Oklahoma Olmstead Strategic Plan

Prepared by the

Oklahoma Olmstead Strategic
Planning Committee

August 3, 2006

Making Choices a Reality in Oklahoma

Olmstead Strategic Planning Committee
Values and Principles

OKLAHOMA INDIVIDUAL AND FAMILY SUPPORT PRINCIPLES ... are guiding truths that shape the way individuals, families and service providers interact ... establish common ground upon which individuals, families, advocates and service providers operate ... form the basis for program policy and practice.

WHEN WE ENGAGE WITH INDIVIDUALS AND FAMILIES WE WILL ...
HONOR THEIR EXPERTISE and right to make choices that they know to be in their own best interest.

RESPECT AND ACCEPT THEIR VALUES that are based in personal preferences, cultural beliefs and life-ways.

SUPPORT INDIVIDUAL AND FAMILY RELATIONSHIPS that are safe, stable and long lasting.

FOCUS ON THE ENTIRE FAMILY as it is defined by the family.

PROMOTE FLEXIBLE SERVICE AND FUNDING supporting individual and family control of who, what, when, where and how supports are provided.

AFFIRM LIFESPAN PLANNING AND SELF-DETERMINATION that encourages decision making and planning for independence beginning within the family when children are young, following the individual throughout their life and including aging issues.

ASSURE PARTNERSHIPS THAT ACTIVELY INCLUDE INDIVIDUALS AND FAMILIES in planning, development, implementation and evaluation of policies, practices and personal programs.

PRACTICE OPEN COMMUNICATION promoting a clear understanding of all aspects of systems policy, procedure, practice and all other information regarding them.

RECOGNIZE THE IMPORTANCE OF THE COMMUNITY ...

Developed by the Oklahoma Family Support Partnership / Center for Learning and Leadership / UCEDD University of Oklahoma Health Sciences Center, College of Medicine.

Table of Contents

APPENDICES

SECTION I

Executive Summary

The Oklahoma Legislature created the Olmstead Strategic Planning Committee (Committee) to assist the state in implementing the U.S. Supreme Court's decision in *Olmstead v. L.C.*, which requires states to provide services that enable individuals with disabilities to live in community settings rather than in institutions. (See Olmstead Overview, page 41)

The legislature charged the Committee with drafting the Oklahoma Olmstead Strategic Plan (Plan) to be submitted to the legislature and the Governor. The Plan outlines strategies to assure that persons with disabilities are provided with the services and supports necessary to move out of an institutional settings, if they so desire.

As stated in the Americans with Disabilities Act of 1990, the term 'disability' means, with respect to an individual: (A) a physical or mental impairment that substantially limits one or more of the major life activities of such individual; (B) a record of such an impairment; or (C) being regarded as having such an impairment.

Oklahoma Senate Bill 2017 (2006) extended the work of the Committee through June 30, 2007. The purpose of this extension was to utilize the Committee to work with state agencies to ensure implementation of the Oklahoma Olmstead Strategic Plan. The make up of the Committee and the longevity of its membership provides a rare opportunity for an alliance between individuals and groups with diverse interests.

The Oklahoma Olmstead Strategic Planning Committee includes representatives from state agencies, advocacy organizations, local service providers, individuals with disabilities and families of individuals with disabilities. This Committee is well positioned and uniquely qualified to provide technical assistance to state agencies and other entities in the service delivery systems as they change policy and infrastructure to support the Oklahoma Olmstead Strategic Plan.

The Plan includes information about recent developments made by the state of Oklahoma. These developments include legislation to improve certain aspects of service delivery and policies. The developments demonstrate progress in establishing the infrastructure needed to achieve the goals set forth by the Oklahoma Olmstead Strategic Planning Committee. These developments were achieved through the collaboration and coordination of the Committee members. They reflect a strong commitment to enable people with disabilities to live, work and play in their home communities instead of living restricted lives in institutional settings.

The Plan also contains a section on cross-systems recommendations. This section addresses changes that will impact services in all systems. Disabilities can happen to anyone at any time, so every system has a role in serving people with disabilities.

Oklahoma Senate Bill 2017 also contains a requirement for Oklahoma to develop a pilot program for individuals to transition from institutional settings to community-based service and for Oklahoma to adopt People First Language. People First Language means that people with disabilities are people first and they just happen to have a disability. (See page 12 for more detail.)

State of the State

The growing need for community-based services for persons with disabilities in Oklahoma surpasses the current capacity to meet those needs. Oklahoma must enhance the statewide infrastructure to support people with disabilities who desire to live in their local communities. This action requires that state agencies have a programmatic and philosophical commitment to developing and improving the quality and capacity of services within the local communities.

According to the U.S. Census Bureau, 19.6 percent of the state's population, or 676,098 Oklahomans age five and older, report they have a disability. Of that 19.6 percent approximately 7.2 percent have disabilities that require support services.

The Oklahoma Health Care Authority reports that 16,717 individuals age 21 and older who receive Medicaid services are living in long-term care facilities.

Community-based services must be a priority above institutional services. Funding should be flexible and adequate to address a range of needs. The policies and practices of the state agencies should support creative and common sense alternatives to institutional placements. The agency personnel must work with the individual, families and community service providers to maintain a high level of trained personnel who have the skills to work in partnership with the individuals with disabilities and their families to meet their needs.

According to the Oklahoma Health Care Authority Annual Report FY05, Oklahoma spends 68 percent of its long-term care dollars on nursing facilities and public and private intermediate care facilities for individuals with mental retardation (ICF-MR).

"Help isn't help unless it is what you need, when you need it."

Focus Group Report on Medicaid Managed Care, Fall 2000

Only 32 percent of the state's Medicaid funds are spent for community supports. Shifting the dollars to community-based services will, in most cases, result in cost savings to the state.

For instance, in 2005 the Oklahoma Department of Human Services (OKDHS), Developmental Disabilities Services Division (DDSD), served 4,448 people in the community with Medicaid home and community-based waivers for $212,234,069 for an average annual cost of $47,700. In public and private ICFs/MR, 1,987 people were served for $113,090,850 at an average annual cost of $56,000.

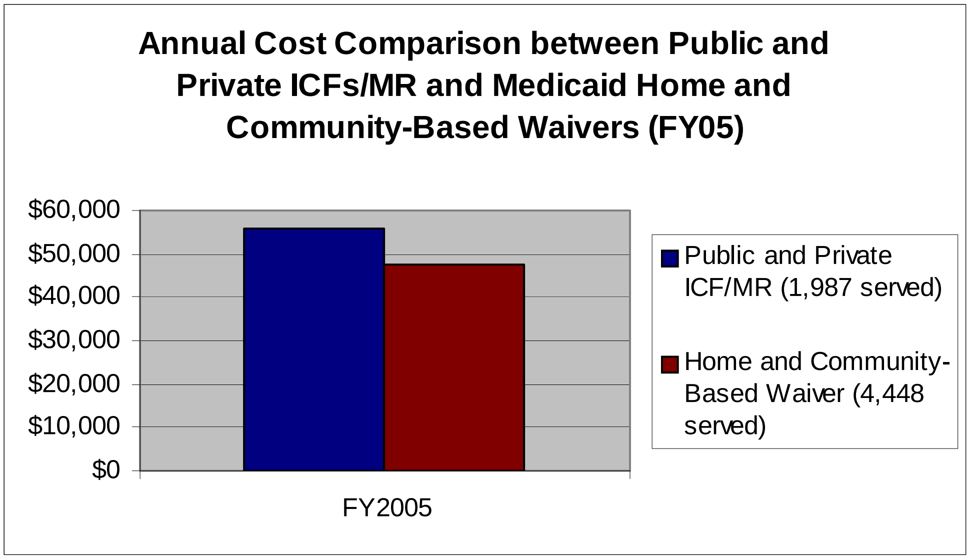
The average annual savings of providing individualized waiver services was $9,200 per person. For people with the most complex disabilities the savings are significantly higher. The average annual cost for the 442 residents of the public ICFs/MR is $147,000 compared with $60,800 for the 1,654 individuals receiving comprehensive services in the community waiver.

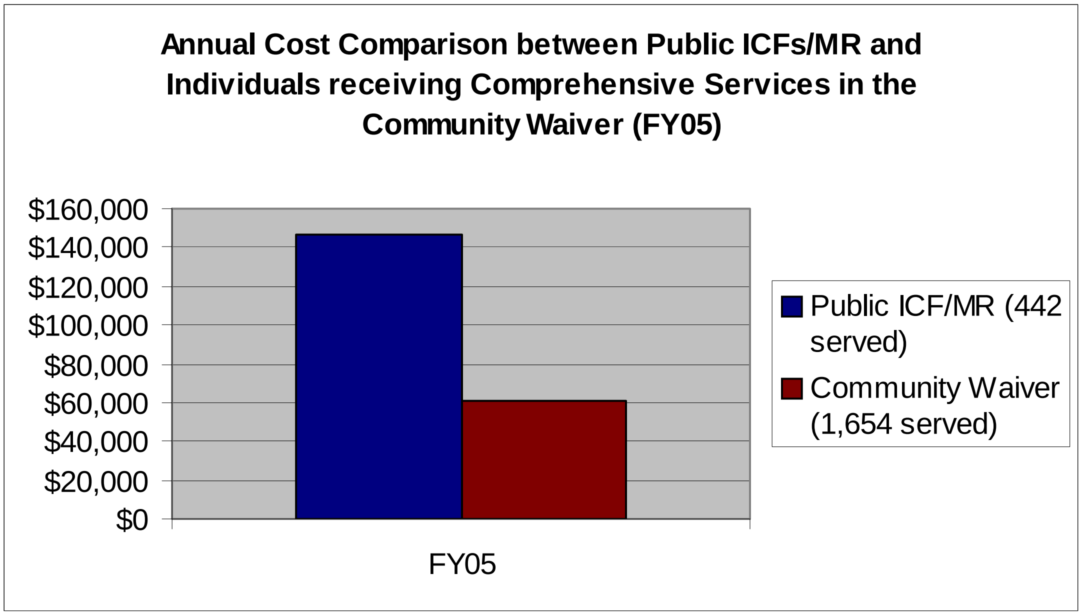
The ADvantage program in Oklahoma is a Medicaid community-based waiver that currently serves 14,700 people who are older than age 60 and/or have a physical disability. The average cost per person in the ADvantage program is $10,000 per year as compared to $40,000 for nursing facilities.

