

• *Report of the*
• DEVELOPMENTAL DISABILITIES TASK FORCE
• **Fulfilling the Promise**
• JUNE 30, 2007

Executive Summary

Tennesseans with developmental disabilities who live among us as neighbors, friends, relatives, and acquaintances are overlooked and neglected by our state system of programs and services for people with disabilities. The programs and services available to them are virtually nonexistent when compared to the broad array of home and community-based service options offered to people with other types of disabilities. In Tennessee, it matters when you acquire your disability and, even more critically, what your disability is called. There is an entire department of state government that administers mental health programs and services for people with mental illness. There are extensive home and community-based services for people with mental retardation. However, there are practically no dollars available to provide long-term care services for Tennesseans who have cerebral palsy, autism, spina bifida, or other developmental disabilities.

Living with developmental disabilities creates a significant impact on Tennesseans and their families. Parenting a child with a disability presents a number of challenges. Many children with developmental disabilities require constant supervision, either for health or safety reasons. Many times parents are forced to quit working in order to care for their children. Families often have to deal with disruptive behavior or bulky equipment that make going out into the community difficult, which isolates the family and the child. Parents must spend a great deal of time and energy trying to secure the proper care and appropriate educational services for their child, sometimes leaving their other children feeling neglected. Another effect on the family is the high cost of health care, therapy, specialized equipment and care-giving. As a result, these families face a higher risk of poverty, and parents have a higher risk of health-care problems than do parents of typically developing children. Providing appropriate home and community based services will assist these families in ensuring the stability of their home.

Adult Tennesseans with developmental disabilities often are faced with the choice to either continue to live at home with their aging parents who provide their care or enter a nursing home. For persons with developmental disabilities, getting a job or attending college is often extremely difficult. With services, training, and today's technology, most people with developmental disabilities could join the Tennessee work force, buy a home, pay taxes, and assume vital roles in our communities.

Families of persons with developmental disabilities other than mental retardation have been waiting for services for many years. The Tennessee legislature, in revising Title 33 of Tennessee Code Annotated in 2000, recognized the need for services for children and adults with developmental disabilities other than

Developmental disabilities take many forms, from mild to extreme. They include cerebral palsy, mental retardation, autism, spina bifida, head and spinal cord injuries and other conditions occurring at birth or during the developmental period. Some people with developmental disabilities require assistance with all activities of daily living, including eating, dressing, bathing, and all self-care related activities.

Above 70 IQ, Beyond Help?

Our daughter Morgan developed normally until 2 years of age, and then began regressing and was diagnosed with autism spectrum disorder at the age of 3½ years. Morgan is now in a life skills class at her middle school. She has had speech therapy, occupational therapy, and behavioral therapy through the public school system and private sources to help her on her journey to independence. Her lack of communication skills has created a wall between her and the independence we hope to see for her some day.

At home, our days consist of endless prompting to help Morgan transition. From waking and getting out of bed—going to the bathroom—eating breakfast—planned activities—lunch and more planned activities—bathroom reminders—dinner—evening routines—then bathing and getting ready for bed. All of this requires assistance that can range from verbal or visual prompting to hand-over-hand help.

She will turn 14 in November 2007. As we look to the future, there are many unanswered questions on how we will continue to meet her needs. Two years ago, we were told to apply for the Medicaid Waiver, because Morgan would need to be in line to get services once they were no longer available through the school system. We called and set up an interview. When the lady came, she saw that Morgan had to be prompted to do activities because she initiates very little on her own. She was also unable to verbally communicate basic information, and was unresponsive to the lady. But when the lady learned that Morgan has an IQ above 70 (does not have mental retardation), she told us that Morgan does not qualify for the Medicaid Waiver.

Morgan needs just as much support as people with mental retardation, but because her disability is the “wrong” type, we are not eligible for those services.

Rudy and Tammy, parents of Morgan

mental retardation and made them eligible for services, effective March 2002. However, in the time since Tennessee’s laws were changed, no funding has been allocated for these persons, the existing programs for persons with mental retardation have not been expanded to include persons with developmental disabilities, nor have comparable programs been developed. Substantial funding from the federal government is available to provide services to people with developmental disabilities, but while Tennessee takes advantage of this federal funding for people with mental retardation, the state does not currently access this federal funding for persons with developmental disabilities. People with developmental disabilities and their families have been waiting for five years for the changes in Title 33 to bear fruit and to enable them to receive services they need in their homes and communities. It is now time to fulfill the promise.

To address this issue, a bill was introduced in the Tennessee General Assembly in January 2006. The legislation was passed unanimously, signed by Governor Phil Bredesen in May 2006 and became Public Chapter 604 and later Tennessee Code Annotated 33-5-212. This legislation created a Developmental Disabilities Task Force charged with studying these issues and developing a plan. The Division of Mental Retardation Services was assigned the responsibility to present the Task Force's report to the House & Senate Government Operations Committees in January 2008.

The Division of Mental Retardation Services established the Task Force in July 2006. The Task Force members represent a broad cross-section of Tennesseans, and include persons with developmental disabilities, family members of persons with developmental disabilities, community service providers, advocacy organizations that represent people with all types of disabilities, and representatives of relevant state agencies, which are the Department of Mental Health & Developmental Disabilities, Tennessee Council on Developmental Disabilities, Division of Special Education in the Department of Education, Bureau of TennCare, Commission on Aging & Disability, and the Division of Rehabilitation Services in the Department of Human Services. A list of Task Force members is found in the appendix.

Recommendations

After a year of research, discussion, and planning, the Developmental Disabilities Task Force produced its recommendations. The members of the Task Force understand that the development of new services is an ongoing process. Therefore, the recommendations call for services to be phased in.

Public Chapter 604 required:

- > A developmental disabilities **task force** to be established by the Division of Mental Retardation Services, which would include the participation of relevant state agencies and offices;
- > A **statewide needs assessment** to be conducted, focusing on the needs of persons with a developmental disability other than mental retardation for whom comprehensive home and community-based services do not exist;
- > An **assessment of the capacity** of the service system in Tennessee to serve individuals with developmental disabilities other than mental retardation;
- > The development of a **plan to provide cost-effective home and community-based services** for Tennesseans with developmental disabilities other than mental retardation;
- > The completion of the assessment and the development of the plan by June 30, 2007.

- Thank goodness someone has finally
- realized that there are people with
- developmental disabilities other than
- mental retardation and that these people
- need LOTS of help.
- *Comment from the Needs Assessment*

Recommendation 1: The State of Tennessee should provide an array of home and community-based services to persons with developmental disabilities, consisting of the development of a

Medicaid Waiver program and a Personal Support program and the expansion of the Family Support program.

Funding Request – State Appropriations

PROGRAM	YEAR 1 (FY 2009)	YEAR 2 (FY 2010)
Medicaid Waiver	(no funds in Year 1)*	\$2,000,000*
Family Support	\$1,000,000	\$1,000,000
Personal Support Program	\$1,350,000	(no new funds)
Information & Referral and Intake	(no funds in Year 1)	\$1,140,000
TOTAL	\$2,350,000	\$4,140,000

*A major advantage of a Medicaid Waiver is the federal funding available. According to the Federal Register, November 30, 2006, Tennessee’s Federal Medical Assistance Percentages (match rate) for Medicaid programs will be 63.71% federal and 36.29% state for FY 2008. Medicaid Waiver funds would not be available during Year 1 due to the time that is needed to develop and submit the federal application. The Task Force is not aware of the FY 2009 match rate but assumes it will be similar to that for FY 2008.

Recommendation 2: TennCare eligibility criteria for Medicaid Waiver home and community-based services should include persons who have developmental disabilities.

Recommendation 3: Applicants for services who do not have mental retardation should not be required to undergo intelligence testing in order for eligibility to be determined.

Recommendation 4: Responsibility for administering services for persons with developmental disabilities should be assigned to the Division of Mental Retardation Services in the Department of Finance & Administration.

Recommendation 5: Information and referral and access to the system should be easy, flexible, competent, consistent and timely.

Recommendation 6: Persons with developmental disabilities should be provided the opportunity and support to self-direct their services.

How does the definition of Mental Retardation differ from Developmental Disability?

