



**Event:** Olmstead Decision and Welfare-to-Work Regional Meeting

**Date:** August 23-24, 2000

**Location:** The Westin Peachtree Hotel, Atlanta, Georgia

## 1. SUMMARY

The Olmstead Decision and Welfare-to-Work ACF Region IV Meeting was held on August 23-24, 2000, at The Westin Peachtree Plaza Hotel in Atlanta, Georgia. More than 80 participants attended, including State Temporary Assistance For Needy Families (TANF) Directors, and Welfare-to-Work (WtW) administrators along with representatives from State Medicaid offices, and representatives of the Developmental Disabilities Network (State developmental disabilities councils, protection and advocacy agencies, and the university affiliated programs). The focus of this Regional meeting was to examine how the Olmstead Decision and Welfare-to-Work initiatives can be incorporated into each States' Strategic Plan.

During this meeting, there was discussion regarding development of comprehensive, effectively working State plans to strengthen community service systems, and to involve people with developmental disabilities and their families actively in the design of such plans. States were also encouraged to address the placement of all individuals who are unnecessarily institutionalized or at risk of institutionalization and to advocate for community-based services and support for people with disabilities.

On June 22, 1999, the United States Supreme Court issued the Olmstead v. L.C. Decision. The Court based its ruling in Olmstead on sections of the Americans With Disabilities Act (ADA) and Federal regulations that require States to administer their services, programs and activities "in the most integrated setting appropriate to the needs of qualified individuals with disabilities." In its ruling, the Court said that unjustified institutionalization of people with disabilities is discrimination and violates Title II of the ADA.

During the regional meeting specific issues pertaining to the Olmstead Decision and Welfare-to-Work issues for people with developmental disabilities were highlighted. Several meeting participants stated that in the process of developing a State plan there needs to be participation of "key stakeholders" who receive, provide, administer, and monitor disability services when decisions are made regarding the developmentally disabled. There was a call for both the ADA and the Olmstead Decision to be actively implemented on a nationwide basis on

behalf of disabled adults and children. There were also issues concerning the maintenance of insurance and other benefits in light of one's ability to return to work or be gainfully employed. Many shared the belief that a safety net is needed to create health care and other benefit systems not predicated on employment.

Meeting participants were strongly encouraged to move away from "hiding" the disabled in institutions or placing them in inappropriate work environments. Customized work evaluations, comprehensive vocational assessments and proven screening processes were some of the tools offered to ensure that this "hiding" does not occur. Participants stated that moving disabled individuals without serious consideration being given to their welfare, abilities, and their families' wishes is not acceptable. Community integration was discussed at length as the preferred means of care whenever feasible.

## **2. PARTICIPANTS**

Approximately 81 persons representing State Temporary Assistance to Needy Families (TANF) Directors; Welfare-to-Work administrators; State Medicaid representatives; State developmental disabilities councils; State protection and advocacy agencies; university affiliated programs; several area action centers; and other interested parties attended the meeting.

Participants also included Blake Austensen from the Welfare Peer Technical Assistance (TA) Network, who assisted Ramona Warren with the facilitation of the meeting. Ms. Warren is the Manager of the Child Welfare/Developmental Disabilities Unit in the Southeast Regional Hub of the Administration for Children and Families. She previously worked as manager of TANF and Child Care in the Southeast Regional Hub. Michele Tapp, AFYA, Inc., was also on site as the official recorder/note taker for the meeting. The regional Administration for Children and Families (ACF) Divisions of Developmental Disabilities and Temporary Assistance to Needy Families (TANF) sponsored this regional meeting with assistance from, and collaboration with, the Department of Health and Human Services regional offices of Health Care Financing Administration (HCFA), Office for Civil Rights (OCR), the Department of Labor, and the Social Security Administration. ACF's Central Office of Equal Employment Opportunity provided interpreter services. The ACF Southeast Regional Hub was encouraged by the information exchanged during this meeting and looks forward to collaborating with partners who are involved with programs or activities to ensure that individuals with disabilities have the opportunity for integration into the most appropriate setting to meet their needs.