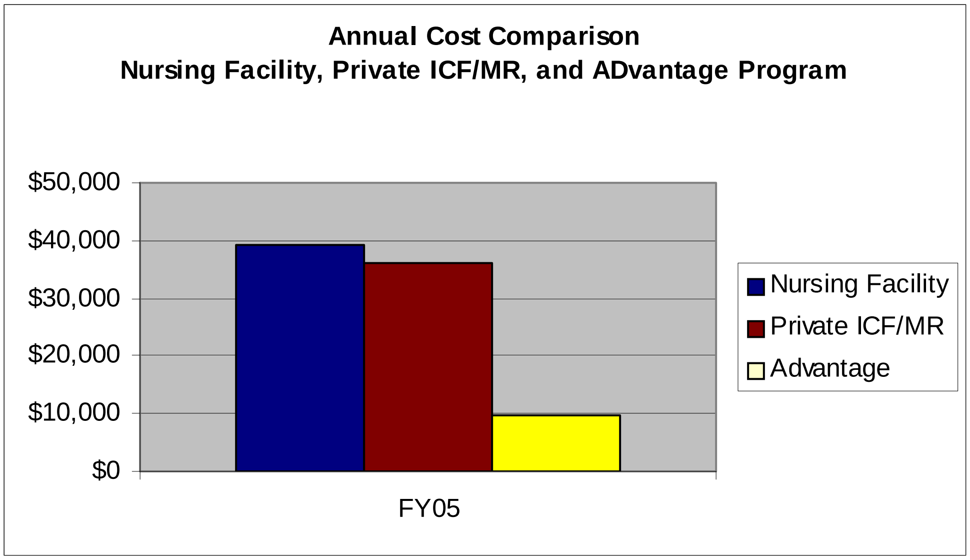
There are other services that contribute to the infrastructure of community-based services and supports. These services include physically accessible and affordable housing and transportation. Persons with disabilities often are restricted from leaving an institutional setting because they cannot find housing that is physically accessible nor do they have accessible transportation. These factors subsequently affect their ability to secure employment.

In order for persons with disabilities to live in the community they must have access to the services that are available to all citizens of Oklahoma. The Oklahoma Olmstead Strategic Plan addresses the fact that all state and local services need to be accessible and responsive to our citizens with disabilities. It is not the job of one agency to meet all the needs of persons with disabilities.

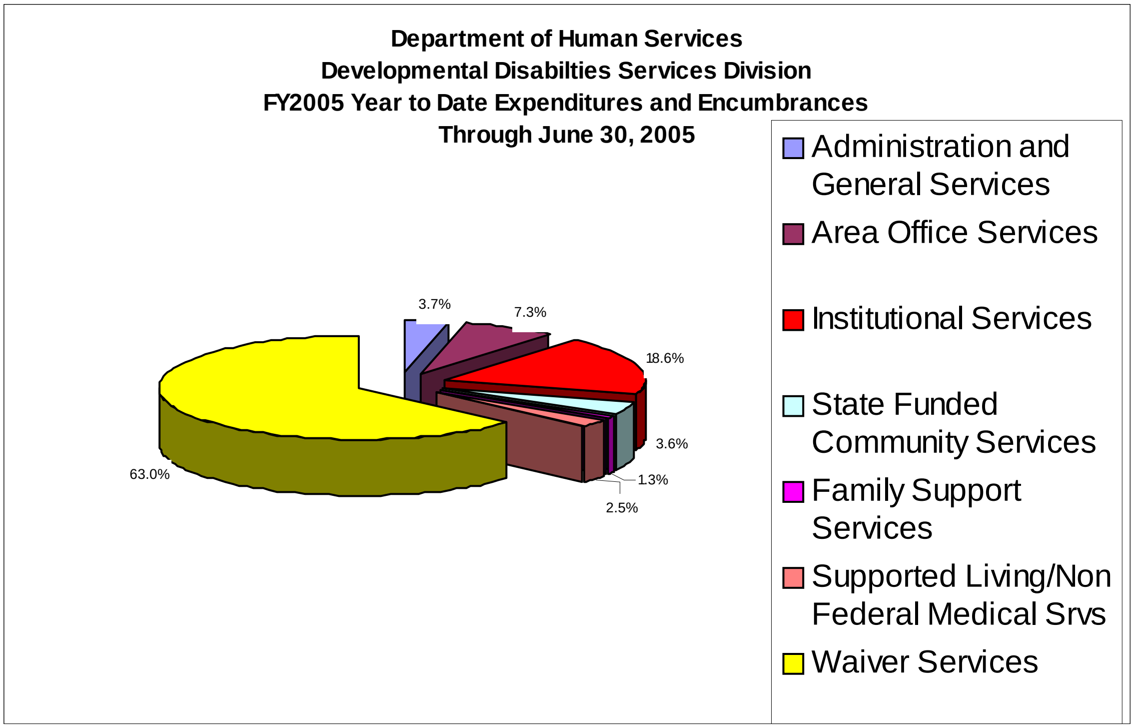
There must be a coordinated effort across all service systems. Human service agencies cannot provide adequate support if there is no affordable housing, no transportation to get to work, and limited employment options for people with disabilities. If we provide these services for people with disabilities within the municipal and state structures, it also will be available to other citizens.



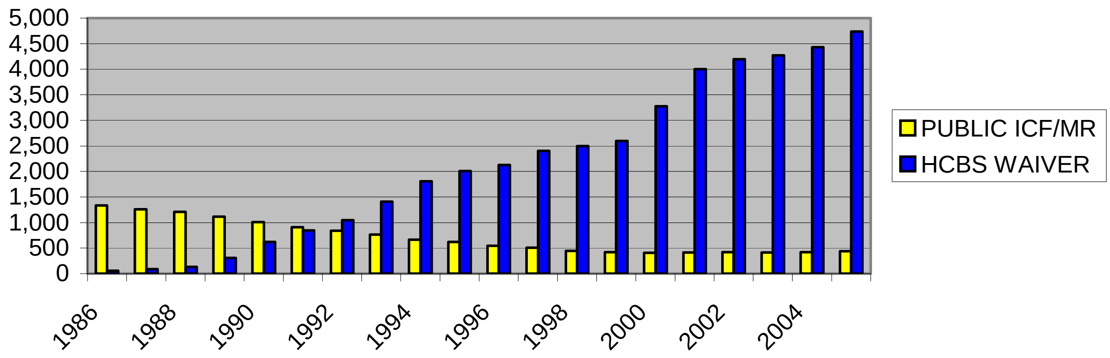




Annual Cost Comparison
Nursing Facility, Private ICF/MR, and ADvantage Program



Department of Human Services
Developmental Disabilties Services Division
FY2005 Year to Date Expenditures and Encumbrances
Through June 30, 2005



20 Year Comparison of Institutional Population/Community Population

SECTION II

Recent Developments

Senate Bill 2017: Opportunities for Independent Living Act

The Opportunities for Independent Living Act (SB 2017) was signed into law by the Governor on June 7, 2006. This Act extends the work of the Olmstead Strategic Planning Committee until July 1, 2007, creates the Opportunities for Independent Living Act, and provides for People First Language.

The Opportunities for Independent Living Act:

1) Instructs the Oklahoma Health Care Authority (OHCA) to establish and maintain a three-year pilot program to assist qualified individuals with disabilities living in institutions to transition into the community;
2) Authorizes OHCA to enter into contracts with organizations that are consumer-controlled, non-residence-based, community-based, nonprofit organizations with experience in transitioning persons with disabilities into community settings;
3) Authorizes OHCA and contracted entities to establish an effective system that allows money to follow pilot program participants from the institutional setting to the community;
4) Increases pilot participant access to safe and affordable housing; and
5) Authorizes OHCA to use available funding to assist eligible persons to:
    a) Pay rent deposits;
    b) Pay utility deposits;
    c) Purchase initial household supplies;
    d) Purchase basic initial household appliances; and
    e) Purchase initial furniture and pay moving costs.

Beginning November 1, 2006, all new and revised statutes, administrative rules, local laws, ordinances, charters, or regulations promulgated or any publication published by the state or any political subdivision that refers to persons with disabilities shall:

1) Avoid language that implies that a person as a whole is disabled, or equates persons with their condition, such as "the mentally ill," "learning disabled," "mentally retarded," or equates a person with their condition, such as "epileptic," "autistic," or "quadriplegic"; and
2) Replace non-respectful language by referring to persons with disabilities as persons first. For example, persons with disabilities, persons with developmental disabilities, persons with mental illness, persons with mental retardation, persons with autism, or persons with epilepsy.

Self-Directed Care Act

The Oklahoma Self-Directed Care Act, 56 O.S.Supp.2005 § 198.12 *et seq*., was signed into law by Governor Brad Henry on June 6, 2005. This Act is a major victory for people with disabilities in Oklahoma. The Act contains the following measures:

- Establishes a self-directed services pilot in the Oklahoma Department of Human Services' home and community-based waivers;
- Establishes a self-directed services pilot in the Medicaid State Plan Personal Care Services;
- Instructs the Department of Human Services (OKDHS) to appoint an advisory committee of consumers, family members, advocates, providers and the Center for Learning and Leadership to assist OKDHS in the development of policies and procedures for self-directed services and a functional needs assessment tool;
- Provides for a feasibility study on the future design and implementation of expanding home and community-based waiver services to unserved and underserved populations such as people with traumatic brain injury, spinal cord injury, and other developmental disabilities without a diagnosis of mental retardation.
- Provides for Medicaid money to follow a person whether he/she is moving from an institutional placement into the community or from the community into an institutional placement.