- > Both mental retardation and developmental disability occur before the onset of adulthood (before age 18 for mental retardation and before age 22 for other types of developmental disability).
- > Both mental retardation and developmental disability are defined by substantial limitations in adaptive behavior.
- > To be classified as having mental retardation, however, a person must have a significant intellectual disability, with an IQ of 70 or below.
- > Many people with a developmental disability do not have mental retardation even though they have substantial limitations in adaptive behavior and need similar home and community-based services.

Recommendation 7: An adequate provider network for developmental disabilities services should be developed.

Recommendation 8: Strategies to expand the supply of skilled direct support professionals should be developed and implemented.

Recommendation 9: The Division of Mental Retardation Services' quality management system should be reviewed and expanded as needed to ensure it is responsive to services developed for persons with developmental disabilities.

Recommendation 10: The Division of Mental Retardation Services should establish an ongoing planning process to guide the development and evaluation of home and community-based services for people with developmental disabilities.

When Tennessee's General Assembly approved Title 33 revisions to include people with developmental disabilities other than mental retardation, many Tennesseans with developmental disabilities and their families believed that funding and needed services would soon follow, that the administration and the legislature had made a promise to help provide the care that was previously unavailable. Seven years later, Tennessee has not met this legislative intent of Title 33. The Developmental Disabilities Task Force urges the executive and legislative branches of Tennessee government to join together to address the needs of Tennesseans with developmental disabilities. **Now is the time for the State of Tennessee to fulfill the promise!**

Tennesseans with Developmental Disabilities

People who have autism, cerebral palsy, spina bifida, various genetic, neurological and chromosomal disorders, or head or spinal cord injury sustained early in life are considered to have developmental disabilities. Mental retardation¹ is also considered to be a developmental disability. People with developmental disabilities, regardless of the cause, require assistance and support in order to participate in typical activities of daily life.

Definition of Developmental Disability in Tennessee Law From Title 33, Tennessee Code Annotated

“Developmental disability” means a condition based on having either a severe chronic disability or mental retardation;

“Severe, chronic disability” in a person over five years of age means a condition that:

- (A) Is attributable to a mental or physical impairment or combination of mental and physical impairments;
- (B) Is manifested before age twenty-two (22);
- (C) Is likely to continue indefinitely;
- (D) Results in substantial functional limitations in three or more of the following major life activities:
 - (i) Self-care;
 - (ii) Receptive and expressive language;
 - (iii) Learning;
 - (iv) Mobility;
 - (v) Self-direction;
 - (vi) Capacity for independent living; and
 - (vii) Economic self-sufficiency; and
- (E) Reflects the person’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is likely to continue indefinitely and to need to be individually planned and coordinated.

“Severe, chronic disability” in a person up to five years of age means a condition of substantial developmental delay or specific congenital or acquired conditions with a high probability of resulting in developmental disability as defined for persons over five years of age if services and supports are not provided;

“Mental retardation” means substantial limitations in functioning:

- (A) As shown by significantly sub-average intellectual functioning that exists concurrently with related limitations in two or more of the following adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work; and
- (B) That are manifested before age eighteen (18).

¹ On a national level, the term “mental retardation” is increasingly being replaced by the term “intellectual disability.” Although the Developmental Disabilities Task Force supports the use of “intellectual disability,” this report will use “mental retardation,” since state laws and rules use that terminology.

Defining Developmental Disabilities

The term developmental disabilities is defined both in federal and state law. In federal law, the definition is written as a functional definition, that is, the definition considers the level of functional needs of an person rather than the diagnosis or condition that resulted in the developmental disability. In 2000, Tennessee laws adopted the functional definition of the federal government but, in addition, identified mental retardation as a specific type of developmental disability.

Estimates

Identifying the number of Tennesseans who meet this definition of developmental disabilities other than mental retardation is challenging. Studies indicate that people with developmental disabilities comprise between 1.2 and 1.65 percent of the United States population (federal Developmental Disabilities Act). Approximately 1% of the US population is estimated to have mental retardation, leaving 0.2%–0.65% having developmental disabilities other than mental retardation. From this, it can be projected that between 12,078 and 39,252 Tennesseans have developmental disabilities other than mental retardation. Determining the number of people who may need home and community-based services is even more difficult. This lack of data exists because no state agency is currently charged with keeping records regarding this population.

Assessment of Need

In an effort to obtain additional information about Tennesseans with developmental disabilities and their families, the Developmental Disabilities Task Force conducted a Tennessee Needs Assessment. The Task Force mailed out 3,600 surveys to persons with developmental disabilities other than mental retardation who are currently receiving Family Support² services as well as persons with developmental disabilities on the waiting list for the Family Support program. Through collaboration with the Vanderbilt Kennedy Center University Center for Excellence in Developmental Disabilities, an online version of the survey was also developed. Information about the online survey was sent to approximately 80 agencies that provide services to persons with disabilities in Tennessee with a request that they notify their stakeholders of the opportunity to participate in the Needs Assessment.

As of June 21, 2007, 1,159 valid responses to the Needs Assessment were received and the data analyzed by a Vanderbilt Kennedy Center researcher.

² Family Support is a small, state funded program, administered by the Division of Mental Retardation Services, that provides funding for limited assistance for people with all types of disability in their homes. This survey was limited to persons with developmental disabilities.

REPORT OF THE DEVELOPMENTAL DISABILITIES TASK FORCE

Geographic Diversity – Responses were received from persons living in 83 of Tennessee’s 95 counties. The counties with the highest number of persons responding were Shelby, Williamson, Davidson, Knox, Bradley, Rutherford, Hamilton, Putnam, Sumner, Washington, Wilson and Madison.

COUNTY	#	%	COUNTY	#	%	COUNTY	#	%
Anderson	7	.6	Hamblen	12	1.0	Montgomery	17	1.5
Bedford	10	.9	Hamilton	38	3.3	Morgan	2	.2
Benton	2	.2	Hancock	3	.3	Obion	12	1.0
Bledsoe	11	.9	Hardeman	1	.1	Overton	4	.3
Blount	13	1.1	Hardin	13	1.1	Polk	6	.5
Bradley	53	4.6	Hawkins	10	.9	Putnam	30	2.6
Campbell	1	.1	Haywood	1	.1	Rhea	1	.1
Cannon	2	.2	Henderson	7	.6	Roane	4	.3
Carroll	3	.3	Henry	5	.4	Robertson	8	.7
Carter	5	.4	Humphreys	5	.4	Rutherford	47	4.1
Cheatham	10	.9	Jackson	1	.1	Scott	3	.3
Claiborne	5	.4	Jefferson	1	.1	Sequatchie	3	.3
Clay	1	.1	Johnson	1	.1	Sevier	5	.4
Cocke	4	.3	Knox	61	5.3	Shelby	208	17.9
Coffee	7	.6	Lake	2	.2	Smith	5	.4
Crockett	1	.1	Lauderdale	6	.5	Stewart	1	.1
Cumberland	14	1.2	Lawrence	8	.7	Sullivan	8	.7
Davidson	72	6.2	Lincoln	3	.3	Sumner	30	2.6
DeKalb	9	.8	Loudon	2	.2	Tipton	13	1.1
Dickson	13	1.1	Macon	6	.5	Unicoi	4	.3
Dyer	9	.8	Madison	24	2.1	Warren	7	.6
Fayette	11	.9	Marion	6	.5	Washington	27	2.3
Fentress	4	.3	Marshall	5	.4	Wayne	3	.3
Franklin	7	.6	Maury	4	.3	Weakley	9	.8
Gibson	11	.9	McMinn	9	.8	White	3	.3
Giles	9	.8	McNairy	4	.3	Williamson	76	6.6
Greene	6	.5	Meigs	4	.3	Wilson	26	2.2
Grundy	4	.3	Monroe	3	.3	Other	48	4.1

TOTAL 1,159

FULFILLING THE PROMISE

Developmental Disabilities of Persons Participating in Needs Assessment

TYPE OF DEVELOPMENTAL DISABILITY	#	%
Cerebral Palsy	206	20.70
Autism	198	19.90
Neurological Impairment	102	10.25
Blind/Visual Impairment	82	8.24
Physical Impairment	91	9.15
Traumatic Brain Injury	75	7.54
Spina Bifida	46	4.62
Deaf/Hearing Impairment	36	3.62
Spinal Cord Injury	31	3.12
Health Impairment	37	3.72
ADD	23	2.31
Cystic Fibrosis	3	0.30
Epilepsy	6	0.60
Other	62	5.93
TOTAL	998 *	100%

* Type of developmental disability was not provided by 161 persons who responded to the survey. Percentages were calculated on the responses for this particular item.