### 3. MEETING SUMMARY

*[Note: The majority of the following summary includes excerpts of quotes and is written from the perspective of the speakers themselves.]*

#### A. Welcome, Introductions, and Goals for the Day

##### **W. Kenneth Jackson, Deputy Regional Administrator Administration for Children and Families**

It is hopeful that the *Olmstead Decision* will encourage the development of opportunities for people with disabilities to be placed in mainstream society. Moreover, it is the goal that hard to place individuals will be afforded the chance to work in jobs that lead to self-sufficiency. The challenge is to secure supportive settings for these individuals and to allow them to maintain their “dignity and self expression.” Many of these individuals do not want a handout, but an opportunity for an honest day’s labor.

Aggressive strategies are needed to bring them to a point of receiving their “fair share of the American dream.” Accordingly, when the developmentally disabled are not presented with opportunities to work, their talent is lost and promises go unfulfilled. We cannot afford to lose skills and imagination anymore. We have to knock down the levels of prejudice and ignorance.

The Department of Health and Human Services (DHHS) is leading by example. HHS is spearheading a program that targets college students with developmental disabilities and seeks to move them into areas of gainful employment.

To successfully mainstream those who have been placed on the sidelines in society takes the effort of more than one group or entity. “This is a partnership and we will be with you every step of the way.”

##### **Ramona Warren, Program Manager, Child Welfare/Developmental Disabilities, Administration for Children and Families**

This is an important meeting and a platform to share challenges as well as successes. “A lot of activity and effort is underway to advance discussions and work evolving around Welfare-to-Work and Developmental Disabilities. There is a trend to move things forward and to ensure that our communities are inclusive. It is critical that we work with communities, advocacy groups, and other interested parties.”

**Carlis V. Williams, Southeast Regional Hub Director  
Administration for Children and Families**

This meeting marks the 10<sup>th</sup> anniversary of the Americans with Disabilities Act (ADA). This Act is “one of the most historical acts” in this country. Both the ADA and the Olmstead Decision can be proclaimed under the banner of “inclusion.” Let’s join in celebrating the ADA. Old stereotypes are beginning to be shattered. The United States Department of Health and Human Services and partner agencies continue to make progress in implementing ADA in real ways: enabling developmentally disabled toddlers and pre-schoolers to learn in inclusive Head Start Programs; allowing the disabled the choice and support needed to move into their own homes; actively removing the stigma associated with the mentally ill and other groups of disabled individuals.

My favorite Star Trek character, Captain Jean Luc Picard, would rally his troops for conquests by saying “make it so.” In like manner, participants must continue in the work to ensure equity for the disabled. Parity will occur as advocates “make it so.”

**Ann Rosewater, Regional Director, U.S. Department of Health and Human Services**

The Welfare-to-Work and Olmstead Decision are clearly related and affect each other.

Effective work and placement of individuals with disabilities must be steered from “hiding people.” Moreover, the work in this particular arena should be inclusive of everyone—especially those who will be directly impacted by legislation for the disabled. “We see that the adversarial approach to making changes for persons with developmental disabilities is not productive.” Ms. Rosewater noted that there are a variety of ways in which we are building new alliances to ensure that ADA and the Olmstead Decision activities come to fruition.

**4. MEETING HIGHLIGHTS**

**Renard Murray, Health Insurance Specialist, Medicaid, Health Care Financing  
Administration**

President Clinton signed “The Ticket to Work and Work Incentives Improvement Act of 1999” (TWWIA) on December 17, 1999. Passage of this law marks a significant advancement for people with disabilities since enactment of the ADA. The legislation modernizes the employment services system for people with disabilities and makes it possible for millions of Americans with disabilities to join the workforce without fear of losing their Medicare and Medicaid coverage.

More specifically, the Medicaid Buy-In is designed for individuals between the ages of 16 and 65 who would be SSI eligible except for earnings. If a State covers individuals who continue to be disabled, they may cover those who are employed with a medically improved disability, but continue to have a “severe medically determinable impairment.”