The Self-Directed Care Act will allow an individual or a representative to do the following through a fiscal agent:

- Hire and fire staff who will provide support services in the home of the individual;
- Purchase basic services to assist in:
    Getting in and out of bed, wheelchair or motor vehicle;
    Bathing, grooming, personal hygiene, dressing and eating;
    Acquiring, retaining and improving self-help, socialization and adaptive skills;
    Respite services; and
    Health maintenance activities.
- Purchase ancillary services:
    Includes housekeeping chores that are essential to the health and welfare of the consumer; and
    Transportation services to enable the consumer to gain access to waiver services and other community services, activities and resources.

- Set the rate of pay for in-home personal care attendants and Habilitation Training Specialists within the established Medicaid rates;
- Homemaking chores;
- Purchase medical supplies, incontinence supplies and adaptive equipment at the most cost effective location;
- Purchase day care and respite services; and
- Purchase home modifications and assistive devices.

Since the passage of law:

- The Self-Directed Services Advisory Committee and OKDHS Developmental Disabilities Services Division began work on the pilot program in November 2005.
- The pilot program has been scheduled to begin in August 2006.
- The Center for Learning and Leadership, in collaboration with the Oklahoma Department of Human Services (OKDHS) Developmental Disabilities Services Division (DDSD), has developed the first section of Self-Directed Services Training. The training includes a basic overview of self-directed services in Oklahoma, a brief history of the U.S. Supreme Court's *Olmstead v L.C.* decision, the Oklahoma Olmstead Strategic Planning Committee, the Oklahoma Self-Directed Services Act, and recommended guidelines for implementation. Additional sections are planned, which will include training for individuals with disabilities, parents/guardians and case managers.

Tax Equity Fiscal Responsibility Act (TEFRA)

The Oklahoma Health Care Authority (OHCA) implemented this program October 1, 2005. In Section 134 of the Tax Equity and Fiscal Responsibility Act of 1982 (TEFRA), states were granted a state plan option to make Medicaid benefits available to certain children with severe disabilities who would not ordinarily be eligible for Supplemental Security Income (SSI) benefits because their parents' income was too high.

The TEFRA 134 State Plan enables children with special health care needs or disabilities to qualify for Oklahoma Medicaid coverage and be cared for at home instead of in an institutional setting. TEFRA funding in Oklahoma was made possible by the passage of House Bill 2660, which is the tax on tobacco.

Children who qualify will be given a Medicaid card and all state plan Medicaid services, including but not limited to, inpatient and outpatient treatment, pharmacy, physical therapy, occupational therapy, speech therapy, medical equipment, personal care assistance, and non-emergency transportation for medical appointments.

As of April 2006, only 61 children have been enrolled in the program. The Olmstead Strategic Planning Committee has a concern that a more restrictive pediatric nursing level of care is being used instead of the nursing facility level of care as stated in OHCA policy.

Recommendation:

Oklahoma should use the nursing facility level of care for eligibility determination as stated in OHCA policy.

Oklahoma Employer/Employee Partnership for Insurance Coverage (O-EPIC)

O-EPIC is designed as a safety net for people who cannot access private health coverage through their employer. On November 1, 2005, the Oklahoma Health Care Authority (OHCA) began accepting applications from employers and on December 1, 2005, began accepting applications from employees. This phase of O-EPIC is called Premium Assistance. To be eligible, employers must have fewer than 25 employees. Employees and spouses are eligible if their income is at or below 185 percent of the Federal Poverty Level.

O-EPIC also includes an individual plan for self-employed individuals, workers whose employers do not provide health coverage, workers who are not eligible to participate in their employer’s health plan, sole proprietors not eligible for small group health coverage, and people who are currently seeking employment. These individuals will have incomes above Medicaid eligibility, but their income cannot exceed 200 percent of the Federal Poverty Level. The target date for the individual plan is October 1, 2006.

Oklahoma has one of the highest rates of uninsured people in the country. In 2003, the rate was 20.4 percent uninsured, compared with a 15.2 percent national rate. O-EPIC is the first phase of a statewide initiative designed to use public and private partnerships to make health insurance more affordable.

This initiative is a good start, but it does not go far enough to meet the health care needs of all people with disabilities.

Rate Increases for Medicaid Providers

Most of the reimbursement rates for Medicaid providers have been raised to the same reimbursement rates as Medicare.

House Bill 1094, the appropriation bill for the Department of Human Services, included an increase in funding to pay an increased hourly rate for services provided in home and community-based settings. A total amount of 70 percent of this increase was designated by the legislature to be used for direct care worker wages and benefits.

Developmental Disabilities Waiting List

Many have concerns about the number, length and growth of waiting lists in particular and continued inadequate funding for community services in general. Nationally, including Oklahoma, there is a significant gap between the need for and the availability of publicly funded long-term services and supports for people with disabilities. The reality is that more people need services and supports than the delivery system is able to provide. This gap takes the form of waiting lists.

The Oklahoma Department of Human Services, Developmental Disabilities Services Division (DDSD), has demonstrated expertise in developing and implementing community-based services. With only a modest increase in funding available for community services and supports, DDSD has reduced the number of people on the waiting list for waiver services. Since July 1, 2004, DDSD has removed 3,238 people from the waiting list while at the same time an average of 94 new applications per month were received. As of March 31, 2006, the waiting list totaled 3,036.

House Bill 2842: The Medicaid Reform Act of 2006

The Oklahoma Medicaid Reform Act of 2006 (HB 2842), involves sweeping changes to the state Medicaid program. While the Olmstead Strategic Planning Committee and the Coalition to Ensure Access to Health Care (Coalition) agree with many points of the Act, there are nevertheless a number of concerns.[1]

This Act creates some positive changes listed below by instructing the Oklahoma Health Care Authority to:

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[1] The summary of HB 2842 was prepared for the Coalition by Monica Barczak, Ph.D., Community Action Project, Tulsa, Okla.

- Conduct a needs analysis to design a database of clinical utilization information or electronic medical records for Medicaid providers;
- Design and implement an electronic prescribing pilot;
- Track spending trends for prescription drugs;
- Develop an incentive reimbursement rate for nursing facilities that includes quality of life indicators, quality of care indicators, family and resident satisfaction surveys, state Department of Health survey results, employee satisfaction survey results;
- Develop a formal program for disease management to improve the quality of care and reduce the cost of care;
- Continue to develop alternatives for long-term care;
- Establish a Cash and Counseling program;
- Reduce use of emergency room care; and
- Establish a discount program for hospital charges for qualified self-pay patients who have incomes up to 300 percent of the Federal Poverty Level.

The main proposal of the Medicaid Reform Act is to implement a waiver program in which Medicaid beneficiaries will be issued an "instrument of value" that they would use to purchase health insurance from commercial insurance companies. The program would begin as a pilot in one area of the state by 2008 and could be extended statewide by 2013, if the pilot program is proven to be successful.

1. All Medicaid beneficiaries in the pilot area would be eligible except those older than age 65 and those deemed uninsurable. Uninsurable is defined as when the cost of enrolling an individual in a private plan is more expensive than that person remaining in the traditional Medicaid program. This vague definition creates great risks for people with disabilities, children with special health care needs, foster children and other vulnerable populations. The following questions have not been answered:

    - Who determines if an individual is insurable?
    - How much will it cost to determine if each Medicaid beneficiary is insurable?
    - What happens if an insurable individual's health status changes?

2. The Medicaid Reform Act creates no defined benefits standards for the commercial insurance plans and raises the following concerns:

    - How would we ensure that the commercial insurance companies offer the full scope of medical services required by federal Medicaid law?

- Why are there no requirements in the Act about a minimum number of participating commercial providers?
- What happens if someone is deemed insurable, but the only plan he/she is offered provides only minimum, catastrophic care?
- What happens to someone who requires a great deal of medical care and exhausts the instrument of value?

3. For children in families with income between 133 percent and 185 percent of the Federal Poverty Level, a co-payment and other cost-sharing requirements are included. Research shows that even modest cost-sharing can hinder access to needed services or lead to the loss of coverage.

4. There is no requirement for any input or participation from beneficiaries, advocates, providers, or public officials in the development of the program.

SECTION III

Cross Systems Recommendations

People with disabilities do not have enough quality services and supports in the community to meet their needs. Individuals continue to languish on interminable waiting lists for services; receive inadequate or poor quality services; are forced to impoverish themselves in order to get services; or are forced to live in more costly institutions away from family, friends, and community life.

Oklahoma has to increase the availability of support services to enable individuals with disabilities and individuals who are aging to live in their own home and communities. Every person should have a choice for community options before an institutional placement is considered or approved. All Oklahomans should have the choice of where they live, work and play.

1. Oklahoma should develop a plan to divert people from institutional care.

Every person at risk of an out-of-home placement should be interviewed and assessed for community options before a decision regarding placement is made. Community placement should be the first option available and should be explored before an institutional placement is even considered. People currently living in institutional placements should also be interviewed to determine if they would choose to live in the community if supports were available.

Recommendations:

1.1) Develop and provide community-living transition training for families and young people with disabilities that affirms lifespan planning and self-determination. (See Olmstead Strategic Planning Committee Values and Principles on page 2.)