Gender

GENDER	#	%
Male	658	57.3
Female	490	42.7
TOTAL	1,148 *	100.0%

* Gender was not provided by 11 persons who responded to the survey. Percentages were calculated on the responses for this item.

Age Distribution

AGE GROUP	#	%
0-2	33	2.9
3-5	81	7.0
6-17	340	29.6
18-21	217	18.9
22-39	324	28.2
40-59	135	11.7
60-79	20	1.7
TOTAL	1,150 *	100.0%

* Age group was not provided by nine persons who responded to the survey. Percentages were calculated on the responses for this particular item.

Ethnic Background

ETHNIC BACKGROUND	#	%
White non-Hispanic	867	76.7
Black/African-American	211	18.7
Prefer not to identify	17	1.5
Latino/Hispanic	13	1.1
Asian or Pacific Islander	12	1.1
Native American	11	1.0
TOTAL	1,131 *	100.0%

* Ethnic background was not provided by 28 persons who responded to the survey. Percentages were calculated on the responses for this item.

Living Situation – A great majority, 84.2%, of the respondents reported that they live either with their parents or with other family members. A cross tabulation between age group and living situation that included 968 respondents indicated that 524 of those 968 living with their parents or other family members are age 18 or above and 323 are age 22 or above.

The Needs Assessment did not request information regarding whether the living situation was due to preference or to the lack of another more valued option. In the Comments section of the Needs Assessment, people did report that they are living with their parents or other family members because they have no other choice.

Primary Caregiver – When asked to identify their primary caregiver, 68.7% of respondents reported that either their parents or other family members were their primary caregiver while 24.1% identified themselves as their own primary caregiver.

TennCare/Medicare – Of 1,159 persons responding, 670 or 57.8% reported that they are on TennCare and 163 or 14.1% reported that they receive Medicare.

Need Additional Services – Of the 1,127 persons who responded to the question about needing additional services, 858 or 76.1% said that they do need additional services while 269 persons or 23.9% reported they do not need additional services at this time. More information regarding the services that were identified as being needed will be provided in the section on Programs, Services and Funding.

Carol's Story

I live in Knoxville with my parents, Billy and Jean Smith. I'm 31 years old, and I have mixed cerebral palsy. When I was born, I had a breathing problem. I stopped breathing, and I got brain damage. At 16 months the doctor told my parents I had cerebral palsy. We were living about 50 miles from Knoxville, and my parents drove me to Knoxville three times a week for therapy.

Then I started in the school system and later a Least Restrictive Environment class. I did this to get in with the regular education students. But it wasn't what I wanted. I wanted to learn. Some people think if you have cerebral palsy that you can't learn.

Since I couldn't control my hands, I was told I would not be able to operate a power wheelchair. However, the University of Tennessee's Rehabilitation Engineering Program designed a head control that allowed me to operate my chair. This was my first experience with technology to make my life better. It was recommended that I get a computer to use at school. My parents kept insisting until the school finally got it. I used a head pointer to hit the keys.

FULFILLING THE PROMISE

My parents kept fighting to get me into regular classes. Then a miracle happened. The company Mom worked for closed, and she got her retirement fund. She then hired an attorney, and I got into the regular program. I worked hard to show them I could learn. I used a communication device, and it was my key to being successful in class. With help from the East Tennessee Technology Access Center (ETTAC) I took the same classes as everyone else. I felt like a real person in a real world. I graduated in 1998.

At this time we looked into finding me a personal assistant. There were no funds for that. I applied for the Medicaid Waiver program but was turned down because my IQ was above 70.

I went to college for two years, but then dropped out because I couldn't do math. I started doing public speaking and volunteering in hopes that a job would come along that I could do. When The Arc of Tennessee got the grant to do the People Talking to People project, I wrote up a resume just to see if I could. The guy who interviewed me said I did a great job. That's how I got my first job. I've been working for The Arc for three years. I'll never forget the feeling I had when I got my first paycheck.

Dad and Mom have always been here to help me. Mom has muscular dystrophy, but she never complains. Instead she and Dad take care of me. I'll never be able to repay them for the care they've given me. I worry what will happen to me when they can no longer care for me. That is a question I think of every day. I have fought all my life to overcome my disability only to be told by the TennCare doctor that maybe the best solution is to put me in a nursing home. I do not want to go to a nursing home. I want to stay in my own home. I ask you if it makes sense to pay hundreds of dollars per day for a nursing home when I can stay in my own home with a little help. I fail to see any wisdom in this at all. I don't want people feeling sorry for me. I'd like someone there to help people like me to get the things that we have to have to survive. I'm trying to help myself. I just want a level playing field to compete for my share of the American dream.

Programs, Services & Funding

Recommendation 1: The State of Tennessee should provide an array of home and community-based services to persons with developmental disabilities, consisting of the development of a Medicaid Waiver program and a Personal Support program and the expansion of the Family Support program.

People with developmental disabilities are, in some circumstances, able to access services available to eligible Tennessee residents (early intervention, special education, Medicaid, Vocational Rehabilitation, and housing programs). These are very beneficial programs for some Tennesseans with developmental disabilities, but these programs are not designed to provide the specific type of home and community-based services needed by most people with developmental disabilities.

- There seem to be hundreds of people
- employed by various agencies, churning out
- reams of materials and studies and PowerPoint
- presentations chock full of acronyms just so
- that they can tell me, “We don’t have any
- money, “ “We don’t have any services,” “Try this
- other department, division, service, whatever...”
- that turns out to be completely useless. I am
- thinking of changing my name to “Ryan that
- falls through the cracks” because that perfectly
- describes my situation.

Comment from Needs Assessment

The current array of home and community-based services available for Tennesseans with developmental disabilities is characterized by two vital gaps: 1) there are no targeted statewide long-term care programs to support children and adults with developmental disabilities in their homes and communities and 2) existing programs that provide limited home and community-based services to persons with developmental disabilities offer an insufficient level of services in many cases and are at full enrollment capacity.

Limited-service Home and Community-Based Programs

Three state-funded programs provide some level of services to a number of persons with disabilities. Financial and enrollment limitations prevent them from addressing the needs of many Tennesseans with developmental disabilities. None of these programs is specifically targeted to persons with developmental disabilities. These three programs are:

- > the **Personal Care Attendant Services** program administered by the Division of Rehabilitation Services in the Department of Human Services which serves only 14 persons and has a waiting list of 36 persons, and
- > the **Family Support** program and the PASS (**Personal Assistance Services and Supports**) project administered by the Division of Mental Retardation Services. Both programs are excellent models of how persons with disabilities in Tennessee can be supported to live in and participate in their communities. The PASS project only serves seven persons and no funding is available for expansion. The Family Support program provides funding for

support services to over 4,000 families across the state each year but had a waiting list of 5,371 persons at the end of March 2007.

Long-term Care Programs

Tennessee does offer one home and community-based long-term care program for which some people with developmental disabilities persons may be eligible. This Medicaid Waiver program, administered by the Commission on Aging & Disability, is only for people who need the level of care provided by a nursing home. Children or young persons with developmental disabilities who are under age 21 are not eligible for this program. In addition, many adults with developmental disabilities are not eligible since they do not need nursing home care.

Needed Services

In an effort to obtain meaningful information about the services needed by Tennesseans with developmental disabilities and their families, the Developmental Disabilities Task Force conducted a statewide Needs Assessment. The Task Force mailed out 3,600 surveys and established an online Web version of the survey. Approximately 80 disability agencies across the state were informed about the online survey and were asked to share it with their constituents. As of June 21, 2007, 1,159 valid responses were received.

Of the 1,127 persons who responded to the question about needing additional services, 858 (76.1%) indicated they need additional services. The Needs Assessment also asked persons with developmental disabilities and their families to identify the types of services they would require to support them in the community.

