 (34%)	28 (37%)
Medical and mental health care	383 (48%)	210 (46%)	135 (41%)	38 (50%)
Case management	31 (4%)	17 (4%)	11 (3%)	3 (4%)

Residential support	78 (10%)	17 (4%)	48 (15%)	13 (17%)
Job supports	26 (3%)	1 (<1%)	18 (6%)	7 (9%)
Other	162 (20%)	114 (25%)	44 (13%)	4 (5%)

Individuals and their families are paying out of pocket for a variety of services. Nearly 80% in each age group are paying entirely or in part for some services they receive.

What are the barriers to individuals and their families being able to access or receive the services and supports they need?

The information in this section was gathered through the focus group sessions.

Why is it difficult for people to access services? What seems to get in the way?

Funding

- Limited system funding
- Very limited individual funding
- Financial inflexibility (e.g., income limits, sliding scales)
- Waiting for the funding cycle

“One size fits all” mentality

- Lack of flexibility in service delivery
- Limited local access for most people
- Limited city/town responsibility and accountability
- Rigid eligibility exclusions

The bureaucratic “maze”

- Information and services are almost impossible to find; people experience ‘the run around’, ‘dead-ends’, ‘call here...call there’
- Lack of cross-agency communication
- Lack of responsiveness - many workers in the system don’t seem to care - most people are not known by anyone in the system
- Paid staff just don’t seem to know the answers to most questions

For school-age kids, school is the sole provider - what about non-educational needs?

Transportation is costly, uncoordinated, difficult to arrange. The current arrangements don’t meet needs.

Employment - no meaningful work, limited job supports, BRS’ short-term focus not helpful

Medicare just doesn’t cover what people need

Low and inconsistent service quality

Observations concerning individual and family experiences in the current service system

The number of people who need a service is consistently higher than the number of people who are receiving the service. Many services that people are receiving are simply not meeting people’s needs.

In terms of services meeting needs, family services and supports are the least effective, receiving the lowest scores in response to the question “To what degree is the service meeting your needs?”

Individuals and their families are paying for services. There are no real differences between children and adults with regard to self-paying. Medical and mental health care is being paid for by both individuals (41%) and families (46%). Transportation is being paid for by 34% of adults with developmental disabilities. Thirty percent of families are paying for some aspect of education including supplemental education, tutoring, speech, occupational therapy, summer programs, and other services.

The problem/issue of employment is woven throughout the data.

Conclusions

The survey and focus group data strongly support the notion that people with developmental disabilities are not getting the services and supports necessary for them to lead independent and productive lives in the community.

Family supports and services are underdeveloped and often non-existent.

Families are actively providing financial support whether they want to or not. Families and individuals are currently paying for a number of their services or supplementing their service plans with self-purchased services and supports. The ability and willingness of families and individuals to pay for services varies from family to family. Some families pay because they have no choice but truly are not able to do so, other families are able to pay and do so willingly. Still more families can not pay for services and so their family members go without needed services.

There are a number of systems issues related to people purchasing their own services: economic issues, service availability issues (case management), systems won't contract with individuals.

The funding system lacks flexibility – both in terms of accessing funds, purchasing services.

Employment is a real problem for people with developmental disabilities – unemployment, under employment, transportation, job training, job supports, job searching/placement, short term services with minimal employment as the goal, public attitudes, discrimination, earnings put benefits at risk, lack of ongoing services. The unemployment rate of people with disabilities is rising despite many efforts. BRS mandates and priorities don't serve the needs of the people. BRS appears to be under-funded to serve the number of people who need services

The bureaucratic maze is frustrating and inefficient. Many people who need services do not have the systems savvy to navigate the maze. Others feel that the maze is set up specifically to prevent them from accessing needed services.

Question 3: What would be the best way to organize, coordinate, and deliver the services that individuals and families need?_

Focus group participants were asked to describe a more effective system. Many thought-provoking ideas were shared. They are summarized in this section.

- **The birth-to-three is a good model – It’s personal, provides in-home supports, includes service coordination, is family focused, and is an entitlement.**
- **“One stop shopping”**
 - Central location to make information readily available
 - Case manager/service broker who can assess, determine eligibility, advocate, develop service plan, secure services, problem solve
 - Local access
 - Third party
- **Flexible funding**
 - Voucher/credit card to pay for services and equipment maintenance
 - Sliding scales and individual/family contributions
 - Flexible income caps based on individual assessment
- **Statewide database available to all state agencies with individual and service information**
- **People with developmental disabilities must have real input and real power at the policy level**
- **Working transportation system regulated at state level**
- **Eligibility based on functional needs**
- **Assisted living, in-home supports, respite service**
- **Individualized service plan developed from a ‘menu’ of services**
- **Major improvements to Personal Care Assistant system**
- **Workers in the field take a customer service mentality - responsiveness and respect**
- **A “Husky” type plan for adults to improve coverage**
- **Sufficient, knowledgeable medical care**
- **Public awareness and understanding**

The IFSS Committee supports and advances the conclusions and recommendations made by the focus group participants.