1.2) Develop a pre-screening comprehensive checklist to inform every individual at risk of out-of-home placement of all options and resources in his/her own community.
1.3) Assure a pre-screening process occurs prior to discharge planning from a hospital or rehabilitation facility to ensure the person has the necessary supports to return to his/her home.
1.4) Enact a 90-180 day grace period to Medicaid eligibility rules for a person who must be in a skilled nursing facility or rehabilitation setting for short-term recovery to assure the person does not have to become impoverished to receive care.

2. Oklahoma should provide information on all community options to individuals at risk of out-of-home placement.

Many people enter institutions because they are not aware of home and community-based options available to them. Assessments should be in person and face-to-face. Every person must be provided the information necessary to make an informed decision regarding the type of service that best meets his/her needs and desires.

Effective outreach and educational materials must be developed and distributed to ensure that people with disabilities have access to information regarding all options available.

Recommendations:

2.1) Oklahoma should develop an agency wide collaborative program that would allow its citizens to access all services they need from an accessible comprehensive entry point. (The program shall be located in accessible centers where people with disabilities can receive a menu of services available from all state agencies and have the opportunity to apply for services.)
2.2) Use and promote all possible entities for informing citizens about the points of entry, such as, Oklahoma Areawide Services Information System (OASIS), 2-1-1, Joint Oklahoma Information Network (JOIN), Centers for Independent Living, public school systems, public libraries, non-profit organizations, town meetings, conferences, and media campaigns involving legislators, agency heads, and the Governor.
2.3) Explore public-private partnerships by placing one-stop centers in high traffic businesses, such as Wal-Mart and Target stores, and accessing viewers through cable companies.

For more information see Appendix O: Marketing Plan

3. Oklahoma should streamline the application process.

> *"It's lack of information, more than anything else. Who to ask. Where to go. When you don't get the answer that you need, where do you go from there?"*
> — Focus Group Report on Medicaid Managed Care, Fall 2000

People seeking services have a right to quick entry, timely eligibility determination, consistent medical eligibility criteria and information about the range of services available.

The vision for a streamlined application process is a dramatic departure from the application procedures that state government has offered applicants in the past. Most applicants have had to go to a myriad of agencies, facilities, and offices, each with a different application process and different eligibility criteria, increasing the likelihood that the individual abandons his/her efforts entirely, or settles for a more restrictive placement than is necessary. It has been one of the chief complaints by consumers and advocates.

A common application and a streamlined application process would prevent many of the problems people currently encounter, causing them less frustration and providing care in the least restrictive setting. It would also eliminate cumbersome paperwork and allow counselors to spend more time with an individual seeking services.

> *"When a family gets a 'NO,' they don't have the strength to knock on the next door."*
> DDSD/CLL Forum in Stillwater, 2005

Recommendations:

3.1) Create a uniform referral application for all state agencies and service providers.
3.2) Create an application that can be sent electronically to the appropriate agency or agencies upon completion.
3.3) Develop an information-sharing system that maintains consumer privacy rights according to HIPAA, but also allows agencies and service providers to access information through a centralized, Web-based information management system.

4. Oklahoma should provide financial assistance for those who wish to transition from an institutional placement to their own homes or community.

A major concern of the Olmstead Committee is that it is much easier for a person to enter an institution than to receive services in the community. Once a person has entered an institution, it is incredibly hard to leave. Many supposed "short-term" stays in an institution become extended stays that last the rest of a person's life.

> *"I have been on a waiting list for low-income housing for two years."*
> — Comment at DDSD/CLL forum, 2005

Most people who enter the institution have had to divest themselves of all property and financial resources. When they are ready to move back to the community they have no funds for rent, utility deposits, furniture and household supplies. Further, they may need some level of physical support that is not available to them because the service is too expensive or there is a shortage of qualified providers in the community.

Transitioning from an institution requires assistance and funding. Support services assist in making the move to the community, but there is a need for housing assistance, rent and utility deposits, furniture, household goods, medical supplies, durable medical equipment, home modifications and temporary intensive personal care services. Transition to community services is not only the best choice for an individual's quality of life, it is also the most fiscally responsible choice since community placement is less expensive than institutional care.

2006 first quarter data gathered by the Centers for Medicare and Medicaid Services (CMS) identified 3,597 Oklahomans living in nursing facilities who indicated a desire to leave and receive services in their own home in their own communities.

Recommendations:

4.1) Assure that when individuals enter a hospital or rehabilitation center, discharge strategies emphasize transition back into the community with needed supports.

4.2) Explore agency-funding sources to provide initial rent subsidy until section 8 vouchers are available.

4.3) Pursue transition start-up funding after the pilot program established by state law is completed.

5. Oklahoma should establish a Division of Disabilities within the Oklahoma Department of Human Services.

Many disability groups have minimal or no representation in any policy development activities within state agencies. There is no office or agency where people who are not eligible for home and community-based waiver services can apply for services and there is no funding to avoid institutional placements.

These populations include people who have a traumatic or acquired brain injury, spinal cord injury, amyotrophic lateral sclerosis, multiple sclerosis, and autism or a developmental disability with no diagnosis of mental retardation. This gap in policy, funding and practice has significant implications for the quality of life of these individuals and their caregivers.

Recommendations:

5.1) Expand the eligibility criteria of people served by the OKDHS Developmental Disabilities Services Division (DDSD) to include people with disabilities who are not eligible for the ADvantage program through the OKDHS Division of Aging and those with other diagnoses who are at risk of out-of-home placement.

5.2) Utilize the existing DDSD infrastructure, which would eliminate the need to duplicate administrative services, helping to assure that new money appropriated to serving people with disabilities is devoted to services and not additional administration.

5.3) Change the name of DDSD to the Division of Disabilities.

6. Oklahoma should address the direct care work force crisis.

> *"The wages for direct care staff need to match their responsibilities. People can make more flipping hamburgers than taking care of someone with a disability."*— Consumer at Listening Session at 2003 Governor's Conference

People who are aging and who have disabilities often require the services of direct care professionals to assist with daily activities such as personal care, home maintenance, and employment. A high quality direct care work force is an essential component of successful community living. Oklahoma has a serious shortage of qualified direct care workers. This work force includes personal care attendants, habilitation training specialists, home health aides, and certified nursing aides.

Recommendations:

6.1) Oklahoma should facilitate a collaborative public-private initiative, including DDSD providers, ADvantage program providers and OHCA to design a system-wide career ladder plan to classify direct care professionals according to training and experience. This will create "portability" of training and experience as direct care professionals move among employers who serve people with different types of disabilities in different programs.
6.2) Oklahoma should consider a direct care professional certification program based on industry established quality principles and standards.
6.3) Oklahoma state agencies should collaborate with private providers to identify and implement best practices in recruitment, training and retention strategies.
6.4) Based on industry best practices standards, Oklahoma should establish parity between and among agencies and programs regarding direct care professional training requirements.
6.5) Oklahoma should develop policy that encourages regular assessment of compensation to community and direct care workers to ensure a realistic, living wage as well as parity among comparably skilled workers regardless of employment settings.

7. Oklahoma should work to end the institutional bias of Medicaid. Community services must become as easy to access as institutional services.

According to Association of University Centers on Disabilities (AUCD) Past President David Johnson, "A national long-term services policy should not favor institutions above home and community-based services. It should allow families and individuals real choice regarding where and how services should be delivered."

In their desire to "hold out" for community-based services, many individuals linger for years on service waiting lists or settle for inadequate or poor quality services. Many times people who need services are forced to either impoverish themselves or to maintain a low economic status in order to qualify for and/or keep services, or are forced to live in more costly institutions away from family, friends, and their community.

Many disability organizations have long advocated for reforming the institutional bias in the Medicaid program. As the Medicaid statute is currently enacted, nursing home care services are mandatory services. See 42 U.S.C. Section

1396a(10)(A), incorporating Section 1396d(a)(4)(A); Fisher v. Oklahoma Health Care Authority (10th Cir. 2003).

Currently on a national basis, more than 75 percent of Medicaid long-term care dollars are spent on institutional services, leaving few dollars for community-based services. Oklahoma is currently spending 68 percent of Medicaid long-term care dollars on institutional services.

Ending the institutional bias by ensuring that funding is available and admission processes are user friendly for community services, "would assure that government funded long-term care would conform to both the U.S. Supreme Court Olmstead decision, and the President's New Freedom initiative, which mandated that all federal departments operate in accordance with the Americans with Disabilities Act (ADA)." (Mark McClellan, director of the Centers for Medicare and Medicaid, press release from ADAPT, April 25, 2005)

Recommendation:

7.1) Oklahomans should advocate to amend the Medicaid law that establishes a mandatory preference for funding nursing home care above community-based long term care services whenever people choose them.

8. Oklahoma agencies should appoint Olmstead coordinators to implement and monitor the Oklahoma Olmstead Plan.

Olmstead coordinators will work within their respective agencies/service delivery system to ensure compliance with the Oklahoma Olmstead Plan.

Recommendations:

8.1) Identify and train Olmstead coordinators within all agency/service delivery systems identified in the Olmstead strategic planning process.
8.2) Incorporate a consumer satisfaction component and allow coordinators access to data for refinement of the system.

9. Oklahoma should assure that people with disabilities have a voice in the legislature.

Recommendations:

9.1) The Governor of Oklahoma, Speaker of the House of Representatives and President Pro Tempore of the Senate should each designate a staff person to act as liaison with the Olmstead Strategic Planning Committee and, later, Olmstead coordinators to develop, coordinate and monitor a legislative plan to enact the recommendations of this Committee.

9.2) Agencies and government officials should appoint individuals with disabilities to boards, councils and other decision-making entities.

10. Oklahoma should address service funding needs.

According to the 2000 Census Bureau survey 19.6 percent or 676,098 of the respondents in Oklahoma reported some type of disability. Of those persons, the U.S. Census Bureau also reports that 7.2 percent or approximately 48,680 Oklahomans have disabilities that are severe enough to require support services.