The “Medicare Connection” also translates into an extension of the current 39 months of free Medicare Part A after a trial work period. Now, Medicare coverage, under TWWIA, is available for an additional 4½ years.

Specific elements within the TWWIA Infrastructure Grants are also instrumental in paving the road to parity and equity for the disabled. These grants are 100 percent Federal Financing Participation (FFP) and are created to design, establish, and operate infrastructures that support working individuals with disabilities. States are to conduct outreach campaigns to inform individuals about the infrastructures; States must also provide “personal assistance services” under Medicaid. The allotment is \$150,000,000 over 5 years. TWWIA Demonstration Grants cover workers with potentially severe disabilities; these individuals are defined as being between the ages of 16 to 64, meets State established criteria of physical or mental impairment and who can reasonably be expected to become blind or disabled unless the full range of Medicaid services is provided. \$250 million has been allocated for funding beginning in FY 2001. Additionally, States must meet the maintenance of effort (MOE) requirement. Several TWWIA, SSA changes have occurred since implementation of the legislation. Accordingly, these changes include, but are not limited to:

- Creation of a Ticket to Work and Self-Sufficiency program
- SSI and SSDI disability beneficiaries can use “tickets” to obtain VR services, employment services and other support services through Employment Networks
- Expedited reinstatement of benefits
- Prohibition of disability reviews based on work activity if individuals have received benefits for 24 months.

**Kathy Burton, Project Director, Florida Developmental Disabilities Council**

In 1998, the Florida Developmental Disabilities Council received \$1.6 million from the U.S. Department of Labor in the round one Welfare-to-Work (WtW) competitive grant. It is a 3-year (July 1998 - July 2001) grant and we’re optimistic we will receive an extension. The Florida Council partnered with the Seminole Community College and the Palm Beach Habilitation Center in this competitive grant that targets the hardest-to-serve welfare participants,

with learning and other disabilities for job placement in the tourism industry. Our work opens the door into the workforce development system in a way that we have not been involved before. There are a lot of Federal and State initiatives right now that are changing the workforce development system. In this period of change it's a time for us to advocate for persons with disabilities.

The initial design of the grant was the Supported Employment Model; this is a successful model that has been used since the '80s and provides ongoing support for clients. To date, there are 177 participants in the program between the ages of 17 to 57, and 63 of these individuals are working. We targeted WtW and TANF clients with disabilities based on the high unemployment rates among these clients; also prevalent among this targeted population are hidden disabilities and the staggering level of poverty. The 1990 Census indicated that 22 percent of working age people with disabilities live "on or below the poverty level." An additional 12 percent are classified as "near poor." Almost 60 percent of long-term TANF recipients are people with disabilities—42 percent have learning and behavioral disabilities, 15 percent have emotional disabilities, and 18 percent have some degree of mental retardation. These statistics were "confirmation" of the need to extend services within this population. As we continue working with the project, we are finding that these numbers are "bearing out."

In some arenas we've had success but in others "we have a long way to go." Literacy challenges and lack of work skills are now seen as only part of the challenges for these clients. Their disabilities are not the only issues that arise; family relationships, emotional struggles, and financial situations must be considered when placing disabled clients. Some other issues are people with disabilities not being identified and referred for service; high turnover of caseworkers, privatization, and the lack of reliable transportation and child care. The program provides assessments, matching the participant to an appropriate job and employer; job coaching; and long-term support and follow-up, including "follow-along" counselors for up to three years after placement.

### **Becky Crowe and Annette Perryman, Goodwill Industries**

Goodwill received a \$5 million Welfare-to-Work competitive grant for the funding period of July 1998 through June 30, 2001. This grant led to the creation of *Good Works*, the brainchild of Georgia Department of Labor Commissioner Michael Thurmond and operationalized by Goodwill. The Georgia Department of Labor provides funding to assist those remaining on the welfare rolls transition into employment before their benefits expire December 31, 2000. Key elements of *Good Works* include customized work evaluation, comprehensive vocational assessment, analysis of financial and personal situations, participation in hands-on paid work

experience, seminars, computer basics, computer-based keyboarding, literacy, GED, and other tutorials, and counseling. Partners for this program are Richmond Burke County Job Training Authority, Department of Family and Children Services, Georgia Department of Labor, Department of Rehabilitative Services, and Ready for Work - Substance Abuse Treatment Facility.