Recommendations of the Individual and Family Services and Supports Committee

The Individual and Family Services and Supports Committee submits the following recommendations to the Advisory Commission. Our recommendations are based on our thorough review of the data we have collected. Our hope is that we have accurately reflected the concerns and ideas of the many people who took the time to share their thoughts with us.

Eligibility

- Use functional assessment and not the diagnoses and age cut off as a way of determining whether or not someone is eligible for services.

System Access

- Set up a central entry point that people can access regardless of diagnosis.
- Every person who enters the system should leave with either a service plan or a referral.
- Set up a central location to make information readily available.
- Ensure local access.

Service Coordination and Service Planning

- Case management/service coordination must be a key component of whatever system we design. Individualized service planning is essential in the revised system.
- Service development must involve more comprehensive thinking about the range of needs, not just focused on vocational needs. The coordination of the variety of services people need is very important.
- Funding and ability to purchase services should be part of the service planning discussion.
- Each person should have an individualized service plan developed from a 'menu' of services.
- Case manager/service broker who can assess, determine eligibility, advocate, develop service plan, secure services, problem solve is an important position in the new system.

Service Quality

- Establish cross agency communication and information sharing.
- Build a statewide database of individual and service information that is available to all state agencies.
- Create a system that is easy to navigate.
- Develop an appeals process with regard to eligibility determination.
- Train workers in the field to take a customer service mentality of responsiveness and respect.

Systems Improvements

- There must be a major review of the system for children with developmental disabilities and their families to develop partnerships, services, and system.

- Use Birth-to-Three model as a basis for designing a new system. The Birth-to-Three model's strengths include: single point of entry, comprehensive individualized services, service coordination, zero-reject entry, and local access.
- Focus efforts on major improvements and redesign of the service system around young people in transition
- The whole notion of employment of people with disabilities needs to be revisited. We need a public policy shift with all levels of government highly involved.
- Build a working transportation system regulated at state level.
- Develop assisted living, in-home supports, respite services.
- Make major improvements to PCA (Personal Care Assistant) system.

Funding

- Promote flexible funding.
- Authorize flexible income caps based on individual assessment.
- Develop a voucher/credit card to pay for services and equipment maintenance
- Develop a system of sliding scales and to support individual/family contributions.

Inclusion

- Individuals with disabilities must be directly and actively involved in efforts to design and revise the service system.
- Include individuals with disabilities as leaders in the developing system and invest in the development of future leaders through mentorships, internships and other development activities.
- Design and develop ways for high school and college students with disabilities to learn and practice leadership.

Healthcare

- Train and develop sufficient, knowledgeable medical personnel.
- Create a "Husky" type healthcare plan for adults to improve coverage.

List of Appendixes

- Appendix A Tasks and activities of the
Individual and Family Services and Supports Committee
- Appendix B. Committee membership list
- Appendix C. Questionnaire
- Appendix D Focus group materials
- Appendix E Cities and towns from which surveys were returned
- Appendix F Observations/Conclusions/Recommendations Table

Appendix A Tasks and activities

Major Tasks and Activities of Commission
<u>1. Identify the types of services and supports needed for persons with developmental disabilities, who do have mental retardation, and their families</u>
Individual and Family Services and Supports Committee Tasks:
1.2 Identify primary service and support needs of individuals who do not have mental retardation and their families 1.2.1 Gather, review, and summarize existing data (e.g., needs assessments, Family Support Council Report) 1.2.2 Assess self-identified service and support needs of individuals and their families in areas to include, but not limited to, employment, education, community support, health, housing, and family support
<u>2. Define the population to be served</u>
2.1 Identify the group(s) (cohort) who need services and supports based on an analysis of inventory and focus group findings 2.2 Describe each cohort (define) 2.3 Rank each cohort's service needs in order of their significance (i.e., within cohort) 2.4 Describe the relative strengths of each cohort (i.e., how are they doing within the current context) 2.5 Describe the critical or unsolved needs for each cohort (i.e., what portion of the cohort is underserved or unserved) 2.6 Develop preliminary written recommendations based on findings and present them to Commission

Appendix B. Individual and Family Services and Supports Committee membership list

Stacy Hultgren, Co-Chair
Shelton

Marijke Kehrhahn, Co-Chair
East Hampton

Karen Charest
Wallingford

Karen Dillon
Windsor

Joann Miller
Greenwich

Rep. Teresa Gerratana
New Britain

Elizabeth Platt-Suski
Southington

Jan Hasenjager
New Britain

Nanfi Lubogo
East Hartford

Paul Seigel
New Haven

F. Jay Sullivan
New Britain

Steven Barnwell
New London

Staff to the
Committee

Barbara Pankosky
Department of Mental Retardation

Edward Preneta
Council on Developmental Disabilities

Mary Botticelli Christensen
University of Hartford

**Connecticut Community Survey
May 2001**

**Service and Support Needs of People
with Developmental Disabilities**

We need your help!

Thank you for taking the time to fill out this important survey. The survey is being conducted by The Advisory Commission on Services and Supports for Persons with Developmental Disabilities. This legislative commission will use the information you provide to develop recommendations for changing Connecticut's systems that provide support to individuals with developmental disabilities.