Since Oklahoma's current Medicaid waivers, ADvantage and developmental disabilities waivers, provide home and community-based services to approximately 20,000 people, there is an unmet need for support services for at least 28,000 individuals who could benefit from some level of support. These supports would assist these people in gaining or maintaining a life of independence in their communities.

The Oklahoma Olmstead Plan cannot be implemented without additional funding. For too long, the needs of Oklahoma citizens with disabilities have largely been ignored because most were relegated to institutions or remained at home with little or no support. We need to recognize that people with disabilities can live successfully with support in their homes and communities, and deserve to enjoy the rights and privileges of all citizens.

Services provided in the community are more cost efficient than institutional services, but more importantly, the quality of people's lives improves and their level of satisfaction increases dramatically when services are provided in their homes and communities.

Recommendation:

10.1) Oklahoma should increase funding to provide services to 36,000 additional people with disabilities during a ten year period.

The following set of assumptions and cost projections depict the necessary increase in state funding and resulting influx of federal matching funding if our current home and community-based waivers (ADvantage and developmental disabilities) are expanded to serve an additional 36,000 individuals with disabilities severe enough to require assistance. The overall time frame for the expansion is 10 years. Average costs are based on current populations served.

However, it is anticipated that services will include people with disabilities, such as traumatic and acquired brain injury, developmental disabilities without mental retardation, who are currently not receiving state disability services. For persons with disabilities who are currently receiving their services in nursing homes or other institutions, letting the dollars follow the person into community services will be an additional funding source.

Current waiver basics:

- There are approximately 15,000 people on the ADvantage waiver at a cost of approximately $10,000 per year when case management and administrative costs are included.
- There are approximately 5,000 people on the developmental disability waivers at a cost of approximately $30,000 per year when the various waivers are combined and case management and administration are included.

Assumptions:

- Add an additional 3,600 persons served per year: 2,400 persons per year to ADvantage and 1,200 persons per year to the developmental disability waivers;
- ADvantage waiver uptake is assumed to be 200 net growth per month;
- Developmental disability waivers uptake is assumed to be 100 net growth per month;
- Within developmental disability waivers new recipients will go 85 percent to the in-home supports waiver and 15 percent will go to the home and community-based services waiver;
- The current developmental disabilities waiting list of approximately 3,000 persons is assumed to be part of this expansion;
- State dollar match is assumed to be exactly 30 percent;
- System capacity is assumed to keep up with client intake assumptions;
- At the end of nine years, an additional 36,000 persons could access services that would allow them to remain in their homes and communities; and
- Annualization costs will extend into the 10th year of the expansion.

Based on these assumptions, the additional cost is as follows and the targeted number of additional persons to whom service can be expanded will be met during year eight of the expansion:

Fiscal Year	Additional State Funding Needed per year	Additional Federal Match Gained per year	Total	Cumulative Additional Persons
FY-2008	$9,750,031	$22,750,073	$32,500,104	3,600
FY-2009	$18,000,058	$42,000,134	$60,000,192	7,200
FY-2010	$18,000,058	$42,000,134	$60,000,192	10,800
FY-2011	$18,000,058	$42,000,134	$60,000,192	14,400
FY-2012	$18,000,058	$42,000,134	$60,000,192	18,000
FY-2013	$18,000,058	$42,000,134	$60,000,192	21,600
FY-2014	$18,000,058	$42,000,134	$60,000,192	25,200
FY-2015	$18,000,058	$42,000,134	$60,000,192	32,400
FY-2016	$18,000,058	$42,000,134	$60,000,192	36,000
FY-2017	$8,250,026	$19,250,062	$27,500,088	

11. Oklahoma should assure that all informal, non-paid caregivers have an opportunity for a temporary break, or respite, from their full-time caregiving responsibilities.

Nationally, 82 percent of people with disabilities live with a parent or other relative. The National Family Caregiver Alliance reports that these caregivers save the taxpayers $259 billion a year.

According to the ARCH National Respite Resource Center and the National Respite Coalition, respite is the most frequently requested family support service among the more than 50 million family caregivers nationwide. Respite provides family caregivers with relief necessary to maintain their own health, bolster family stability, keep marriages intact, and avoid or delay much more costly nursing home or other out-of-home placements.

> *"I just pray every day for the strength to take care of my husband and then I feel guilty when I need some time away. I just need to take a short break and restore my strength so I can do what I need and want to do for my husband."* — Ruth, caregiver of husband

The Oklahoma Respite Resource Network (ORRN), formed in 1998, is a collaborative of private and public agencies, advocates, and families. During the past four years the ORRN has redirected $2.1 million a year to a respite care voucher program that is serving more than 5000 families across the state. This program allows caregivers the ability to hire their own provider and set the rate of pay. The average cost per hour of this program has been between $5.62 and $5.92.

> *"Just taking a short break makes me less cranky. Then I can get back in the harness and do what I have to do."* — Judy, caregiver to sister and mother

In a survey conducted by the Oklahoma Respite Resource Network, 88 percent of caregivers agreed that respite allowed their loved one to remain at home, 98 percent stated that respite made them a better caregiver, 98 percent said respite reduced stress, and 79 percent reported that respite contributed to the stability of their marriage.

Recommendations:

11.1 Oklahoma should adequately fund respite programs in all service delivery systems.
11.2 The Oklahoma Health Care Authority should approve respite care as a Medicaid-compensable service.
11.3 The Division of Children and Family Services should develop a respite program for foster parents.

SECTION IV

Issue Specific Recommendations

12. Health Care Challenges

Issue: Oklahomans with disabilities lack access to adequate health care for a variety of reasons related to the structure and financing of the health care system at local, state and federal levels. Although there are urgent health needs among all Oklahoma citizens that require the state's attention, these serious concerns are amplified among people with disabilities. Factors include:

Approximately 75 percent of adults with lifelong disabilities live at home with family caregivers and more than a quarter live with aging caregivers older than 60 years of age. Source: Association of University Centers on Developmental Disabilities (AUCD) www.aucd.org/leg

- Oklahoma has one of the highest rates of uninsured individuals in the nation. Twenty percent of Oklahomans have no health coverage, compared with a 14.1 percent average for the nation (Oklahoma State Department of Health, 2004). High proportions of Oklahomans with disabilities live at or near poverty level and cannot afford health care that would support their ability to live in their communities.
- Many Oklahomans with disabilities are prevented from working because of fear of loss of their Medicaid health benefits, eligibility for which is based on income. Oklahoma has only partially implemented a Medicaid Buy-In program that would increase opportunities for citizens with disabilities to work by increasing allowable income levels and providing opportunities for working individuals with disabilities to pay Medicaid premiums based upon earnings.
- Oklahoma ranks 40th in the nation in the overall health status of its citizens, increasing the barriers to Oklahomans with disabilities, who not only are at risk for the same chronic health problems as any citizen, but who also face these risks at earlier ages with a thinner margin of health and greater risk for developing secondary conditions. There is limited data available for the development of appropriate measures to address the specific prevention and health promotion efforts for individuals with disabilities of all ages in Oklahoma. Many of the current prevention and health promotion efforts fail to consider the specific needs of people with disabilities.

- Health is a concern not only to individuals with disabilities, but also to their families and caregivers. According to the National Alliance for Caregiving and AARP (2004), caregivers provide unpaid care to an adult aged 18 or older in 21 percent of all U.S. households.
- The Centers for Disease Control confirms reports from Oklahomans with disabilities that health care facilities are frequently inaccessible, do not have the equipment needed to serve people with disabilities, and are staffed by health care professionals who lack information on how to communicate with, assist and care for the needs of people with disabilities.

Recommendations:

12.1) Immediately implement Medicaid Buy-In for people with disabilities.
12.2) OHCA will pay for all necessary assessments when making the disability determination for TEFRA.
12.3) Increase the rate for Personal Care Services in the Medicaid State Plan.
12.4) Increase number of qualified medical providers for Medicaid.
12.5) Implement Cash and Counseling by July of 2008.
12.6) Increase the eligibility criteria for Medicaid from 185 percent to 250 percent of the Federal Poverty Level.
12.7) Implement 'Money Follows the Person' by July 2008.
12.8) Remove the requirement that only Ph.D. level licensed psychologists can provide counseling services and assessments. Allowed licensed master of social work (MSW) and licensed professional counselors (LPC) to provide these services.
12.9) Put statewide resources in place for technical assistance, training and information dissemination to promote healthy lifestyles among the state's citizens with disabilities and to increase access to training for health professionals relative to health promotion and prevention of secondary conditions among people with disabilities.
12.10) Require the Oklahoma State Department of Health to increase surveillance data on health needs of individuals with disabilities to facilitate development of appropriate services to address the needs.

Durable Medical Equipment / Assistive Technology

It is estimated that at least 25 million persons have mobility problems. Of these, approximately 500,000 use wheelchairs. Source: www.dizabled.com/helping

> *"Why does it take so long to get needed equipment?*
> *It took eight months to get a new wheelchair for my child.*
> *By the time she got it, she had almost grown too much to fit it."*
> Parent comment at DDSD/CLL Forum in Stillwater, OK, 2005

Recommendations:

12.11) OHCA should develop objective instructions for durable medical equipment (DME) provision so that health care providers, DME suppliers and individuals with disabilities can understand both the criteria and documentation needed to acquire and pay for the needed DME.
12.12) Remove automatic restrictions on bath and toilet aids that not only limit people to the home, but also limit them to their beds. Bath and toilet aids should be considered DME and therefore a mandatory service of Medicaid.
12.13) OHCA should develop and implement procedures for needed repair to DME.
12.14) OHCA should create and maintain an effective DME inventory and retrieval system.
12.15) OHCA should establish a policy that provides a fee-for-service system for credentialed assistive technology professionals (ATP).
12.16) Funding should be provided for nursing facility residents to be able to access needed assistive technology on an individual basis while they reside in a nursing facility. As the resident transitions to the community so should the equipment.