The following table represents the most commonly requested services needed to address the wide-ranging functional abilities and needs by persons with developmental disabilities. A service such as Information and Referral is common to persons with all types of developmental disabilities and is a basic component of any service delivery system. More specialized services, such as Personal Assistance, are very specific to persons with physical disabilities or who need assistance with adaptive behavior. It is important to recognize that an essential service may be needed by a relatively small number of people. Thus, services must be flexible in order to address individualized needs.

REPORT OF THE DEVELOPMENTAL DISABILITIES TASK FORCE

Needed Services³

SERVICE	PERSONS NEEDING	%
Information and Referral – someone to provide information about available services and how to apply for them	522	45.0%
Therapy – physical, occupational, or speech therapy	337	29.1%
Respite – services provided on a short-term basis to offer relief to unpaid family caregivers	308	26.6%
Assistive Technology (or Repair/Maintenance) – equipment or supplies needed to improve or maintain functional capabilities of persons with disabilities; may also include maintenance or repair of equipment or supplies	281	24.2%
Transportation – public or private transportation to access services or necessary community resources	260	22.4%
Home Modifications – changes to the home to make it more accessible	240	20.7%
Employment Services – services to help persons with developmental disabilities get or maintain a job	239	20.6%
Personal Assistance – someone to help with everyday activities in the home or in the community; may include assistance with bathing, dressing, taking care of personal hygiene, and other activities of daily living; may also include housekeeping chores and meal preparation	218	18.8%
Service Coordination – someone to help manage a person’s services	214	18.5%
Education – post-secondary education	207	17.9%
Vehicle Modifications – services to make a vehicle accessible	187	16.1%
Behavioral Services – adaptive interventions to address challenging behavior	169	14.6%
Day Services/Training – out-of-home services provided to adults for the purpose of enhancing or maintaining the person’s skills	157	13.5%
Specialized child care or before/after school care – accessible child care staffed by appropriately trained professionals that allows families of children with developmental disabilities to maintain employment	155	13.4%
Homemaker Services – someone to help with general household activities, such as meal preparation and routine cleaning	150	12.9%
Residential Services – living arrangement, either alone or with two or three other persons, with around-the-clock staff support	103	8.9%
Personal Emergency Response System – a way for people who live alone to call for emergency assistance in case of accident or other emergency	88	7.6%
Nursing – in-home nursing services to meet medical needs	61	5.3%

³ Total exceeds 100% because respondents were asked to identify all the services they need.

Recommended Programs

The Needs Assessment conducted by the Developmental Disabilities Task Force found that 85.4% of the survey respondents live with their families and 72.6% identified their parents or family members as their primary caregiver. These families contribute their time and resources to provide the care needed to keep their family member at home. Many families need some assistance or support to ensure the stability of their home. The programs recommended by the Task Force provide a way for these families to partner with the state to support their family member in the home through low-cost programs providing a vital array of services. Without the support of these programs, many families may be forced to ask for costly out-of-home placements and more extensive public assistance.

In order to provide a comprehensive array of cost-effective home and community-based options for people with developmental disabilities, the Task Force recommends:

- > the development of a Medicaid Waiver program;
- > the development of a Personal Support program based on the PASS demonstration project;
- > the expansion of Family Support; and
- > the development of a locally-based Information and Referral and Intake system

The Medicaid Waiver, the Personal Support program, and Family Support are designed to work together to provide a comprehensive array of cost-effective home and community-based options for people with developmental disabilities. Family Support is designed to serve a large number of people with a lower level of services at minimal cost. The Medicaid Waiver provides a greater level of services at a higher, but reasonable, cost and serves people whose needs cannot be met adequately by Family Support. The Personal Support program is for people who need more in-home support than Family Support can provide but are not eligible for the Medicaid Waiver. All three of these programs are necessary for a fully integrated system of services. Eliminating the development and funding of any of these programs would have a detrimental effect on Tennesseans with developmental disabilities.

Medicaid Waiver

A Home and Community-Based Services Waiver, also known as a Medicaid Waiver, should become the primary program Tennessee uses to provide comprehensive long-term care services to persons with developmental disabilities. The Medicaid Waiver program was developed by the federal government in 1980 to provide an alternative to institutional care and allows states to use Medicaid funds to pay for services in people's homes and in their communities. The federal Centers for Medicare & Medicaid Services continue to encourage states to design these programs to be more flexible to meet the needs of diverse groups of persons with disabilities. Across the country, Medicaid Waivers have become the principal programs used to provide home and community-based services.

In order to get Medicaid Waiver services, a person must:

- > belong to a specified Waiver population,
- > need the same level of care that is required for admission to an institution and
- > meet financial eligibility requirements.

Personal Support Program

Not everyone with developmental disabilities who needs home and community-based services will meet the eligibility criteria for a Medicaid Waiver. The Task Force recommends the development of a Personal Support program based on the successful demonstration of the PASS project (Personal Assistance Services and Supports), a model project funded by the federal Centers for Medicare & Medicaid Services. The project, which is administered by the Division of Mental Retardation Services, provides personal assistance and other needed services

- When asked if they could live in the community
- without personal assistance services,
- participants in the PASS demonstration project
- responded:
- “My needs...are such that living in the
- community without my personal assistant
- would be impossible.”
- “No.”
- “We lived without a personal assistant for years,
- with no support, but our quality of life was
- much worse.”

to persons with disabilities other than mental retardation. Federal funding ended after the successful demonstration of the project and state funding now provides personal assistance to the seven program participants. With an annual total program cost of \$72,800, an average of \$10,400 per person, the PASS project has proven to be very cost-effective compared to other alternative programs such as nursing homes.

The Personal Support program would serve people with developmental disabilities who are not eligible for the Medicaid Waiver. The individuals targeted for long-term participation in this program are primarily persons with developmental disabilities who are able to work but whose level of income makes them ineligible for Medicaid services. For example, a person with an income of \$24,000 would not be eligible for a Medicaid Waiver but neither would that person be likely to have the financial resources to pay for a personal assistant to help them attend to self-care needs. Providing a limited array of services to these persons will keep them as taxpaying residents living in homes and communities across Tennessee rather than having to give up their jobs and move to a nursing home.

Family Support

Family Support is a cost-effective state-funded program that provides minimal but critical support to persons with any type of disability and their families. Family Support is a very flexible, family-friendly program that receives guidance and oversight from local, district, and state councils composed of a majority of persons with disabilities or their family members.

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Family Support funding may be used, based on the choices of each family, for such services as respite, personal assistance, housing costs, special equipment and supplies, home modifications, before and after care, homemaker services, transportation, vehicle modifications, and health-related services. By helping with some of the costs associated with supporting a family member with a developmental disability living at home, Family Support provides a low-cost high-impact way for the state to partner with families of persons with developmental disabilities. Although Family Support is an effective way to impact the lives of many people for the smallest investment, and is an integral component of the array of home and community-based services, the program was not designed to provide comprehensive services that are needed by many people with developmental disabilities.

- Family Support is not just a name it is what they do. Families come first. They help us better care for our disabled family members.
- Disability is not the end of the world but when you meet so many obstacles and closed doors you can feel like giving up. The people who work at Family Support are knowledgeable and helpful. Most of all they are caring and compassionate. You are more than a number on a case file and we are always treated with respect and dignity.

Comment from Family Support recipient

Funding for Family Support was \$7,679,400 for FY 2007. The level of funding has not increased since FY 2005 and was not targeted for a funding improvement in FY 2008. With a waiting list of 5,371 persons at the end of March 2007, the need for expansion of the program is well documented.

The Task Force is opposed to the diversion of any Family Support funds to match a Medicaid Waiver program for several reasons. First, in FY 2006, Family Support provided services to 4,307 persons, of whom 2,027 (47%) had a developmental disability other than mental retardation. Many of those persons would not be eligible for a Medicaid Waiver. Family Support fills gaps in services that no other program fills. Second, Family Support is an extremely cost-effective program with an average cost during that FY 2006 of \$1,783 per person. No other program can serve as many people for this amount of funding.

- I greatly appreciate the help I get from the Family Support Program but I need so much more than the program can provide. My mother will not be able to care for me forever and she should not have to. I want the opportunities that all people enjoy.