*The focus of the Commission's work is on the support needs of those individuals with developmental disabilities who **DO NOT** have mental retardation or a mental disorder. This is why we are not including individuals with mental retardation or mental disorders in this survey. The group we want to reach would include people with physical disabilities associated with conditions such as cerebral palsy, spina bifida, muscular dystrophy, and others, autism spectrum disorders, epilepsy, significant learning disabilities, acquired brain injury, or significant health impairments.*

Your responses to this questionnaire are very important and will help shape the future of services and supports for citizens with developmental disabilities in Connecticut.

Please take about 15 minutes to complete all of the questions and then mail the questionnaire back as soon as possible and no later than July 10. Questions may be answered by an individual with a disability or a person who provides primary support to the individual such as a family member, guardian, caregiver, or advocate.

Completion of the survey is both voluntary and confidential. Therefore, returning a completed survey implies informed consent. If you have questions about the survey or the results, please contact Stacy Hultgren, Co-chair, Individuals and Families Services and Supports Committee at (203) 924-0457 or Barbara Pankosky at (860) 418-6150.

PLEASE DO NOT FILL OUT THIS QUESTIONNAIRE

IF your/the person's disability is classified as
mental retardation or mental/emotional disorder

OR

**If you are/the person is considered eligible for services from the
Department of Mental Retardation.**

Return the survey to:

*Department of Mental Retardation
460 Capitol Avenue
Hartford, CT 06106
Attn: Planning and Development*

INSTRUCTIONS

Please fill out the questionnaire by checking the boxes that best represent your answer to each question. It is important to answer each question as carefully as you can. Your answers will be important in helping to improve the current service system.

All your responses are anonymous and confidential. Your participation in this survey is completely voluntary. Therefore, returning a completed survey implies informed consent.

For purposes of this questionnaire, a DEVELOPMENTAL DISABILITY is a mental or physical impairment that is life long, results in substantial limitations, and is identified before the age of 22-yrs.

IF THE DISABILITY IS MENTAL RETARDATION OR MENTAL DISORDER,
OR
IF YOU ARE CURRENTLY ELIGIBLE FOR DEPARTMENT OF MENTAL RETARDATION SERVICES

Please **DO NOT** complete the questionnaire.

PLEASE RETURN THE COMPLETED SURVEY IN THE ATTACHED ENVELOPE BY JUNE 30.

1. What is the zip code of the primary residence of the person with the developmental disability?

WRITE ZIP CODE HERE

--	--	--	--	--

2. What is your relationship to the person with the developmental disability? *(Check one item below)*

Self Parent Other family member Foster parent Caregiver Staff member Other

3. How old is the person with a developmental disability?

WRITE AGE HERE

--

4. Where does the person with a developmental disability usually live? *(Check one item below)*

<input type="checkbox"/> Family home (no support)	<input type="checkbox"/> Home/apartment (no support)	<input type="checkbox"/> Group home
<input type="checkbox"/> Family Home (with support)	<input type="checkbox"/> Home/apartment (with support)	<input type="checkbox"/> Specialized institution
<input type="checkbox"/> Nursing facility	<input type="checkbox"/> Foster home	<input type="checkbox"/> Other _____

5. Was your/the person's disability identified before the age of 22-yrs? Yes No

6. IF YOU/THE PERSON WITH A DEVELOPMENTAL DISABILITY IS UNDER AGE 22,
do you expect him/her to need any of the following supports after age 21: supported living, residential services, employment assistance, continuing education, transportation, assistive technology, or other special services?

Yes No Don't know

7. Please tell us a little bit about your/ the individual's support needs.

Check the box that best represents your thoughts about the current need for support in each of these areas. Use these explanations to help you decide

- 1 = Independent** Person requires no direct assistance. May require occasional support or adaptations. No special staff or personal assistance is required on a regular basis.
- 2 = Moderate support** Person needs some assistance or support to complete basic life or work activities and assure health and safety.
- 3 = Direct assistance or supervision** Person usually requires direct and ongoing assistance and training to complete basic life or work activities and assure personal health and safety.
- 4 = Comprehensive support** Person always requires staff support, supervision, or training to complete most activities. Safety or health is jeopardized without the immediate presence of staff or family members.

	N/A	1	2	3	4
Self Care: eating, dressing, personal hygiene, bathing, taking medicines	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Communication: speaking, understanding conversation, answering questions, writing messages	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Learning: counting money, reading, recalling information, acquiring new skills, understanding TV shows	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Mobility: moving around, using stairs, getting in/out of bed, entering or exiting buildings	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Independent Living: shopping, housekeeping, leisure time activities, use of public transportation	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Self Direction: making decisions, staying safe, making friends, managing finances	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Employment: performing tasks required for regular and ongoing employment	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Health and medical care: monitoring and managing chronic medical conditions, use of prescription medication, specialized treatments	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP
Behavioral health/control: behavioral issues that jeopardize self or others and corresponding treatment and monitoring	<input type="checkbox"/> doesn't apply	<input type="checkbox"/> IND	<input type="checkbox"/> MOD	<input type="checkbox"/> DIR	<input type="checkbox"/> COMP