There are currently 120 participants in *Good Works*, which takes a holistic intensive approach to help individuals get the tools needed to succeed in the work place. We have set up a career center with Job Connection Office offering intake, assessment, training and placement services to the hard-to-employ, non-custodial parents and the learning disabled. The participants use community resource brokering services and *Good Works* provides ongoing assistance for about one year to assure success in the employment setting with participants who get jobs.

Collaboration is key to the program's success. This premise is the foundation for the mission of Goodwill, whose mission is to build lives, families, and communities—one job at a time—by helping people discover their natural talents through work and career development services. In the past 12 months, Goodwill brokered the employment of 1,463 people, generating more than \$22 million in new payroll purchasing power, which leads to self-sufficiency for the individuals placed.

### **Randy Fadler, Department of Labor/Employment and Training Administration**

The Department of Labor (DOL) has 29 Welfare-to-Work competitive grants and 46,000 WtW competitive grant clients. Approximately 132,000 clients will be served. DOL is doing our part and making significant improvements; but there is more work to be done. More needs to be done to have persons with developmental disabilities begin to work and have job opportunities. The eligibility requirements for the WtW competitive grants were recently revised and can be at DOL's Web site ([wtw.doleta](http://wtw.doleta)). DOL's Web site also has an ETA disAbility Online link which has updated information on "The Ticket to Work and Work Incentives Improvement Act of 1999" (TWWIA).

Under the Workforce Investment Act (WIA) of 1998, States were to establish workforce investment boards to provide workforce investment activities, through statewide and local workforce investment systems, that increase the employment, retention, and earnings of participants, and increase occupational skill attainment by participants, and, as a result, improve the quality of the workforce, reduce welfare dependency, and enhance the productivity and competitiveness of the Nation. As of July 1, 2000, the States of Florida, South Carolina, Tennessee and Kentucky have workforce investment boards in place. Twenty million dollars has

been set aside for the WIA/One Stop Shops to carry out statewide employment and training activities such as initial assessment of skill levels, aptitudes, abilities and supportive service needs; job search and placement assistance, and where appropriate, career counseling. These services will empower individuals with disabilities to obtain employment and achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society. A list of stakeholders has been developed with the names of eligible providers of training services. To date, 30 million of the 50 million Americans with disabilities are of working age. He noted that hidden disabilities would impact the disabled as they seek to retain and advance in being gainfully employed.

**Janie Tapp, Administration for Children and Families/Temporary Assistance to Needy Families (TANF)**

Attempting to match individuals with disabilities with the services they need has gotten to be a real quandary for TANF providers. As a result, there is more talk about partnering in “unique” ways to get more needs met effectively. Now we need to get serious about collaboration. There is a need to put money together rather than remaining as discrete entities. The Department of Labor and the Department of Health and Human Services (TANF) need to work together and each offer what they are able to. All of the agencies that receive money to provide services to families, individuals, and children need to be seen as part of the movement to help get people off welfare and into jobs. These linkages are critical to addressing the needs of individuals beyond the welfare rolls. We want to make sure these individuals have “the best shot” at making a life for themselves without being dependent on public assistance.

The Office of the Inspector General (OIG) published a report in August 1999 that looked at employment programs for persons with developmental disabilities. The report indicated that some barriers which impede the development of employment programs are: a lack of transportation; fear of losing Medicaid or a monthly Supplemental Security Income check; negative perceptions held by employers; and a lack of flexible financing arrangements among State entities. Some of the other barriers to employment programs for persons with developmental disabilities are poor job matching; high speed production jobs which are too stressful, outdated pre-vocational training models (being trained for jobs that no longer exist); sheltered workshops and offering too many financial incentives to employers. These barriers may be addressed by the Work Incentives Improvement Act of 1999, which will expand Medicaid options for States and encourage SSI beneficiaries to return to work by providing an assurance that cash benefits will remain available if employment proves unsuccessful.