13. Employment

Issue: Many individuals with disabilities need assistance in obtaining and maintaining employment services in the community. Currently the Department of Rehabilitation Services (DRS) is the primary agency providing employment assistance to Oklahomans with severe disabilities. DDSD provides employment assistance for people with mental retardation, but only through the home and community-based waivers.

Thousands of Oklahomans have one or more physical or mental disability and this number continues to increase. Disability is a natural part of the human experience and in no way diminishes the right of individuals to pursue meaningful careers and to enjoy full inclusion and integration in the economic, social and cultural mainstream of American society.

Recommendations:

13.1) Secure a funding stream for ongoing job coach support services for crisis management and/or job changes for people with disabilities who are not covered through another program.
13.2) Provide additional incentives to employers to hire people with disabilities beyond the targeted tax credit.
13.3) Supported Employment emerging best practices should be fully supported with the new Memorandum of Understanding between the Department of Rehabilitation Services (DRS) and ODMHSAS.

14. Accessibility of Workforce Centers

Issue: The U.S. Department of Labor Workforce Centers, also known as One-Stops, or "the employment office," are not fully physically or programmatically accessible to persons with disabilities.

Recommendations:

14.1) Enforce minimum standards of accessibility as provided for in Section 188 of the Workforce Investment Act and the Americans with Disabilities Act, Title II.
14.2) Train agency personnel at the state and local level on the Workforce Center mandate to provide services to all job seekers, regardless of disability.
14.3) Develop mutual understanding between partnering agencies in Workforce Centers to address the needs of all job seekers, regardless of disability.
14.4) Require local Workforce Center boards to develop and enforce interagency agreements between partners to address accessibility issues. Locate Workforce Centers in fully accessible buildings and locations.

15. Mental Health

Issue: Our nation's mental health care system is "fragmented and in disarray,"[2] leaving many people without the health care, housing, transportation and

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[2] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

employment they need to function as independently and productively as possible and placing them at high risk of institutionalization or incarceration.

The diagnosis of mental illness is often more disabling than the illness itself. There are myths and misinformation about mental illness that lead to an over-reliance on congregate housing and the isolation of people from the larger community. People living with mental illness have expressed their right and desire to live in communities of their choice, and to participate in the full range of community resources available to all citizens.

Services are often delivered through a crisis driven medical model. People must qualify for services based on degree of illness rather than prevention of escalation of symptoms. Inconsistent admission criteria and provider self-referral following the assessment process limits access to care and decreases effectiveness. The lack of provider choice in rural areas can also be a deterrent to adequate care. A fear of the emergency detention process keeps people from seeking services.

Adequate funding is needed for evidence-based and emerging best practices from both Medicaid and state dollars. These practices currently include:

- Program for Assertive Community Treatment (PACT);
- Supported Employment;
- Illness Management and Recovery;
- Family Psycho-education;
- Consumer-run programs; and
- Systems of Care/wraparound services.

Recommendations:

15.1) No ODMHSAS funding should go toward new congregate housing and all current residential facilities contracted through the Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS) should meet Recovery Home initiative criteria established by ODMHSAS.
15.2) Initiatives undertaken by the state’s new Innovations Center for Mental Health and Substance Abuse Services should identify how infrastructure development supports implementation of the Oklahoma Olmstead Strategic Plan.
15.3) All residential facilities for children and youth, licensed by ODMHSAS, OKDHS, Office of Juvenile Affairs (OJA), or OHCA should follow principles and guidelines for Systems of Care (see Glossary).
15.4) Expand community-based care options available to children and youth with severe emotional disturbance (SED) placed in the

custody of Oklahoma Department of Human Services, Division of Children and Family Services.

15.5) Expand community-based mental health services throughout the state to provide integrated care for people with mental illness and co-occurring conditions such as substance abuse and/or other disabilities.

15.6) Expand mental health courts and jail diversion services statewide to provide treatment and recovery-based alternatives to incarceration for nonviolent offenders with serious mental illness including pre-employment and employment programs.

16. Transportation

Issue: Oklahoma lacks adequate transportation for people with disabilities to fully participate in work and community life. For thousands of Oklahomans, finding adequate transportation services is an ongoing struggle, and it is an even greater barrier for people with disabilities.

Gathering information on the 62 federal funding streams has proved more problematic than anticipated. All of the human service agencies have agreed to participate in identifying federal funding amounts, utilization and total expenditures; however, some agencies do not collect this information in an easily accessible way. At the 2005 UWR Summit the Federal Funding Data Collection workgroup was formed to gather the state’s information.

A data collection format has been established. This data base will be shared with the Oklahoma federal interagency Coordinating Council on Access and Mobility (CCAM) grant project staff to assist in their identification of state funding streams and the barriers to coordinated service provision.

Recommendations:

16.1) Pursue “swipe card” billing that bills proper agency for public transportation and allows the person access to any transportation source (interconnection of services and memorandums of understanding).

16.2) Blend systems and funding systems to create a single seamless, coordinated transportation network.

16.3) Services provided through the ADvantage program should include the purchase and installation of vehicle modifications, which would be excluded from the cost cap as a one-time purchase.

16.4) Fully implement United We Ride (UWR) initiatives.
    a) Create a database for tracking state and federal transportation funding.

b) Develop strategies for meeting the transportation needs of older adults, people with disabilities, and individuals with lower incomes during natural or man-made disasters.

In 2006 grant money will be available from the Department of Rehabilitation Services (DRS) to focus on use of best practices described by United We Ride to expand and enhance transportation services for DRS clients, as well as others with disabilities. Project areas to be considered will include coordinated transportation planning, vehicle sharing, transportation system coordination and consolidated access, and reporting and evaluation.

17. Housing

Issue: Oklahomans with disabilities lack access to safe, accessible, affordable, and integrated housing.

Nationally, approximately 750,000 people with developmental disabilities live with aging parents. Fewer than 10 percent of people with disabilities own homes compared to 71 percent of people without disabilities. (www.aucd.org, Legislative Brief on Housing)

The Oklahoma Department of Mental Health and Substance Abuse Services provided services to 38,066 Oklahoma citizens in FY05.[3] Of these people, 2,052 self-identified as homeless with 51 percent living in community shelters and 49 percent living on the street. At least two programs are working on this issue: the Project for Assistance in Transitions from Homelessness (PATH) and the Governor's Interagency Council on Homelessness.

Housing often is not accessible for people who use wheelchairs or other forms of mobility assistance. Frequently the bathrooms do not have grab bars and doorways are not wide enough to permit wheelchairs to get through. Additionally, landlords are not required to pay for modifications, but through the Fair Housing Act, they must allow the tenant the right to make the necessary accommodations that would allow full enjoyment of the premises.

Recommendations:

17.1) Expand the mission of the Governor's Task Force on Homelessness and Housing to coordinate statewide planning for inclusion of accessible housing for individuals with disabilities. Members of this organizing task force should include Olmstead Strategic Planning

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[3] All Oklahoma specific statistics were provided by ODMHSAS Decision Support Services.

Committee, Home of Your Own, public housing authorities, Oklahoma Housing Finance Agency, and other appropriate housing groups as identified. Representation by individuals seeking or accessing housing services must be included in the task force.

17.2) State policies and contracts should be reviewed to ensure consistency with informed choice and community integration.

17.3) Promote a capacity-building initiative between the public housing authorities and community-based and state organizations to develop creative housing options for serving people with disabilities in the most integrated setting.

17.4) Study ways to simplify the housing application process to make it more user-friendly.

17.5) Set-up and maintain an ongoing inventory of public housing on a local level that meets standard requirements for accessibility.

17.6) Transition plans should include the provision of home modifications and adaptive equipment in a timely manner.

18. Quality Assurance

There are many systems of quality assurance (a term that refers to the policies and processes used by each state agency to assess and improve the effectiveness of the services provided to their clients) and monitoring across state agencies. Many of these systems look at contract compliance, and not how services are delivered. Quality assurance systems do not typically assess if the services delivered were what the individual or family needed.

Oklahoma should assure that people with disabilities, advocates and families are included in the development, implementation and evaluation of their services.

The Committee found that agencies that investigate complaints, or monitor for quality, frequently have to refer the investigation to another agency for enforcement. The enforcement agency might not have the same philosophy. It was also found that there are no set standards for what a quality assurance system should be.

Recommendations:

18.1) Each state agency and service provider should adopt the Oklahoma Olmstead Quality Assurance Principles. (Appendix M)

18.2) Each state agency and service provider should have a clear plan for incorporating improvements recommended by people with disabilities, advocates and families into the agency’s services, programs and policies.

18.3) Each state agency and service provider should have an education and training component to inform individuals with disabilities and families about their choices, rights and a way to give feedback about their satisfaction with services.

19. Appeals Process

An individual who is denied services by a state agency should be afforded an opportunity to appeal the denial. The appeals process should be sufficiently formal to ensure that individuals similarly situated receive equal treatment, but should not be so formal as to intimidate the individual or his/her lay representative. The individual should be given clear explanations of the process and have access to well-trained and experienced advocates. The appeals process should include an opportunity for settlement prior to the hearing.

Recommendation:

19.1) State agencies should adopt and implement the Appeals Process Guiding Principles found in Appendix N of this report.

20. Advocacy

Advocates work in a variety of ways to improve quality of life for individuals with a disability as defined since the Olmstead decision.

Advocacy means helping someone by speaking or acting in his/her best interest.

Individual advocacy enables people to have a voice in the decision-making process, especially when those decisions affect their quality of life.

While many individuals with disabilities are able to self-advocate, there is also a need for advocates who work on behalf of individuals who cannot advocate for themselves. Advocates must take the individual's perspective in trying to resolve the problem. If the individual can represent his/her self, the advocate may assume a mediator role to ensure that the individual's views are heard and that everyone participates in determining the resolution.