Comment from Family Support recipient

Recommended Funding

The members of the Task Force understand that the development of new programs and services is an ongoing process. The recommendations do not call for exaggerated financial resources and do not call for services to become immediately available for all persons with developmental disabilities. The Task Force recommends that \$2,350,000 be allocated for FY 2009 and \$4,140,000 be allocated for FY 2010 to develop services for persons with developmental disabilities.

Funding Request – State Appropriations

PROGRAM	YEAR 1 (FY 2009)	YEAR 2 (FY 2010)
Medicaid Waiver	(no funds in Year 1)*	\$2,000,000*
Family Support	\$1,000,000	\$1,000,000
Personal Support Program	\$1,350,000	(no new funds)
Information & Referral and Intake	(no funds in Year 1)	\$1,140,000
TOTAL	\$2,350,000	\$4,140,000

* A major advantage of a Medicaid Waiver is the federal funding available. According to the Federal Register, November 30, 2006, Tennessee’s Federal Medical Assistance Percentages (match rate) for Medicaid programs will be 63.71% federal and 36.29% state for FY 2008. Medicaid Waiver funds would not be available during Year 1 due to the time that is needed to develop and submit the federal application. (The Task Force is not aware of the FY 2009 match rate but assumes it will be similar to that for FY 2008).

Medicaid Waiver: Although a Medicaid Waiver is the primary program recommended by the Task Force, that program cannot be implemented during FY 2009. It will take approximately one full year to develop the required federal application, submit it to the Centers for Medicare & Medicaid Services, respond to any issues raised about the application, receive approval for the program, and prepare for program implementation. Therefore, initial funding for the Waiver is requested in FY 2010. In FY 2010, a state allocation of \$2,000,000 would bring in an additional \$3,511,160 in federal funds, a total of \$5,511,160 in available funding. With the funding level anticipated to average \$20,000 per person, the program could enroll approximately 275 persons.

Personal Support Program: The \$1,350,000 recommended for the Personal Support program would serve approximately 100 additional persons in Year 1 and would cover both the cost of direct services as well as the administrative costs for the program. No additional funding for the PASS project is recommended for the second year, allowing program development to focus on the Medicaid Waiver.

- **Personal Support program**
- When asked about the most important priority for the PASS demonstration project, participants responded:
- “To move from an experiment status to a permanent one.”
- “Getting help to more people/ participants.”
- “Get it to more people who need help.”

Family Support: It is projected that an allocation of \$1,000,000 each year would provide services to an additional 560 persons in both FY 2009 and in FY 2010.

Information and Referral and Intake: People with developmental disabilities and their families need reliable, consistent and timely information about available services and programs. Access to

FULFILLING THE PROMISE

an intake system for those services should be local and easy. More details regarding this aspect of the service system are provided in the Recommended Practices section of this report.

During subsequent years, the Task Force recommends that the Division of Mental Retardation Services expand the Medicaid Waiver, the Personal Support program, and Family Support to meet documented needs. Information gathered during the implementation of the programs recommended for Years 1 and 2 should be used to determine the level of future funding requests for those particular programs.

The Task Force also recommends that the state continually assess the persons enrolling in the Medicaid Waiver for persons with developmental disabilities, the Personal Support program, and Family Support as well as the needs of persons on the waiting list to determine the need for additional programs in the future.

Eligibility

Recommendation 2: TennCare eligibility criteria for Medicaid Waiver home and community-based services should include persons who have developmental disabilities.

Title 33 of Tennessee Code Annotated makes persons with all developmental disabilities legally eligible for services. These laws apply to two of the three programs recommended for funding by the Developmental Disabilities Task Force (Family Support, Personal Support program). However, these laws do not impact the Medicaid Waiver because eligibility criteria for that program are governed by rules adopted by the Bureau of TennCare.

Federal regulations permit each state to make persons with “related conditions” eligible for Medicaid Waiver services in addition to persons with mental retardation. The federal government has adopted a definition of “related conditions,” however, each state is permitted to establish its own eligibility criteria rather than using the federal definition. Through its rulemaking process, Tennessee has established a much narrower definition of “related conditions,” which is:

1200-13-1-.15 Criteria for Medicaid Reimbursement of Care in an Intermediate Care Facility for the Mentally Retarded (ICF/MR) (1) (n) Related Conditions – a severe chronic developmental disability likely to continue indefinitely which results in impairment of intellectual functioning equivalent to that of individuals with mental retardation and which requires specialized services similar to those needed by such individuals.

This definition, by limiting “related conditions” to include only impairments to intellectual functioning, denies services to persons with non-intellectual disabilities, such as cerebral palsy, other physical disabilities, and autism. Opening up the state’s eligibility criteria, as permitted by the federal government, would permit Tennessee to obtain federal Medicaid funds to pay for home and community-based services for persons who have developmental disabilities other than mental retardation. Specifically, replacing TennCare’s current definition of “related

Federal Definition of “Related Conditions”

Persons with related conditions means individuals who have a severe, chronic disability that meets all of the following conditions:

- (a) It is attributable to—
 - (1) Cerebral palsy or epilepsy; or
 - (2) Any other condition, other than mental illness, found to be closely related to mental retardation because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, and requires treatment or services similar to those required for these persons.
- (b) It is manifested before the person reaches age 22.
- (c) It is likely to continue indefinitely.
- (d) It results in substantial functional limitations in three or more of the following areas of major life activity:
 - (1) Self-care.
 - (2) Understanding and use of language.
 - (3) Learning.
 - (4) Mobility.
 - (5) Self-direction.
 - (6) Capacity for independent living.

conditions” located in state rules with the federal definition of “developmental disability” would allow Tennessee to access those federal funds.

The Task Force recommends including in a revised definition of “related conditions” an exclusion similar to that in Tennessee Code Annotated, 33-5-103, which specifies that if a person has a developmental disability solely on the basis of having a mental illness or serious emotional disturbance, the person is not eligible to have services or supports provided for persons with developmental disabilities.

Recommendation 3: Applicants for services who do not have mental retardation should not be required to undergo intelligence testing for eligibility to be determined.

While the Task Force supports the use of intelligence testing as a tool in determining eligibility for persons with mental retardation, it concluded that intelligence testing should not be required for persons for whom there is no history of an intellectual disability. At the request of the Task Force, TennCare staff contacted the Atlanta Regional Office of the Centers for Medicare & Medicaid Services regarding the requirement that intelligence testing be a part of determining eligibility for a Medicaid-funded Waiver for developmental disabilities. The current opinion by Centers for Medicare & Medicaid Services is that a complete psychological evaluation, including intelligence testing, must be performed even for persons who do not have an intellectual disability. However, research conducted by the Task Force found that some states’ Medicaid Waiver programs do not require intelligence testing when the person has a non-intellectual disability. Unnecessary intelligence testing is not a prudent use of state financial resources and, therefore, the Task Force recommends that it not be included in the eligibility determination process. A more suitable eligibility determination process would focus on the level of the person’s adaptive functioning.

Administration Of Developmental Disabilities Services

Recommendation 4: Responsibility for administering services for persons with developmental disabilities should be assigned to the Division of Mental Retardation Services in the Department of Finance & Administration.

Ensuring that people with disabilities and their families have access to a coordinated system of services is dependent on a single state agency having responsibility for the task of coordinating existing services and assuming leadership in developing new services and programs. The Task Force believes that the Division of Mental Retardation Services is best positioned to assume the role of lead state agency for people with developmental disabilities.

Title 33 of Tennessee Code Annotated contains the state's mental health and developmental disabilities laws. Both the Department of Mental Health and Developmental Disabilities and the Division of Mental Retardation Services, located in the Department of Finance and Administration, are responsible for carrying out these laws. Comprehensive revisions to Title 33 in 2000 resulted in the expansion of eligibility for state services to Tennesseans who have developmental disabilities other than mental retardation (effective March 2002). It was envisioned that the Division of Mental Retardation Services, which was already serving Tennesseans with all types of disabilities through the Family Support program, would continue to be the state agency responsible for developing and administering services for people with all types of developmental disabilities, including mental retardation. While the Division of Mental Retardation Services has continued to be the lead agency for persons with mental retardation and the administering state agency for the Family Support program serving people with a wide variety of disabilities, the Division has not been assigned responsibility for the systematic planning and development of comprehensive services for persons with developmental disabilities.