### **Sue Jamieson, Attorney for Plaintiffs in Olmstead Lawsuit**

The disabled are often disregarded in “mainstream society.” They are in front of their televisions with their heads bowed down. They’re revolving in and out of institutions. Many are living their whole lives in a mental retardation facility. I don’t see an acknowledgment to move them into the community. If you are segregated in some intermediate care facilities for people with mental retardation (ICF/MRs) in this country, you are completely isolated from society. You remain as forgotten as if the ADA had never been passed.

The *Olmstead* case was brought by two Georgia women whose disabilities include mental retardation and mental illness. At the time the suit was filed, both plaintiffs lived in State-run institutions, despite the fact that their treatment professionals had determined that they could be appropriately served in a community setting. The plaintiffs asserted that continued institutionalization was a violation of their right under the ADA to live in the most integrated setting appropriate. The *Olmstead Decision* interpreted Title II of the ADA and its implementing regulation, which oblige States to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities.” In doing so, the Supreme Court answered the fundamental question of whether it is discrimination to deny people with disabilities services in the most integrated setting appropriate. The Court stated directly that “Unjustified isolation . . . is properly regarded as discrimination based on disability.” It observed that “institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life,” and “confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” This decision confirms what we already believe: that no one should have to live in an institution or a nursing home if they can live in the community with the right support. Our goal is to integrate people with disabilities into the social mainstream, promote equality of opportunity and maximize individual choice.

The *Olmstead Decision* said States are obliged to “make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program or activity.” Institutionalization severely limits the person’s ability to interact with family and friends, to work and to make a life for him or herself. Meeting the fundamental alteration test takes into account three factors: the cost of providing services in the most integrated setting; the resources available to the State; and

how the provision of services affects the ability of the State to meet the needs of others with disabilities.

The State's treating professionals should determine whether or not community placement is appropriate for the individual; however, there is a fear of legal ramifications, on their part. Other aspects to consider include whether the individual is opposed to community placement and whether this type of placement is appropriate. Persons with disabilities should be involved in the placement process.

To help States comply with the Court ruling, HCFA and the HHS Office for Civil Rights have begun working with States and the disability community toward the goals of promoting home- and community-based services; honoring individual choice in service provision; and acknowledging that resources available to a State are limited by the need to serve both community-based and institutionalized persons.

**Roosevelt Freeman, Regional Manager, Office for Civil Rights**

It is important for society to make a commitment to the most vulnerable. In this new role, (Mr. Freeman was just appointed as Regional Manager of the Department of Health and Human Services' Office for Civil Rights), my primary responsibility is to enforce their civil rights. We had an integration mandate that existed previously, but only for those who had received resources from the Federal government. Not everybody embraced the opinion that inappropriate institutionalization constituted discrimination. But even if you do not treat these individuals "badly" or poorly, you can still violate the civil rights principles.

If one plan exists for administering services and maintaining the rights of the disabled, States can execute the plan individually. Given the structure of the State, the plans can be tailored in a manner that is most effective for the particular regions. While States will have separate methods for achieving goals of integration and equity for the disabled, all plans have to be compliant in specific areas. There is also a need to remember that some individuals may not meet the standard of having a disability if their condition is alterable upon taking medication. There is a need for all stakeholders to be active participants in administering effective plans. This will only be achieved, as stakeholders (i.e., advocates, consumers, etc.) become an integral part of the process.

Key Points for State Plans:

- Must be comprehensive work plans that cover all disabled individuals in the various groupings
- Must provide an opportunity for the disabled to participate in the planning process in “meaningful ways”
- Must include community innovative services
- Must be compliant with existing statutory framework
- Must have the tools necessary to assess those in institutions and those at risk of being institutionalized.