8. Please check all the disability diagnoses or classifications that apply to you/the person:

- | | | |
|---|--|--|
| <input type="checkbox"/> Acquired Brain Injury | <input type="checkbox"/> Hearing Impairment | <input type="checkbox"/> Social/Emotional Disorder |
| <input type="checkbox"/> Attention Deficit Disorder | <input type="checkbox"/> Learning Disability | <input type="checkbox"/> Speech impairment |
| <input type="checkbox"/> Autism Spectrum Disorder | <input type="checkbox"/> Mental Retardation | <input type="checkbox"/> Spina Bifida |
| <input type="checkbox"/> Asperger Syndrome | <input type="checkbox"/> Muscular dystrophy | <input type="checkbox"/> Tourette's Disorder |
| <input type="checkbox"/> Cerebral Palsy | <input type="checkbox"/> Neurological Impairment | <input type="checkbox"/> Visual Impairment |
| <input type="checkbox"/> Epilepsy | <input type="checkbox"/> Orthopedic impairment | <input type="checkbox"/> Other: _____ |
| <input type="checkbox"/> Health impairment/ chronic illness | <input type="checkbox"/> PDD | |
| | <input type="checkbox"/> Rett's Disorder | |

9. For each of the services listed in the left column, check the box that indicates your current need for each of the supports and services. Be aware that you may not currently need a service because of your age group or circumstances. If that is the case, simply check “No need”. Next, if you are currently receiving the service listed, check the box that tells the extent to which it is meeting your needs. If you are not currently receiving the service, leave the answers under the second heading blank.

SERVICE/SUPPORT	To what extent do you need the service or support listed to the left?				If you are receiving the service, to what extent is it meeting your needs?			
	No Need	Little Need	Mod Need	Great Need	Not at all	A little	Mod- Erate- ly	Com- plete- ly
SERVICES AND SUPPORTS TO THE INDIVIDUAL WITH THE DISABILITY								
Assessment Services (specialized evaluations and assessments)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Assistive Technology (equipment, vehicle modifications, and adaptations)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Personal Assistant (employed by person to provide direct service/support)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Community Inclusion Services (assistance to access/participate in community activities)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Education (school-based education for all age groups)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Life Skills Training (education and training in basic life skills)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Case Management or Service Coordination (assistance with locating and securing benefits/programs)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Financial (Cash) Subsidy (payments from govt agencies directly to individual)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Welfare Services (provide temporary housing, food, clothing)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Housing Assistance (subsidy, financing, modification, locator services)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Residential Support in Home (independent living support or support in family home)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Placement in a Residential Program (includes residential school, group home, etc.)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Transition Support: School to Work (assistance moving from high school to employment)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Job Placement/Job Training (assistance with finding a job and learning to do a job)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
On-the-job Support (assistance on current job from support provider agency)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp

Day Program (specialized day program that does not have job focus)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Transportation Services (individualized and adapted transportation)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Legal Services (consultation and legal representation)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
SERVICE/SUPPORT	To what extent do you need the service or support listed to the left?				If you are receiving the service, to what extent is it meeting your needs?			
	No Need	Little Need	Mod Need	Great Need	Not at all	A little	Mod- Erate- ly	Com- plete ly
Medical and Health Care (direct service health care and/or funding or subsidy)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Mental Health Care (direct mental health care and/or funding or subsidy)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Social Skills Training/Behavior Management (specialized behavior and social skills training services)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Recreation Services (supports or services for leisure and recreation activities)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
SERVICES AND SUPPORTS TO INDIVIDUAL'S FAMILY								
Family/Caregiver Education and Training (special information or training for parents or caregivers)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Family Counseling or Support Group (counseling services or parent/peer networks)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Respite care : out of home (overnight or weekend care at a center or program)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Respite care: in-home (in-home caregiver to provide temporary relief/assistance)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp
Funding to purchase support services for family (direct funds to family for purchase of necessary services/equipment)	<input type="checkbox"/> No	<input type="checkbox"/> Little	<input type="checkbox"/> Mod	<input type="checkbox"/> Great	<input type="checkbox"/> No	<input type="checkbox"/> little	<input type="checkbox"/> Mod	<input type="checkbox"/> Comp

10. Are you currently paying 'out of pocket' for your own services? Yes In Part No

If YES, which services are you paying for? (check all that apply)

- | | | |
|---|--|---|
| <input type="checkbox"/> Assistive Technology | <input type="checkbox"/> Case Management | <input type="checkbox"/> Transportation |
| <input type="checkbox"/> Personal Assistant | <input type="checkbox"/> Residential Support | <input type="checkbox"/> Medical/Mental Health Care |
| <input type="checkbox"/> Education and Training | <input type="checkbox"/> Job Support | Other: _____ |

These last questions are about your experiences with the service system and in your own community.