When advocating for another, objectivity is required to determine the validity of the complaints. Sufficient information must be gathered to have an accurate understanding of the problem and to plan a resolution strategy.

"Families and self-advocates have a body of information and experience that is needed by service providers, policy makers and people in education. Yet, their individual voices are often a whisper in the noise of systemic change." (Center for Learning and Leadership training initiative project, non-competing renewal application)

Recommendations:

20.1) Oklahoma should establish a comprehensive listing of organizations that provide advocacy and training opportunities for people who want to advocate for themselves or family members.
20.2) Oklahoma should require boards, task forces, and committees representing the needs and interests of people with disabilities to include people with disabilities and/or their advocates in policy development. These groups must support and train self-advocates to be effective participants in the processes.
20.3) Oklahoma should support parent organizations and self-advocacy organizations by providing financial support to attend training and conferences, stipends to pay for care of their family member when attending meetings or conferences, and travel reimbursement.
20.4) Oklahoma should support Oklahoma Court-Appointed Advocates for Vulnerable Adults, which trains persons to advocate for persons who are unable to advocate for themselves in legal proceedings.
20.5) Equal access through provision of any needed accommodations shall be provided on request.

21. Oklahoma should actively promote equal access and full integration of individuals with disabilities in all aspects of community-based living.

Oklahoma is committed to serving people with disabilities fairly and with respect through a philosophy of equal access. Oklahoma is committed to providing full access to and participation in the opportunities afforded its non-disabled citizens. Oklahoma shall meet the access needs of its citizens with disabilities through the use of appropriate accommodations. Oklahoma will provide access to services respective of differences in cultures.

For individuals with sensory and cognitive disabilities, the following barriers exist:

1) Limited access to interpreters for people who are deaf.
2) Limited interpreter training opportunities.
3) Limited access to readers for individuals who are blind.
4) Limited access to alternate formats such as Braille, large print information, or disc.
5) Limited access to facilities that can put information into Braille format.
6) Limited access to information in simplified or appropriate language. For example information at a reading level of sixth grade education or below or in alternate languages.

For individuals with physical disabilities:

1) Access will be provided through compliance and enforcement of the ADA.

Recommendations:

21.1 Promote interpreter training as a career opportunity.
21.2 Provide all written materials in simplified and alternate formats and in appropriate language formats.
21.3 Educate businesses and service providers regarding service delivery in accessible and appropriate formats.
21.4 Promote compliance with the Americans with Disability Act for physical, sensory, cognitive, and emotional disabilities.
21.5 Reduce attitudinal barriers though educational and training opportunities.
21.6 Oklahoma should increase funding to provide solutions that address the above access issues.

APPENDICES

Appendix A: Olmstead Overview

Sue Jamieson, lead attorney, Atlanta Legal Aid Society, E.W. (Elaine Wilson), and L.C. (Lois Curtis)

In *Olmstead v. L.C.,* 527 U.S. 581 (1999), two women who resided in a psychiatric unit of a Georgia hospital brought claims through the Americans with Disabilities Act (ADA), challenging their confinement in a segregated environment.

The plaintiffs were dually diagnosed with mental illness and mental retardation. Their treatment professionals concluded that each of the women could be cared for appropriately in a community-based program. However, the state asserted that it was already using all available funds to provide services to other persons with disabilities.

On appeal, the United States Supreme Court held that "unjustified isolation" is discrimination covered by the ADA and the states are required to provide community-based treatment for persons with disabilities when the state's treatment professionals determine that such placement is appropriate, the affected persons do not oppose such treatment, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with disabilities.

What did the Supreme Court say about institutionalization?

Unjustified isolation is regarded as discrimination based on disability.

- "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."
- "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."

Olmstead v. L.C. interprets Title II of the ADA and its implementing regulations:

- The ADA requires states to administer their services, programs, and activities in the most integrated setting appropriate to the needs of individuals with disabilities. (Sue & Sue, 2003).
- It challenges states to develop more opportunities for individuals with disabilities through more accessible systems of cost-effective community-based services.
- A public entity shall 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. 28 CFR 35.130(b)(7) (1998).

A state can show that it has satisfied the reasonable-modifications regulations by demonstrating that it has a:

- Comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings; and
- A waiting list that moves at a reasonable pace not controlled by the state's endeavors to keep its institutions fully populated.

Appendix B: Appointed Members of the Olmstead Strategic Planning Committee

Senator Bernest Cain
Senator Constance N. Johnson
Representative Bill Nations, Co-Chair
Representative Kris Steele, Co-Chair

Rose Ann Percival, Facilitator
OKDHS/Developmental Disabilities Services Division

Doug Bursey, Parent
Jan Moss, Parent
Lance Schneiter, Advocate
Michael Upthegrove, Self-Advocate
Norma Ferguson, Advocate
Mary Ann Paulsen, Parent
Earl Snow, Self-Advocate
Nancy Ward, Self-Advocate

Charlotte Bowen, Oklahoma Statewide Independent Living Council
Lori Hauge, Bios
Jeff Hughes, Progressive Independence, Inc.
Linda Jaco / Milissa Gofourth, ABLE Tech
Treasa Lansdowne, Oklahoma Commission on Children and Youth
Carla Lawson, Ability Resources
Vyonda Martin, Center for Learning and Leadership, OUHSC
Kaye Rote, Oklahoma Mental Health Consumer Council
Steve Stokes, Office of Handicapped Concerns
Ann Trudgeon, Oklahoma Developmental Disabilities Council
Kayla Bower, Oklahoma Disability Law Center
Mike Ward, Oklahomans for Independent Living

Tom Bell, Oklahoma State Department of Education
Rick Billings, Oklahoma Long-term Care Authority
Chuck Gressler, DRS Ticket to Work and Work Incentive Act
Michael Harmon, Oklahoma State Department of Health
Jauna Head, Office of State Finance
Howard Hendrick, Oklahoma Department of Human Services
Mary Howell / Linda Parker, Department of Rehabilitation Services
Kenneth LaRue, Oklahoma Department of Transportation
Cassell Lawson, Oklahoma Health Care Authority
Grant Moak and Mark Jones, Office of Attorney General
James Nicholson, OKDHS Developmental Disabilities Services Division
Melody Riefer and Jackie Millspaugh, Oklahoma Department of Mental Health and Substance and Abuse Services
Michael Taylor, Oklahoma Department of Labor

Patricia Bush, DDSD Administrative Support

Appendix C: Resource Members of Olmstead Strategic Planning Committee

Jerry Durbin, DDSD Foster Parent
Barbara Schneeberg, Advocate
Sally Selvidge, Parent
Doris Erhart, Parent
Donna Oliver, Advocate
Michelle Scott, Self-Advocate
Will Watkins, Advocate

Nicole Altobello, Oklahoma Health Care Authority
Carolyn Archer, Oklahoma Mental Health Consumer Council
Dan Arthrell, Community Services Council Tulsa
Rick Barcus, Developmental Disabilities Council
Judy Bryan, Chickasaw Nation Head Start
Nancy Coffer, American Association of Retired Persons
Becky Cook, OU National Center for Disability Education and Training
Richard DeSirey, Daysprings Behavioral Health Services
Sandi Eslick, OSU Health Training Center
Esther Houser, Ombudsman OKDHS
Debie Fidler, Progressive Independence
Troy Honeman, Oklahoma Developmental Disabilities Council
John Gajda, TARC
William Ginn, Office of Handicapped Concerns
Helen Kutz, Progressive Independence
Lisa Latray, Phoenix Residential Services
Kathy Leeper, Oklahomans for Independent Living
Mike Lester, Long-Term Care Authority
Rick Lewis, Progressive Independence
Wayne McGuire, National Association on Mental Illness
Joe Mecham, Progressive Independence
Eddie Miller, Bios
Marilyn Naukam, Naukam Marketing
Dennis Pennington, Oklahoma Health Care Authority
Pam Pulchny, Oklahomans for Independent Living
Tanya Reed, Habilitation Training Specialist
Lisa Rutledge, National Multiple Sclerosis Society
Carol Schneider, ODMHSAS
Travis Smith, OKDHS Legal Division
Carla Tanner, Tulsa Area Alliance on Disabilities
Trevlyn Terry, Oklahoma Health Care Authority
Quinton Underwood, Oklahoma Disability Law Center
Sean Voskuhl, American Association of Retired Persons

Jennifer Cristol, Anastasia Pittman, Sienna Pittman, Senate and House Staff

Judite Ali, Robin Wilmoth, Lisa Bradley,
Lula Potts, Ellen Jensby, Kristina Blalock,
University of Oklahoma School of Social Work Practicum Students

Appendix D: Medicaid / Health Care

More than 600,000 of Oklahoma’s 3.3 million residents have no health insurance. Despite the fact that most of this population qualify as the “working poor,” many either have no employer sponsored private insurance plan or fail to qualify for public programs such as Medicaid, which has strict financial eligibility requirements, or Medicare, which has age and health status requirements.

Thus, it comes as no surprise that the lack of health care is one of the most pressing issues facing Oklahomans today. This issue is even more critical to Oklahomans with disabilities who rank insurance coverage for medical care as their most important need. Many low-income adults, even if they are very poor, simply do not qualify for Medicaid.

Medicaid eligibility for non-elderly adults is extended primarily to those who are pregnant, have a disability, or are low-income parents of a dependent child. The program simply does not have the state funding necessary to extend coverage to all adults or even to all adults with disabilities. Thus, even though the Medicaid program provides a vehicle to capture significant federal financial participation in the form of matching federal dollars, the monthly average Medicaid enrollment of 484,848 in SFY-2003 represented only about 14 percent of Oklahoma’s overall population. (OHCA SFY-2003 Annual Report, page 12)

A new optional federal waiver program called the Health Insurance Flexibility Act (HIFA) allows matching federal dollars to be used as premium assistance for employer sponsored insurance and offers new opportunities to cover more low income working people. Funding for this health insurance expansion is dependent on the tobacco tax.