**Dorothy Smith, Health Insurance Specialist, Health Care Financing Administration**

As the *Olmstead Decision* contact person, I’ve collaborated with several agencies within the Department, including Office of the Regional Director, Office for Civil Rights (OCR), the Office of General Counsel and now with the Administration for Children and Families regarding the *Olmstead Decision* and the States in the Atlanta region. While OCR has enforcement responsibility of the ADA, Medicaid plays a primary role, as a funding source, in facilitating the availability of home- and community-based services in the States.

Medicaid home- and community-based waiver services often make the difference between someone being in the community or being in an institution. These services may include assistance with personal care and grooming, housekeeping tasks, day services, and supported employment. Assistance with personal care is most often provided as a home- and community-based waiver service, rather than a State plan service. The distinction between home and community-based waivers and State plan services are as follows.

**State Plan Services:** The State is required to have a plan that describes the Medicaid services it will provide and the criteria for the services. Certain services are mandatory and others are optional. State plan services must be available statewide and the scope of services must be the same for the entire State. Clients must have a free choice of providers. The Medicaid State Agency establishes the provider enrollment criteria and any provider meeting the requirements must be allowed to enroll. With State plan services, the Medicaid Agency cannot limit the number of people who can receive the services. If someone is Medicaid eligible and meets the criteria for the services, then those services must be provided. There are, however, exceptions to these rules, such as targeted case management. It is a State plan service, but States may restrict it to certain groups or geographical areas.

**Home- and Community-Based Waivers:** When the State wishes to provide services in a manner that is not consistent with the State plan requirements, (e.g., They want to limit services to a certain county or can only make the services available to a limited number of people) then the State applies for a waiver. Medicaid Agencies may apply for several types of waivers. The type of waiver a State applies for is based on the requirement that the State wishes to have waived. Under home and community-based waivers (1915(c)), States may waive comparability and state-wideness. With this waiver authority States may restrict services to a certain county or limit the number of individuals that may receive the services. States are required to advise HCFA in the waiver application the number of individuals that will be served. There is an option that allows States to serve the lesser of the number of individuals indicated in the waiver application or the number of individuals the State is authorized to serve, based on available State funding.

Even though States may limit the number of individuals served through their Medicaid waiver programs, they still have an obligation to make home- and community-based services available as indicated in the *Olmstead Decision*.

As a part of a quality initiative, HCFA has been working for the last 8 months on updating the quality and monitoring protocol for home and community-based waivers. HCFA's goal is to assess and ultimately improve services provided through home- and community-based waiver programs. The review of the monitoring protocol has included participation from the States and advocacy organizations.

Nationally, from 1992 through 1998, the number of clients receiving home and community-based services has increased approximately 218 percent from 235,000 to 514,000. Expenditures have increased approximately 374 percent, from a little more than \$2 billion to more than \$8 billion. In the Atlanta region, there are 41 home- and community-based waivers; this number represents a 41 percent increase since 1990 when the ADA was passed. While this data indicates growth, this progress hasn't been enough to keep up with the need for community based services.

HCFA in support of ADA and the *Olmstead Decision* has released several letters to the State Medicaid Directors. In the January 14, 2000, letter, from HCFA and OCR, the Department offers to provide technical assistance to the States and discusses the role of Medicaid and the OCR in regard to the *Olmstead Decision*. This letter also gives States guidance for development of comprehensive plans. Additionally, this letter highlights HCFA's commitment to review its policies and regulations to ensure that HCFA's policies support States' abilities to make home- and community-based services available.