In order to address the needs of Tennesseans with developmental disabilities, the Developmental Disabilities Task Force recommends that the Division of Mental Retardation Services be formally named the state agency responsible to plan, develop and administer services for Tennesseans with all types of developmental disabilities. This position is consistent with that of the Planning & Policy Council of the Tennessee Department of Mental Health and Developmental Disabilities, which also recommended that responsibility of administering services to persons with developmental disabilities be assigned to the Division of Mental Retardation Services. Further, the Developmental Disabilities Task Force joins with the Planning & Policy Council in recommending that the name of the Division of Mental Retardation Services be changed to the Division of Developmental Disabilities Services to reflect these combined responsibilities. The Task Force also concurs with the Planning & Policy Council recommendation that consideration be given to the creation of a Cabinet level department for developmental disabilities. The Task Force concluded that funding complexities

and systems expertise required to administer services to Tennesseans with developmental disabilities warrant this commitment and attention.

The Developmental Disabilities Task Force has confidence in the ability and capacity of the Division of Mental Retardation Services to assume full responsibility of developing and administering services to persons with developmental disabilities.

Similar Needs

Persons with developmental disabilities, including mental retardation, cerebral palsy and autism, have similar support needs. This need for similar home and community-based services supports the designation of a single administering agency in state government.

The Division of Mental Retardation Services has extensive experience in administering funding and service systems for people with developmental disabilities. The Division currently administers two programs for persons with disabilities other than mental retardation. Approximately 80% of the persons served by the Family Support program, which has been in operation for 15 years, have a disability other than mental retardation. The Personal Assistance Services & Supports program, which began as a federally-funded demonstration project in 2004 for persons with all types of disabilities, has now been converted to an ongoing operation.

Medicaid Waiver Experience

The federal Medicaid Waiver program allows states to secure federal funds to provide home and community-based services for people with developmental disabilities. Through a contract with the Bureau of TennCare, the Division of Mental Retardation Services has operated Medicaid Waiver long-term care services since July 1986.

Self-Direction

With federal encouragement, many programs for persons with developmental disabilities around the country support persons with disabilities to self-direct their own services. The Division of Mental Retardation Services currently operates three programs that include a self-direction component: Family Support, the Personal Assistance Services & Supports program, and the Self-Determination Medicaid Waiver.

Provider Network

The Division of Mental Retardation Services has an extensive network of community providers that is experienced at providing the types of services needed by persons with developmental disabilities.

Operating Guidelines

The Division of Mental Retardation Services has extensive experience with developing operating guidelines for providers that contract to provide home and community-based services. These guidelines are comprehensive and address issues such as provider and staff training requirements and protection from harm, including incident management and investigations. This experience will serve the Division well in developing materials appropriate to programs for persons with developmental disabilities.

Administrative Network

The Division of Mental Retardation Services already has the administrative network in place to implement additional home and community-based programs, including the appropriate contracting processes, billing procedures, and fiscal oversight. The Division also has a strong regional management structure that can oversee both contracted and self-directed services and supports.

Quality Assurance

The Division of Mental Retardation Services has a comprehensive quality management system for home and community-based services that received national recognition for its design and implementation from the American Association on Intellectual and Developmental Disabilities in May 2006.

Recommended Practices

The state should adopt practices and procedures sufficient to assure safe, appropriate and effective services for Tennesseans with developmental disabilities. Safe and effective programs and services meet the needs of people in cost-accountable ways. People who use the programs and services must have confidence in the qualifications of service providers as well as in the integrity of the performance and evaluation processes. The state agency assigned responsibility for administering programs and services must adopt quality service practices and continually seek to improve those practices. For services to be the most cost-effective and appropriate, a set of crucial features must be evident in the service system.

- > A statewide system must be developed that provides accurate and consistent information to persons with developmental disabilities and to the public regarding programs and services.
- > Persons with developmental disabilities should be provided the opportunity and support to make decisions about the services they need and how they want to receive them.
- > There must be an adequate number and variety of service providers in communities that are capable of meeting the needs of people with developmental disabilities.
- > There must be an adequate and skilled workforce.
- > Effective mechanisms for ensuring quality must be implemented and must include strategies for people and their families to determine what constitutes quality services in their particular situation.

Recommendation 5: Information and referral and access to services should be easy, flexible, competent, consistent and timely.

The Division of Mental Retardation Services should develop a statewide system to provide accurate and consistent information to persons with developmental disabilities and to the public regarding programs and services. This system should encompass the functions of Public Awareness, Information and Referral, and Accessing Services. Further, the Division should establish and partner with Local Access Agencies to provide these functions.

Public Awareness

Information must be readily available to the public about programs and services for persons with developmental disabilities as well as contact information when more information or support is needed. A public awareness plan should be developed by the Division of Mental Retardation Services and its partners that includes sharing information on programs and services through a wide array of primary access points. Those public awareness activities should ensure that information is disseminated to all of Tennessee's communities and to all types of health

providers, Early Intervention providers, public school systems, Department of Human Services offices, Vocational Rehabilitation offices, advocacy organizations, agencies that provide services to persons with disabilities, and other community social service organizations. Public outreach activities also should strive to make the general public aware of where to obtain information about programs and services.

Few families know where to turn when a child is born with a disability or when a disability occurs due to other unforeseen circumstances. During this time of strain and anxiety, the family needs ready access to information about whom to contact to learn about programs and services that may be available to assist them. By making information available in many locations in every community, a family's chances of obtaining information and support will be greatly enhanced.

- There is no one place to contact to receive
- information about all of the services available.
- We moved here from another state and it
- seems "hit & miss."
- Comment from the Needs Assessment
- My son has multiple health problems and
- disabilities. It would be very helpful to have one
- place to call to get information on all available
- services for a child. It would be even more
- helpful to fill out one application that is sent to
- all applicable places.
- Comment from the Needs Assessment

Information and Referral

People with developmental disabilities and their families need access to reliable information about available services and programs. The Needs Assessment conducted by the Developmental Disabilities Task Force asked people and their families to identify the specific services they needed. Information and Referral was identified as the most needed service, with 522 (45%) respondents stating they needed someone to provide information and assistance about available services and how to apply for them.

Information and referral staff must be knowledgeable about available programs and services. Their knowledge should encompass not only programs and services specifically developed for people with developmental disabilities but other public and private social service programs for which those persons may be eligible. Staff must also be knowledgeable of local communities and the local resources available within those communities. Staff must be able to communicate effectively and display a caring, helpful attitude.

Timely and easy access to information and referral are significant issues. The Task Force recommends that toll-free numbers should be answered by a staff person during normal business hours. The Task Force also recommends that time lines should be established and followed for initially following up on requests for information and for other components of the information and referral process.

An organization that provides information and referral to people with developmental disabilities will, in all probability, be contacted by persons who have other disabilities. It is equally important that these people are provided with accurate information so they can seek the programs and

services they need. Therefore, staff of these organizations must have knowledge or access to information about all disability programs and services, eligibility criteria and processes for those programs, as well as contact information, to make the appropriate referrals to other programs and services.

Statewide disability information and referral services are being provided by Tennessee Disability Pathfinder, a project of the Tennessee Council on Developmental Disabilities and the Vanderbilt Kennedy Center established in 1997. Pathfinder has a statewide toll-free number and Web site promoted in public awareness campaigns. The Pathfinder Web site has a current database of 1,600 state and community agencies providing disability-related services; it is searchable by service category and county. A statewide directory of disability services in three volumes for East, Middle, and West Tennessee is published also. Pathfinder staff have completed the credentialing test and are certified by the Alliance of Information & Referral Systems (AIRS), the national professional organization for information and referral specialists. Information is provided in English and Spanish.

The Tennessee Commission on Aging and Disability is another significant provider of information and referral services. Many state and community agencies provide information and referral as one part of an array of services. Existing information and referral databases could be improved, for example, by including details of eligibility criteria and documentation needed to apply for services.

Disability information and referral expertise is needed throughout the service system, notably at the local community level. The Task Force recommends the development of an enhanced Web-based, statewide information and referral system that builds on but does not duplicate existing systems. A major enhancement recommended is a Web-based, state-level centralized intake system that includes an online application form for state-funded services.