11. Do you have enough information and support to understand, plan, and secure services that you need?	<input type="checkbox"/> Always <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely
12. Do you control which services you receive and choose who delivers them?	<input type="checkbox"/> Always <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely
13. Do neighbors make you/the person with developmental disability feel welcome in your community?	<input type="checkbox"/> Always <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely

14. Do community groups and associations encourage you/person with developmental disability to participate in activities?	<input type="checkbox"/> Always <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely
15. Do friends help you/person with developmental disability participate in community activities?	<input type="checkbox"/> Always <input type="checkbox"/> Sometimes <input type="checkbox"/> Rarely

Thank you for your help! Please return this survey in the envelope we have provided.

Appendix D Focus group materials

Focus Group Session agenda

We have set aside two hours for the focus group meetings, but only 1.5 hours will be allotted to discussion. The following session agenda reflects a meeting that begins at 6:30 and wraps up at 8:30.

Time	Task	Notes
6:30 – 6:45 (15 minutes)	<ul style="list-style-type: none"> • Greet participants. • Help them get settled and give them a chance to get some food. • Get them started on completing information sheet. • Provide assistance to fill out info sheet as needed. 	
6:45 – 6:50 (5 minutes)	<ul style="list-style-type: none"> • Formal welcome • Overview agenda and background • Ground rules for focus group discussion 	Share the agenda, a short background on the commission, and ground rules. Keep ground rules to a minimum – perhaps three. (See tips for facilitators for suggestions)
6:50 – 7:00 (10 minutes)	<ul style="list-style-type: none"> • Have participants introduce themselves and provide their answer to the introductory question: “What is your most pressing service or support need?” 	Try to allot no more than one minute for each participant for his or her introduction. Reassure them that we will talk in more detail about their service needs.
7:00 – 8:00 (60 minutes)	<ul style="list-style-type: none"> • Focus participants on the key questions of the focus group discussion: • What are services and supports do you currently need? • To what degree are you receiving or accessing those services? • To what degree are you finding and paying for your own services and supports? • What do you think are the barriers to your being able to access or receive the services and supports you need? • What would be the best way to 	Use your judgment to work the group through the questions, suggesting but not pushing topics and probing for detailed information.

	organize, coordinate, and deliver the services you need?	
8:00 – 8:15 (15 minutes)	<ul style="list-style-type: none"> • Focus participant on the ending question: What is the most important idea shared tonight that you want to make sure gets communicated to the legislature? • Go around the table and ask each person to answer. 	
8:15 – 8:20 (5 minutes)	<ul style="list-style-type: none"> • Thank everyone for coming • Provide information on what will happen next 	
8:20 – 8:30	<ul style="list-style-type: none"> • Farewell to participants • Clean up 	
8:30	<ul style="list-style-type: none"> • Debrief with session coordinator • Go home. 	

Information we are looking for and how to get it...

The key questions get at the information we are looking for. For each of the questions there is specific information we would like to have. As the facilitator you will need to gauge the responses of the group and determine what probing questions would make sense.

What are services and supports do you currently need?

Here we are interested in what services and supports people feel they need. Depending on the group, this list could vary considerably. Rather than big 'laundry lists', we would like to see what a person or a family feels they need and to try to understand how they feel they would benefit from receiving that service. You may suggest a service or support that the group seems to be missing to see what the response is, but do not 'push' a particular service on the group. You may want to note any services that the group seems to be totally unaware of.

Here is a list of possible services and supports that people may need. You may suggest service headings from the list – "what about.....?" - if you feel this would help the participants think about their needs.

Assessment Services
Assistive Technology
Personal Assistant/Aide

Community Inclusion
Services
Education Program
Life Skills Training

Case Management or
Service Coordination

Financial (Cash) Subsidy
for person with the
disability
Welfare Services
Housing Assistance
Residential Support
Transition Support
Job Training and
Assistance

Job Placement Support
Day Program
Transportation Services
Legal Services
Recreation Services
Social and Behavioral
Skills Training and
Management
Mental Health Care

Medical and Health Care
Respite care overnight
Family/Caregiver
Education and Training
Family Counseling or
Support Group

To what degree are you receiving or accessing those services?

To what degree are you finding and paying for your own services and supports?

We want to know what services people are actually receiving and how they are accessing those services. What are people's current experiences with the service system? We want to know the degree to which people are paying out of pocket and to what degree other sources (besides state funding) are funding services. We are also interested here in how people feel about sharing the cost of services with state funding agencies. Also, to what degree do people feel that paying for their own services is unreasonably depleting their personal resources?

What do you think are the barriers to your being able to access or receive the services and supports you need?

Why is it difficult for people to access services? What seems to get in the way?

What would be the best way to organize, coordinate, and deliver the services you need?

Use this question to get people to think more 'ideally'. How would participants want to see the services they need organized? Are they leaning toward a case management system, a self-managed system? What do they think of providing grants to families who then coordinate and pay for their own services? What about service brokers? Many families and individuals may be unaware of some of the most innovative options, so you may want to be prepared to briefly explain a few options to find out what the group thinks?

Facilitator responsibilities

Before the meeting:

- Connect with the session coordinator to find out where the meeting is and who will be participating.
- Take some time to familiarize yourself with the questions, the time frame, and the tips for facilitators/moderators.

Day of the meeting:

- Arrive early.