The July 25, 2000, letter from HCFA contains policy changes and clarifications made in response to suggestions that came in from States and advocacy organizations. The letter specifically:

- Clarifies the earliest date of service that Federal financial participation (FFP) can be claimed for waiver services and allows for a provisional plan of care for the first 60 days of waiver eligibility.
- Allows Medicaid reimbursement for the provision of waiver services (i.e., case management and home modification) as a transition service when people are moving from an institution into the community. The policy change allows the provision of waiver services up to 180 days prior to discharge. Prior to this change, there was a 30-day allowance.
- Allows payment for personal assistance services provided under the waiver for up to 30 days when someone is hospitalized or away from his or her home.
- Clarifies that habilitation services (i.e., supported employment) may be provided to all age groups and to all target populations. These services are not limited to persons with mental retardation and developmental disabilities.
- Clarifies the circumstances under which Medicaid home- and community-based waiver services may be provided out-of-state.
- Clarifies that States may be reimbursed for services, usually provided by a nurse, that are provided under the authorization of a nurse.
- Provides clarification that homebound requirement is not applicable to Medicaid. This requirement maintains that the State cannot arbitrarily deny home health services based on the homebound requirement. HCFA has received a lot of feedback from the States regarding this clarification and additional guidance will be forthcoming.

If you have questions about how the policy clarifications and changes will affect activities in your State, you should talk to your State Medicaid Agency waiver staff. The impact of the *Olmstead Decision* in HCFA, in terms of our workload, has not yet been manifested. States are still in the early planning stages and have not begun revising their services. We anticipate there will be amendments to current waivers, development of new waivers, and increases in the number of individuals who will be served in the existing waivers.

It is not too late to propose policy changes to HCFA regarding the future of home and community based waivers. The HCFA *Olmstead* Web site [www.hcfa.gov/medicaid/olmstead/olmshome.htm](http://www.hcfa.gov/medicaid/olmstead/olmshome.htm) provides information on the policy changes and may be used to submit recommendations.

**Pat Seybold, Executive Director of the Kentucky DDC**

The original intent of House Bill 144 was to address the “waiting list” for community-based services for persons with mental retardation and other developmental disabilities in Kentucky. The bill was created to complement, enhance and expand Kentucky’s current Supports for Community Living Medicaid Waiver (SCL). House Bill 144 set forth an allocation of \$50 million in State general funds to be matched with Federal Medicaid funds to expand the current SCL. It was not originally created to address the *Olmstead Decision* although many people who are on Kentucky’s “waiting list” do reside in institutions and will benefit from the legislation. The bill allocates new State general fund dollars to be matched with Medicaid funds to provide a substantial increase in the current level of funding available for community based services and supports. This was the first time in more than 30 years that new State general funds had been allocated for this purpose.

The inception of House Bill 144 began in September 1999, when the Commonwealth of Kentucky participated in the President’s Commission on Mental Retardation (PCMR). This group was asked to propose a plan to address long-term needs of individuals with mental retardation and other developmental disabilities in Kentucky. The two major factors driving the decision to participate in the PCMR were: (1) The fact that in 1999 Kentucky ranked 49<sup>th</sup> in the nation in community based service and supports to individuals with mental retardation and other developmental disabilities. (2) The waiting list in 1999 was more than 1,500. The PCMR is comprised of several representatives: self advocates, State Agency Representatives, community business leaders, State House and Senate (bipartisan) legislative representation, executive directors of protection and advocacy, the University Affiliated Program, the Developmental Disabilities Council, and a variety of service providers.

The initial project of the PCMR team was to establish key objectives prior to beginning the development of the proposed legislation. The first objective was to address the waiting list for community-based services for individuals with mental retardation and other developmental disabilities. The second was to address this need without sacrificing services and supports to individuals currently making the choice to reside in an institutional setting. With these concepts in mind, the group developed the framework for what was to become House Bill 144. I cannot stress enough that the make-up of the PCMR team was “key” to its success upon returning to Kentucky.

The legislation outlines six key mandates for the Commission. They are as follows:

- The development of a statewide strategy to increase access to community-based services and supports for persons with mental retardation and other developmental disabilities
- The second mandate asks the Commission to assess the need and potential utilization of specialized outpatient clinics for medical, dental, and special therapy services for persons with mental retardation and other developmental disabilities.
- The third mandate requires the Commission to evaluate the effectiveness of State agencies and public and private providers, including profit and non-profit providers in: (a) the dissemination of information and education, (b) providing outcome oriented services, and (c) efficiently utilizing available slots and resources including funding streams.
- The fourth mandate requires the Commission to develop and recommend a comprehensive 10-year plan for placement of qualified persons in the most integrated settings, appropriate to their needs.
- The fifth mandate requires the Commission to recommend an effective quality assurance and consumer satisfaction monitoring program that includes recommendations as to the appropriate role of family members, persons with mental retardation and developmental disabilities and advocates in quality assurance efforts.
- The final mandate requires the Commission to advise the Governor and the General Assembly on whether recommendations should be implemented by administrative regulations or proposed legislation for the 2002 General Assembly.