Accessing Services

After an initial screening determines that a person is likely to be eligible for services, the person and family must be provided information and support to assist them with the process of applying for services. Support should be offered in ways that ensure that people have the necessary information to make decisions about their options. This includes providing them with information about specific programs and services as well as assisting them, as needed, with completing application forms and obtaining other documents that are necessary for eligibility determination. People with disabilities and their families also should be helped to navigate the various disability systems until they are actually enrolled into a program or services.

Local Access Agencies

After reviewing the functions and responsibilities associated with Public Awareness, Information and Referral, and Accessing Services, the Developmental Disabilities Task Force concluded

that establishing Local Access Agencies would be the most effective and accessible model to provide people with developmental disabilities and their families with appropriate information about programs and support to access available services. In this model, a local disability organization is contracted to provide these services. While it is not likely to be financially feasible to locate an actual office and staff in each county, it should be possible to designate an agency that is responsible for providing Public Awareness, Information and Referral, and assisting with Accessing Services to people in each county. This model of a local access system has been used for 15 years by the Family Support program and has proven to be extremely effective.

- When asked why Self-Determination was important to them, participants in the PASS demonstration project responded:
- “I know more about my needs than someone else.”
- “I can do my own hiring.”
- “Most important is that I can set my own schedule.”
- “I must be allowed to make decisions on my own and live by the consequences of those decisions.
- The PASS grant enables me to be self-reliant and regain my right to self-direct.”

Functions of a Local Access Agency include:

- > Working with the state to implement the public awareness plan by providing proactive outreach to people with developmental disabilities and families, including increasing awareness of programs and services and how they may be accessed; actively looking for people who might qualify for services; providing information to potential referring sources, and following up on any information received;
- > Providing information to people seeking services, including face-to-face meetings to explain eligibility requirements; discussing specific programs and services; providing information about how to apply for or to access those services and information on a variety of local, state, and federal services;
- > Conducting initial assessments;
- > Providing assistance, as necessary, to complete application forms and collect documentation that is necessary to determine eligibility;
- > Referring applicants to other programs and services, as appropriate to the needs of the person;
- > Helping people with developmental disabilities and families navigate the system and access necessary services until they are enrolled in programs;
- > Providing follow-up and ongoing contact and assistance as needed or requested; and
- > Maintaining and submitting information to designated state organizations for the compilation of data on persons with disabilities who are requesting services.

Recommendation 6: Persons with developmental disabilities should be provided the opportunity and support to self-direct their services.

Self-direction empowers persons with disabilities to make decisions about the services they need and how they want to receive them. Self-direction represents an approach to service delivery that maximizes the ability of the person with a developmental disability to assess his or her own needs,

Martin's Story

This Tennessean with a significant developmental disability is a published author and award-winning community volunteer.

I am an adult with cerebral palsy. The type of cerebral palsy that I have affects my motor coordination and speech. I need help for virtually all activities of daily living, including eating, dressing and transferring to my wheelchair. Despite these challenges, I believe that you should use the abilities that you have to the fullest. My goal is to be active in my community and to use my abilities to advocate on behalf of Tennesseans with disabilities who do not have the services they need.

When I was young, my parents cared for me until they passed away. Then, my grandparents and three uncles took over my care. My grandparents and two uncles have now passed away, and my remaining family caregiver has his own health concerns.

Two years ago, I was fortunate to be chosen to participate in a small pilot program offered by The Arc of Tennessee called PASS (Personal Assistance Supports & Services). Through this pilot program, I and others with similar disabilities demonstrated that we are capable of hiring and supervising our own personal attendants, ensuring that our daily living care is provided for much less money than it would cost to support us in a nursing home. Why in the world can't we divert at least part of the millions of dollars that are going to antiquated ways of caring for people with disabilities (nursing homes) and put these resources into community programs such as the PASS program? In doing this it would give us freedom and dignity, afford us the ability to stay in our homes and enable us to continue our roles as citizens, volunteers and taxpayers.

In 2005, I was elected as the president of the United Cerebral Palsy of Middle Tennessee Board of Directors. In my role with UCP, I advocate for programs like the PASS pilot project to benefit others with cerebral palsy and similar developmental disabilities. In 2006, I received the Mary Catherine Strobel Award for my volunteer work with this group. While we do everything we can to help people through the grants and donations we receive, this will never be enough to cover the lifelong costs our families are facing. Our families need the kind of support that can only come with state and federally funded programs like those offered to persons with mental retardation in Tennessee.

Many of my close friends been forced to move into nursing homes because they have no one to care for them. This is simply wrong. We must recognize people with disabilities as valued equals who have the potential to contribute much to the world around us. Instead of being set apart, people with disabilities should be among those at the very heart of Tennessee communities.

determine how and by whom those needs will be met, and determine what constitutes quality services in his or her particular situation. Self-direction ranges from the person independently making all decisions and managing services directly to using a representative, such as a support broker, to manage needed services. The core concept is that the person with a disability has the primary authority to make choices that work best for him or her.

With self-direction, people with developmental disabilities:

- > Assess their own needs;
- > Establish a written plan of services, identifying which services they need and choosing which services they receive;
- > Choose when and where their services are provided;
- > Select, hire, manage, and terminate direct support staff;
- > Manage their individual budgets by setting staff wages or buying items that enhance their independence;
- > Monitor the quality of services they receive; and
- > Receive the level of support needed to exercise the greatest level of self-direction possible.

Integral Components of a Self-Directed Approach

Person-Centered Planning

In person-centered planning, the focus is on the person for whom the plan is being developed rather than on fitting the person into slots in the current service system. Person-centered planning should promote community inclusion, personal independence to the extent possible, and productivity. Person-centered planning is more than the written plan itself; it includes the plan, the planning process, and implementation of the services needed by the person. Person-centered planning must be dynamic. As a person lives his or her life in the community, needs and choices are likely to change. The plan, planning process, and implementation strategies must be flexible enough to adapt to those changing needs.

Support Broker

Some persons with developmental disabilities may need assistance in performing the functions associated with self-direction. The level of assistance needed will vary among people. A support broker may help the person with the following functions: managing a budget, recruiting, hiring, and supervising direct support professionals, negotiating rates of pay, scheduling services, training providers, and evaluating provider performance. The support broker may provide additional assistance as directed by the individual or family.

Fiscal Agent

Self-direction delegates the responsibility for many business functions to a fiscal agent. This relieves people with a developmental disability from having to perform those tasks and allows them to concentrate on managing their services. Fiscal agents manage a variety of fiscal and payroll-related tasks on behalf of the person they represent. These tasks include managing the person's budget and funds, paying direct support professionals and other providers, processing other employment-related expenses, such as payroll, withholding and other taxes, processing and paying invoices for approved services related to the person's needs, preparing and submitting budget status reports to the person or family, and submitting claims to state agencies that provide funds for the person's services.

Two national pilot projects demonstrated the success of self-direction in the 1990s: (a) the Self-Determination project in 19 states; and (b) the Cash and Counseling project in three (3) states. These programs afforded people or their families the option to direct the design and delivery of services, avoid unnecessary institutionalization, experience higher levels of satisfaction, and maximize the efficient use of home and community services. Based on the experiences and lessons learned from the states that pioneered the philosophy of self-direction through those projects, Independence Plus was created in 2002 by the Centers for Medicare & Medicaid Services, the federal agency that administers Medicaid funding and services, to promote person-centered planning and self-directed service options.

Recommendation 7: An adequate provider network for developmental disabilities services should be developed.

The Division of Mental Retardation Services has a provider network for services available to people with mental retardation. Many of the services needed by people with developmental disabilities are among the services offered by these providers. The Division should survey existing providers regarding their capacity to serve additional people with developmental disabilities other than mental retardation. This survey also should seek information about any challenges or concerns these providers anticipate with the expansion, as well as their ideas for addressing those issues. Also, an expanded network of providers should be developed to address the needs of people with developmental disabilities.

The Division should pursue the use of alternative forms of service delivery. Implementing a self-directed approach enables persons with developmental disabilities to select their own providers and often these providers are not part of the existing provider network. Many Medicaid-funded programs across the nation are establishing systems in which persons with developmental disabilities can hire persons who live near them, friends, or others. To assure that this practice has appropriate safeguards and is not unduly restricted in Tennessee, the Division should 1) review all relevant laws, rules, regulations, and Operating Guidelines and

revise any that impede provider choice; and 2) develop systems that positively encourage and support persons with developmental disabilities to hire and manage their own staff.