- Is the room satisfactory (size, tables, chairs, comfort, sound)?
- Check background noise interference on tape; check to see that tape recorder is working properly
- Facilitate the focus group discussion according to the suggested timelines, using the questioning route provided.

Follow up:

- Debrief session with coordinator
- Prepare a written summary of key points as soon as possible after the meeting.
- Listen to tape at least once and capture key points from the dialogue. Note any points on the tape where especially compelling anecdotes are recorded. These will be transcribed later.
- Submit notes and tapes to your session coordinator.

Coordinator responsibilities

Each focus group session is being coordinated by a member of the Individual and Families Services and Supports Committee. The coordinator will be responsible for many of the logistics of the focus group session. Here is the list of coordinator responsibilities for during and after the meeting. Any help and support you can offer the coordinator is most helpful, but keep in mind that your primary responsibility as facilitator is to run the group discussion effectively.

Coordinator responsibilities during the meeting:

- Bringing and setting up equipment (tape recorder, tape, extension cord) and supplies (participant handouts, name tags or name tents, markers, food, napkins, plates, cups, straws).
- Setting up room and refreshments
- Setting up tape recorder and making sure it works
- Greeting participants as they arrive
- Establishing a place for the coordinator to sit outside of the discussion group
- Note taking during the meeting – specifically note important ideas, compelling stories to listen for on the tape, and non-verbal reactions of participants
- Monitoring recording equipment to make sure it is running and to turn the tape over when it's needed
- Reminding the facilitator when there is a half-hour to go, ten minutes to go, and when time is up.
- Thanking the participants as they leave

Coordinators do not participate in the focus group discussion, but listen attentively and watch to make sure that all participants are comfortable. Coordinators are at the meeting to assist you and to assist the participants.

Coordinator responsibilities after the meeting:

Once the focus group has been conducted, there are only a few things left for the coordinator to do:

- Debrief with facilitator: chat with the facilitator for a few minutes, going over how the meeting went and noting any important ideas.
- Thank you letters: send thank you notes to the meeting sponsor and the participants
- Assemble the Focus Group Meeting Packet and return it to Marijke. The meeting packet should include: Focus Group Session Worksheet, Participant Information Sheets and questionnaires, tapes, coordinator notes from the meeting, facilitator notes from the meeting
- Feedback on analysis: Once the session has been written up, it will be helpful if the coordinator can review and comment on the notes.

Tips for facilitators

Please review the chapter from Focus Groups (3rd Edition) called “Moderating Skills”. The chapter lists many great suggestions for focus group facilitators. Some highlights include:

- Diverse groups: Focus groups will be held for individuals with developmental disabilities, family members of individuals who are under 21 years of age, and family members of individuals who are over 21 years of age. Responses from the various groups may be very different. The group facilitator needs to get a quick impression of the group and then direct the discussion in ways that will be most beneficial in obtaining the most extensive and specific information from that group.
- Ground rules: Many people have not participated in a focus group discussion before. In order to be successful our focus groups will need to provide an avenue for people to share personal information in a comfortable way. The ground rules should be set up to support this type of interaction. I would suggest using some of the following ground rules, but keep the list to a minimum – three or four rules.
 - Be as comfortable as you can be – make it safe for others to share.
 - Respect ideas
 - Avoid making judgments
 - It’s okay to share your view even if it is different from someone else’s.
 - Share the floor – give everyone a chance to participate.
 - Share personal experiences.

Feel free to create your own ground rules.

- The questioning route: Follow the questioning route as you think will best work for the group. The route has been constructed to make sense in terms of sequence. You may find it helpful to move past a question if there doesn’t seem to be much of a response and to revisit it later in the discussion. Time limitations will make this challenging but not impossible. For example, the question about who funds the services may make more sense when talking about the delivery system later in the discussion.
- Balance participation: Use strategies that will help balance participation from the group. If one or two people seem to be dominating an ‘open’ discussion, move to a strategy of ‘going

around the table'. Learn participants' names quickly so you can ask people by name to respond.

- Making people feel comfortable: The most important task for the facilitator is making people feel comfortable enough with you and with the group to share important and personal information. Create a warm, friendly, comfortable environment.
- Eliciting responses: Do not take notes during the group, but devote your full attention to listening and encouraging responses. Keep your own sharing to a minimum and resist the temptation to 'agree' with specific responses. You can say 'yes' or 'I understand', but avoid 'that's good', 'I agree', or "right" as responses. Honor and acknowledge all responses. Make sure that participants know that they do not need to agree with each other and that each has some similar but also many different life experiences.
- Keeping the flow going: When you ask a question in a group, remember that people will need some 'think' time before they respond. Generally, responses from a group to a particular question will start slow, build, peak, and then fall off. Try to gauge when the responses begin to fall off so you are ready to move on to the next question.
- The pause: Use the five-second pause to wait for more responses before you reiterate a question or ask a new one. Reflection time is important and essential for some people. It is okay to give people a few moments to collect their thoughts before the discussion begins. If you find a few people dominating the discussion, this is a good way to prevent one person from always speaking first.
- The probe: Use probing questions to get more information and more detail. Here are a number of probing questions you might use:
 - Would you explain further?
 - Would you give me an example of what you mean?
 - Would you say more?
 - Tell us more.
 - Is there anything else?
 - Say more.