The Governor signed following the passage of House Bill 144, an administrative order that supports the legislation. It includes a mandate for Medicaid to implement an emergency regulation to amend the current Supports for Community Living Waiver to include new language that assures flexibility in service provision and reimbursement.

Further, Medicaid was to implement emergency regulations to assure the timely implementation of House Bill 144. The proposed language includes key wording for consideration of emergency status on the waiting list. The most significant language change includes wording that places individuals who meet the following criteria in the emergency waiting list, thus placing those individuals ahead of others currently on the waiting list but not considered emergency status. While this language is currently embedded within a temporary order, it is clearly a tie to the *Olmstead Decision* and was specifically written for compliance purposes. The proposed language changes will go before the public in the near future.

This legislation only covers persons with mental retardation and other developmental disabilities. Kentucky has formed an Olmstead Commission and has received a Robert Wood Johnson grant to develop a complete plan for all individuals affected by the *Olmstead Decision*. House Bill 144 will be used as a format for that grant and will dovetail with the development of a comprehensive plan for addressing the *Olmstead Decision* in Kentucky.

### **Larry Swabe, North Carolina Council on Developmental Disabilities**

Larry Swabe discussed the Self-determination Project underway in North Carolina. Self-determination refers to modifications in the service system to put people with disabilities or their families in charge of their own lives. Accordingly, the person with a disability would decide what services are needed and direct their purchase using public monies. The State of North Carolina received funding for these efforts through the Robert Wood Johnson Foundation and the North Carolina Developmental Disabilities Council. While funding is critical to realizing these goals, partnership is yet another key. Partners that supported North Carolina's efforts include the Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (DMH/DD/SAS), the Division of Medical Assistance (DMA), and the Division of Vocational Rehabilitation (DVR).

The following describes the pilots:

- **The Mountain Consortium**—consisting of three area programs/DD authorities (representing 13 counties) in Western North Carolina—Blue Ridge, Smoky, and Trend Area Mental Health Programs. This program is responsible for creating a group of support brokers and fiscal intermediaries for the disabled. The Consortium has a very active group of parents and consumers who set policy and procedures for this entity.
- **Project Odyssey**—Partnership between two North Carolina counties (Orange and Person), Chatam Area Program, and Easter Seals of North Carolina. This pilot serves persons with developmental disabilities by offering support brokers and fiscal intermediaries.
- **Challenge 2000**—Self-determination Resource Center—the Center acts as a “business agent” for participants in the project, and serves as a central source of information and education for the project. They are working with an urban area DD authority.
- **The Lighthouse**—Arc of North Carolina—Wilmington—provides leadership to this initiative in collaboration with Area DD Authority. This pilot, from its inception, has included a strong emphasis and partnership with vocational rehabilitation and very strong self-advocate involvement.

By way of reflection and assessment, the pilots may have achieved more success had they forged State partnerships earlier and had better coordination of self-determination related projects. Moreover, a greater focus on developing strong trusting relationships between families/ participants and the professionals, coupled with greater involvement of self advocates, would have been more effective.

## **5. FINAL REMARKS**

In general, participants viewed this meeting as a helpful way to bring pertinent issues regarding the developmentally disabled and their treatment in society, particularly in the workforce, to the forefront. Speakers and participants acknowledged progress has been made with respect to individuals with specific challenges. In hosting this very important meeting, Region IV has made great strides in responding to the Olmstead Decision within the context of WtW and TANF. However, everyone who participated in this meeting agreed that current efforts must continue and be built upon in the future.