Recommendation 8: Strategies to expand the supply of skilled direct support professionals should be developed and implemented.

Aside from families, direct support professionals are the single most essential component to the quality of life, health and safety of people with developmental disabilities. Ensuring access to an adequate supply of skilled and caring direct support professionals is a key component of providing home and community services. Direct support professionals are responsible for helping people with developmental disabilities with their basic self-care and health needs. They also play a critical role in assisting people to gain skills, participate in community life, have a job, make decisions, and become more independent.

Direct Support Professional is defined in the Congressional 2003 Direct Support Professional Recognition Resolution as individuals who receive monetary compensation to provide a wide range of supportive services to individuals with... developmental disabilities on a day-to-day basis, including habilitation, health needs, personal care and hygiene, employment, transportation, recreation, and housekeeping and other home management-related supports and services so that these individuals can live and work in their communities and lead self-directed, community and social lives.

In its report to Congress, *The Supply of Direct Support Professionals Serving Individuals with Intellectual Disabilities and Other Developmental Disabilities*, January 2006, the U.S. Department of Health and Human Services estimated that by 2020 the number of direct support staff needed to meet the nation's long-term support needs will grow to approximately the equivalent of 1.2 million full-time staff, an increase of 37% or 323,000 jobs. This increase is projected to be largely due to population increases, the increased life expectancy among persons with developmental disabilities, the aging of family caregivers, and the expansion of home and community-based services. This increase in demand will occur at a time when it is projected that the labor supply of adults age 18–39 years, who traditionally have filled these jobs, is expected to increase only by 7%.

At the same time that demand for direct support professionals is growing, turnover of existing staff in those positions is very high. The report to Congress mentioned in the preceding paragraph identified 26 studies of turnover that were conducted between 1998 and 2003. These studies computed turnover for residential/in-home community services; vocational and/or day services; and for combined residential/in-home and vocational/day service. The average rate of turnover across all these settings was 50%. High levels of turnover present extremely challenging circumstances for agencies responsible for recruiting, hiring, training, and supervising these staff. Agencies must spend more time performing each of these functions which leads to increased operating costs. Although staff turnover has negative effects on the work of disability providers, even more critically, it has a detrimental impact on the lives of

people with disabilities. By hindering the development of relationships and of trust between staff and people with developmental disabilities and their families, it ultimately affects the quality of services.

The demand for direct support professionals impacts Tennessee as it does all other states. It is essential for the state to work with providers to address this ever increasing demand. Critical components of meeting this demand are paying living wages, providing competitive benefits, and developing fulfilling jobs. While recruiting new staff on an ongoing basis will be essential, it will be equally important to provide working conditions that encourage existing direct support staff to remain in the profession.

Recommendation 9: The Division of Mental Retardation Services' quality management system should be reviewed and expanded as needed to ensure it is responsive to services developed for persons with developmental disabilities.

At the most basic level, quality assurance must guarantee the protection of people with developmental disabilities and assurance of their due process rights. At the highest level, quality assurance systems should measure and promote personal independence, inclusion, and satisfaction with services and outcomes. The Division of Mental Retardation Services has in place a Quality Management System that has been designed using federal quality assurance guidelines for Medicaid-funded services. This comprehensive quality assurance system received national recognition for its design and implementation from the American Association on Intellectual and Developmental Disabilities in May 2006.

As programs for persons with developmental disabilities are developed or expanded, strategies for ensuring quality in those services must be established. The increasing use of self-direction and other innovations in services creates challenges for quality assurance systems that are based on traditional services and provider networks. People who self-direct their services are more likely to live by themselves or with their families and to receive services from less traditional providers. Quality assurance for those persons who self-direct their services needs to be further refined. Tennessee's excellent quality management system should be reviewed to ensure that the mechanisms in place are responsive to these individualized, less conventional models of services. This process of reviewing and developing quality assurance mechanisms should include all stakeholders.

Planning & Development

Recommendation 10: The Division of Mental Retardation Services should establish an ongoing planning process to guide the development and evaluation of home and community-based services for people with developmental disabilities.

Organizational planning and development must be part of the daily operations of an organization, be organization-wide, managed from the top, and involve participation of all stakeholders. This facilitates adaptation to new methods, technologies, challenges and the needs of stakeholders.

The Division of Mental Retardation Services, with the participation of stakeholders, should address the following planning and development activities in establishing services for Tennesseans with developmental disabilities:

- > In collaboration with the Bureau of TennCare, develop and submit an application for a Medicaid Waiver to the Centers for Medicare & Medicaid Services within a time frame to allow implementation by July 1, 2009.
- > Establish program criteria and principles for services for people with developmental disabilities other than mental retardation.
- > Establish a template to guide and shape development of the developmental disabilities service system that includes, but is not limited to, the following elements:
 - Person-centered planning processes;
 - Options for self-directed services;
 - Local access to information, referral and enrollment into services;
 - Responsive and sensitive policies for managing waiting lists;
 - Cost-effective services;
 - Data system used to support planning and development activities;
 - Quality assurance system; and
 - Provider training.

A template to evaluate services and supports as they are planned and developed will assure that good and effective principles are consistently applied.

My name is Sara...

I am writing this story about how I came to be a successful adult with physical disabilities and how tenuous that success can be for me and other people with disabilities. I was born with brittle bone disease that has resulted in at least 100 broken bones during my lifetime.

When it was time for me to enter school, my parents refused for me to be sent to a "special" school and worked tirelessly for me to be mainstreamed (a '70s term for inclusion). These years were full of negotiation for my needs, which amounted to physical help for about 15 minutes once during the day to use the restroom. We got creative... a crossing guard, aides from the resource room, and when all else failed, Mom, who came to school whenever I needed help. Without those 15 minutes each day, I would not have been able to attend school.

I graduated high school in 1989 and began my freshman year at Vanderbilt University. My physical needs stayed the same...simply a few minutes a day. We utilized other students, often supplementing what Voc Rehab would pay with our own money and again, when all else failed, using Mom, who often took jobs close to Vanderbilt to be available to me. I graduated Magna Cum Laude in 1994. At that point, I received a letter from the state that said I had been "successfully rehabilitated," thus the Voc Rehab funds were gone. I attended Vanderbilt for graduate school and completed my Master's in Special Education in 1997. My assistance came from a fellow student, who was paid by my family, and again by Mom.

I worked for seven years as the Americans with Disabilities Act coordinator at Vanderbilt, responsible for coordinating accommodations for faculty, staff and students with disabilities. My help during this time? Mom. I now work at Vanderbilt Children's Hospital, conducting job-training activities for high school students with developmental disabilities. We do not have funds to pay attendant care, thus Mom or sometimes Dad are the only ways that I can be an "independent" wage-earning, tax-paying citizen of Tennessee. When I was 25, I wanted to live on my own. But between medical and prescription costs, it was clear that I was not going to be able to afford rent (or a mortgage) and the cost of an attendant. So the answer? Have Mom move in with me. As any 25-year-old woman knows, living with Mom is difficult. Our solution utilized our creativity once again...Mom bought a condo in the same building as me. Thus, we are close enough for her to help but have the illusion of independence for both of us.

It works now, but I often fear the future...thinking of when Mom can no longer assist me. Can I continue to work and live independently or will I be stuck in a nursing home, robbed of the independence that so many people, including myself, have worked so hard to achieve?

Being born with a developmental disability is not tragic...but not having the community supports to be successful is tragic, for me and other Tennesseans like me.

Conclusion

When Tennessee's General Assembly approved Title 33 revisions to include people with developmental disabilities other than mental retardation, many Tennesseans with developmental disabilities and their families believed that funding and needed services would soon follow, that the administration and the legislature had made a promise to help provide the care that was previously unavailable. Seven years later, Tennessee has not met this legislative intent of Title 33. The Developmental Disabilities Task Force urges the executive and legislative branches of Tennessee government to join together to address the needs of Tennesseans with developmental disabilities. Now is the time for the State of Tennessee to fulfill the promise!



Tennessee Council on Developmental Disabilities. Authorization Number 344044, August 2007. 750 copies. This public document was promulgated at a cost of \$5.92 per copy.

Appendix

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