Appendix E

Cities and towns from which surveys were returned

Andover	East Haddam	Ledyard	Norwich	Stratford
Ansonia	East Hampton	Litchfield	Old Saybrook	Suffield
Avon	East Hartford	Lyme	Orange	Tolland
Barkhamsted	East Lyme	Madison	Oxford	Torrington
Beacon Falls	East Windsor	Manchester	Plainfield	Trumbull
Berlin	Eastford	Mansfield	Plainville	Vernon
Bethel	Easton	Meriden	Plymouth	Voluntown
Bethlehem	Enfield	Middlebury	Pomfret	Wallingford
Bloomfield	Essex	Middlefield	Portland	Washington
Branford	Fairfield	Middletown	Preston	Waterbury
Bridgeport	Farmington	Milford	Prospect	Waterford
Bridgewater	Glastonbury	Monroe	Redding	Watertown
Bristol	Goshen	Naugatuck	Ridgefield	West Hartford
Brookfield	Granby	New Britain	Rocky Hill	West Haven
Canaan	Greenwich	New Canaan	Salem	Westbrook
Canton	Griswold	New Hartford	Salisbury	Weston
Cheshire	Groton	New Haven	Sharon	Westport
Clinton	Guilford	New London	Shelton	Wethersfield
Colchester	Haddam	New Milford	Simsbury	Wilton
Coventry	Hamden	Newington	South Windsor	Winchester
Cromwell	Hartford	Newtown	Southbury	Windsor
Danbury	Hebron	Norfolk	Southington	Windsor Locks
Darien	Kent	North Haven	Stafford	Wolcott
Derby	Killingly	North	Stamford	Woodbury
Durham	Lebanon	Stonington	Stonington	
		Norwalk		

Appendix F

Individual and Family Supports and Services Committee Conclusions and Recommendations

November 15, 2001

Topic	Observations	Conclusions	Recommendations	Categories
Participants in survey and focus groups	Low representation of eastern part of the state, people from rural areas – we could not find people, we could not find services to connect us to people (from local level services and statewide networks)	People in eastern CT and people in rural areas are not being identified, are not being served, do not have access to services, people are not known. Statewide support groups aren't finding people in the rural areas, eastern regions.		
	<p>Observations about meeting the federal definition of developmental disabilities</p> <ul style="list-style-type: none"> • 15% did not meet the by 22 diagnosis; don't know when the condition manifested in those 15% • in terms of diagnoses.... Lots of diagnoses that don't traditionally get classified as DD 	There are many people who do not meet the federal definition by the book, but have disabilities and have service and supports needs.	Recommendation is that we not use the diagnoses and age cut off as a way of determining whether or not someone is eligible.	Access
	Many participants had multiple diagnoses that resulted in them not fitting in to any distinct service agency.	People are shifted around based on distinct diagnoses but the one diagnosis/one agency mentality doesn't work. People have multiple diagnoses that result in their being eligible or ineligible for services from specific agencies and many of these people experience being shifted from agency to agency.	Recommendation is to have a central entry point that people can access regardless of diagnosis.	Access

Topic	Observations	Conclusions	Recommendations	Categories
	<p>We don't have real demographic data on survey participants.</p> <p>Ethnic group representation among focus group participants was good. Questions still remain about whether or not the needs of ethnic groups are significantly different.</p>			
Service and Support Needs	<p>Even the lowest priority service is still needed extensively by a number of people.</p> <p>For those under 18, education is the 'hub' for services for kids. Many of those services are extensively needed by large numbers of kids. There is a lot of concern about what is and is not happening at the education level. Inconsistencies across LEA's mean that where you live determines what you get.</p> <p>Many of the priority needs for those under 18 do not fall under the purview of education— respite, in-home support, family counseling, family subsidies. Families report that there is no place to go for these. The family support system is nonexistent.</p>	<p>Service needs and service configurations are largely individual. Many services that may not be needed by a large number of people are still critical for a small number of people. Survey results should not be used to make a conclusion that some services are not needed.</p> <p>Education has to be a key player. There are questions about whether education's role should be expanded or whether a "third party" should be developed. In all likelihood, education cannot do it alone.</p> <p>No agency has services and supports to kids with disabilities and their families as part of its mission.</p>	<p>Individualized service planning is essential in the revised system.</p> <p>There must be a major review of the system for children with developmental disabilities and their families to develop partnerships, services, and system.</p>	<p>Services and supports</p> <p>Services and supports</p>

Topic	Observations	Conclusions	Recommendations	Categories
	<p>The needs for the Under 18 group are a blend of child supports and family supports. For the Over 18 group, the needs are much more focused on the individual.</p> <p>Over 18: Physical and material well-being are the key concerns for adults. Many of the priority services for adults are primarily contributing to physical and material well-being – medical care, transportation, job training, etc.</p> <p>Need for case management is consistent across age groups.</p> <p>Transition group (18-24 years) has the highest level of needs. This transition period is characterized by a lack of coordination between education and adult system, no case management, anxiety for individuals and families, poor planning, questionable accountability.</p>	<p>A parallel issue to the under 18 group – BRS is the key player for adult services but most needs on the list don't fall under the purview of BRS. Who will pick up the slack?</p> <p>Case management is key to planning and accessing services. This is a missing piece of the system and is critical for coordination of the services.</p> <p>The transition from school to adult life is a critical time for young people with developmental disabilities. In general, the system is not working here.</p> <p>Our findings are similar to the findings of several other groups Children's services task force, CT initiatives, CT Family support council, OSEP self-assessment (particularly transition), Olmstead Plan</p>	<p>Recommendation is that service development must involve more comprehensive thinking about the range of needs, not just focused on vocational needs. The coordination of the variety of services people need is very important.</p> <p>Case management/service coordination must be a key component of whatever system we design.</p> <p>Focus efforts on major improvements and redesign of the service system around young people in transition.</p>	<p>Services and supports</p> <p>Services and supports</p> <p>Services and supports</p>

Topic	Observations	Conclusions	Recommendations	Categories
<p>Current experiences in the service system</p>	<p>The number of people who need a service is consistently higher than the number of people who are receiving the service. Many services that people are receiving are simply not meeting people’s needs.</p> <p>In terms of services meeting needs, family services and supports are the least effective, receiving the lowest scores in response to the question “To what degree is the service meeting your needs?”</p> <p>Individuals and their families are paying for services – nearly 80% in all age groups. No real differences between kids and adults. Most of those people are paying for medical and mental health care in both kids and adult groups Transportation is being paid for by 34% of adults. 30% of families of kids are paying for education. These services might include supplemental education, tutoring, speech, OT, summer programs</p>	<p>The survey and focus groups strongly support the notion that people with developmental disabilities are un-served and under-served.</p> <p>Family supports and services are underdeveloped and often non-existent.</p> <p>Families are actively providing financial support whether they want to or not. Families and individuals are currently paying for a number of their services or supplementing their service plans with self-purchased services and supports. The ability and willingness of families and individuals to pay for services varies from family to family. Some families pay because they have no choice but truly are not able to do so, other families are able to pay and do so willingly. Still more families cannot pay for services and so their family members go without needed services.</p> <p>A number of issues related to people purchasing their own services: Economic issues, service availability issues (case management), systems won’t contract with individuals...</p> <p>The funding system lacks flexibility – both in terms of accessing funds, purchasing services.</p>	<p>“Fix the system!”</p> <p>Flexible funding</p> <p>Cross agency communication, information sharing</p> <p>When people come to an agency they leave with something – either a service plan, a referral,</p> <p>Funding and ability to purchase services should be part of the service planning discussion.</p>	<p>Funding</p> <p>Services and supports</p> <p>Funding Services and supports</p>

Topic	Observations	Conclusions	Recommendations	Categories
	<p>The problem/issue of employment is woven throughout the data.</p>	<p>Employment is a real problem for people with developmental disabilities – unemployment, under employment, transportation, job training, job supports, job searching/placement, short term services with minimal employment as the goal, public attitudes, discrimination, earnings put benefits at risk, lack of ongoing services, The unemployment rate of people with disabilities is rising despite many efforts. BRS mandates and priorities don't serve the needs of the people, BRS appears to be under funded to serve the number of people who need services</p> <p>The bureaucratic maze</p>	<p>The whole notion of employment of people with disabilities needs to be revisited. We need a public policy shift with all levels of government highly involved.</p> <p>All efforts must have major representation of individuals with disabilities (family members, teens, adults) to help revise the system. Leadership roles for individuals with disabilities...</p>	
<p>Improving the service system</p>		<p>We support and advance the conclusions and recommendations made by the focus groups....</p>	<p><u>A system that is easier to navigate in</u></p> <p>Entry process that includes appeals process</p> <p>Birth-to-three is a good model - personal, in-home, service coordination, family focused, entitlement</p> <p>“One stop shopping”</p> <ul style="list-style-type: none"> • Central location to make information readily available 	

Topic	Observations	Conclusions	Recommendations	Categories
			<ul style="list-style-type: none"> • Case manager/service broker who can assess, determine eligibility, advocate, develop service plan, secure services, problem solve • Local access <p>Flexible funding</p> <ul style="list-style-type: none"> • Voucher/credit card to pay for services and equipment maintenance • Sliding scales and individual/family contributions • Flexible income caps based on individual assessment <ul style="list-style-type: none"> • Statewide database available to all state agencies with individual and service information • People with developmental disabilities have real input and real power at the policy level • Working transportation system regulated at state level • Eligibility based on functional needs • Assisted living, in-home supports, respite • Individualized service plan developed from a ‘menu’ of services • Major improvements to PCA system • Workers in the field take a customer service mentality - responsiveness and respect • A “Husky” type healthcare plan for adults to improve coverage • Sufficient, knowledgeable medical 	

Topic	Observations	Conclusions	Recommendations	Categories
			care <ul style="list-style-type: none"> • Public awareness, understanding 	