In 1994, House Bill 1573 created the Oklahoma Health Care Authority (OHCA) and designated it as the single state Medicaid agency effective January 1, 1995. OHCA was charged with purchasing Medicaid benefits, studying state-purchased and state-subsidized health care systems, recommending changes aimed at minimizing the financial burden on the state and providing the most comprehensive health care possible for eligible Medicaid recipients.

To accomplish these mandates, OHCA oversees several health care programs. Most of these programs include services such as primary care, inpatient and outpatient hospital services, prescription drugs, family planning, pregnancy services, dental care, behavioral health services, transportation, and institutional care.

Oklahomans eligible for Medicaid primarily include low-income women and children, the disabled and elderly. Some of these groups are considered "mandatory" eligibility groups and must be covered by the state Medicaid program, while others are considered "optional." The same is true of the covered benefits.

The decision by a state Medicaid program to cover an optional population or optional benefits has important implications for the state and health care providers that otherwise might be paying for or providing health care services without compensation. Federal matching payments through Medicaid often allow states to partially refinance the cost of services that states have traditionally provided at their expense or to pay for services that otherwise might have to be written off by providers as uncollectible debts or charity care.

Unfortunately, the availability of federal matching funds for a particular service or a particular category of individuals does not necessarily mean that a state is able to cover these individuals since the state must first provide their share of the costs. Thus, in Oklahoma, though the Medicaid program does provide the federally required mandatory services for adults such as hospital care and institutional care, it does not pay for many necessary services such as physical therapy, dental services, or eyeglasses, and some services, like prescription drugs, are restricted by monthly or annual coverage limitations.

Additionally, during periods of economic recession resulting in revenue shortfalls, state appropriations, including those to Medicaid, are reduced. In these circumstances, OHCA is forced to eliminate both optional benefits and optional coverage groups, discontinuing services to thousands of Oklahomans with critical health care needs, including persons with disabilities.

By statute, eligibility for the Oklahoma Medicaid program is determined by the Department of Human Services (DHS). Income guidelines outlined by the federal government for mandatory coverage groups and by the state for optional coverage groups must be met in order to be eligible for Medicaid services. Depending upon availability of state funds, a state may choose to be very restrictive or very lenient with regard to coverage of optional groups.

OHCA administers several health care programs that impact persons with disabilities. Among these are SoonerCare. SoonerCare is a managed care program that provides services primarily to low-income children and pregnant women. Additionally SoonerCare covers people with disabilities who are not dually eligible for Medicare and Medicaid, and who do not meet the level of care criteria for institutional care. SoonerCare covers primary care, inpatient and outpatient hospital services, prescription drugs, behavioral health care, transportation, family planning and limited dental care.

Long-term care services, primarily nursing home services (NF) and services in intermediate care facilities for the mentally retarded (ICFs/MR) are mandatory Medicaid benefits. Since Medicare does not cover these services, Medicaid is the only public program that provides substantial coverage for long-term care.

Indeed, Medicaid funded approximately 71 percent of the total actual long-term care bed days in the state for SFY 2003 with total long-term care expenditures accounting for 19 percent ($277,714,649 NF and $32,437,898 for ICF/MR) of the total OHCA Medicaid expenditures. These services include expanded benefits such as coverage of non-emergency transportation with attendant care, eyeglasses, dentures, and an expanded personal needs allowance, and expanded benefit for durable medical equipment and supplies services.

Long term care services through Medicaid are available to individuals who meet the level of care requirements and who are at or below 300 percent of the federal benefit level ($1,692 income per month or about 220 percent of the Federal Poverty Level).

The Medicare Buy-In program is a Medicaid program that impacts people with disabilities who are eligible for both Medicare and Medicaid. Medicare is the primary payer of services and Medicaid is the secondary payer for these individuals. For hospital expenses, Medicaid pays the coinsurance and deductible including skilled nursing services. The deductible and coinsurance are also paid for supplementary medical insurance expenses that are primarily physician services.

Currently the eligibility for this program slightly exceeds the mandatory federal criteria. Another buy-in program, the Qualified Medicare Beneficiary program, assists low-income beneficiaries who are below 100 percent of the Federal Poverty Level.

Medicaid and Social Security have strict income and resource eligibility criteria, which must be met in order to qualify for benefits. These criteria are disincentives to persons with disabilities who want to work to earn more income, but who cannot jeopardize their access to Medicaid, which pays for their health care. Increased income may also jeopardize their access to other social services such as subsidized housing and food stamps.

In many cases, an increase in income will not cover the cost of lost benefits. A resource (savings or equity) limit of $2,000 for an individual is a disincentive for beneficiaries with a disability to accumulate savings for things like a specially equipped van or a down payment on a home. Thus, the incentive for people with disabilities is to stay in the system and live on very limited income, rather than to move outside the system through meaningful employment.

Appendix D.1: Health Care Challenges Position Paper

Issue: Oklahomans with disabilities have inadequate health care. Contributing factors include:

- Poverty
- Physical accessibility
- Communication accessibility
- Health care providers who are unprepared to manage the communication, cognitive, behavioral and other needs of people with disabilities
- Health care intervention that is focused on acute-care, rather than prevention and wellness.

Current Status in Oklahoma

- Oklahoma is in the bottom 10 of the 50 states for people living below the poverty level (American Community Survey, U.S. Census Bureau 2003).
- People with severe disabilities cite lack of income as the number one reason they are unable to get health care (Harris Poll 2000 of Non-Institutionalized Adult Americans with Disabilities).
- People with disabilities report difficulty accessing health care services due to lack of transportation, physical barriers in health care settings and communication barriers.
- Many providers do not fully understand the unique needs of persons with disabilities and lack the training or resources to effectively deal with these needs or make appropriate referrals.
- Health care services related to disability-specific wellness and prevention is limited.
- Transportation options need to be developed across the state. Too many Oklahomans who are not Medicaid eligible do not have a means of getting to medical services, or other services, in the community.

Barriers:

- Many Oklahomans with disabilities have low income yet do not qualify for Medicaid services and they cannot afford private health insurance premiums.
- Many private insurance policies exclude coverage for "pre-existing conditions."
- Many people with disabilities and/or their family members are compelled to remain in poverty to qualify for Medicaid, which is their only option for health care coverage. Poverty limits participation as contributing taxpayers of our communities.

- Many people who live in institutions have richer Medicaid funding for health care services than people with similar disabilities who live in the community.
- Many people with certain types of disabilities, including autism, brain and spinal cord injury, and mental illness are not served by current Medicaid waivers.

Needed Changes and Supports

Policy:

- Involve people with disabilities in identifying needed policy and developing policies and procedures.
- Make sure all policies support the rights of people with disabilities to live, work and play in the communities of their choice.
- Provide additional programs and services for persons who are currently not served, including but not limited to, people with autism, brain and spinal cord injury, developmental disability with no diagnosis of mental retardation, and mental illness.
- Reduce health care costs by providing wellness and prevention programs.
- Increase funding flexibility so individuals and their families can use money more effectively.
- Improve higher education programs to better prepare physicians, nurses, therapists and teachers to serve people with disabilities and their families.
- Provide incentives to increase disability awareness and sensitivity training for health care professionals.

Funding:

- Provide money in advance for travel, mentoring and time to make sure individuals with disabilities and their families are key players in program and policy development.
- Adequately fund services for persons with disabilities.
- Combine dollars of state agencies to make better use of the money we have.
- Seek funding opportunities through public/private collaboratives.
- Provide incentives for businesses to make physical accommodations for people with disabilities.

Supports / Advocacy:

- Make people with disabilities and their families key players in advocating for better services.

- Develop partnerships among advocacy groups to promote equal access to necessary health care.
- Involve advocates in coordinating funding and services and in designing interagency agreements to make better use of available money.
- Support outreach efforts to get buy-in from diverse disability groups on state and federal legislative health care initiatives.
- Partner with local businesses and chambers of commerce to generate resources to help businesses become physically accessible.

Appendix E: Employment

- In 1997, more than 33 percent of adults with disabilities lived in a household with an annual income of less than $15,000, compared to only 12 percent of those without disabilities.
- Unemployment rates for working-age adults with disabilities have hovered at the 70 percent level for the past 12 years.
- Seventy-two percent of Americans with disabilities want to work, but because of the disincentives in federal law, less than 1 percent of those receiving disability benefits fully enter the work force. (Source: www.aucd.org, Legislative Brief on Employment)

In Oklahoma, Developmental Disabilities Services Division funding for sheltered workshops in the fiscal year 2002 was $9.1 million compared to $10.8 million that was spent on integrated employment.

The Department of Rehabilitation Services spends approximately $2.8 million on supported employment serving 1,500 to 1,700 consumers with the most significant disabilities.

Economic hardship is a constant concern for many individuals with disabilities. This single factor keeps many individuals with disabilities and their families from realizing even their most basic needs. Oklahomans with disabilities who participated in a recent survey, *The Needs of Individuals with Disabilities in Oklahoma*, conducted by Esther I. Wilder, Department of Sociology and Social Work, Lehman College, City University of New York, and sponsored by the Oklahoma Office of Handicapped Concerns, reported having a median annual income of just above $8,760 when living alone.

Twenty-five percent of these respondents have annual incomes of less than $5,000. Moreover, the situation is no better in multi-person families, who have a median annual income of $18,133. In comparison, the median annual income of all Oklahoma households was $33,235 in 1999-2000. That same year, the median U.S. household income was $42,168 (U.S. Census Bureau 2001).

For Oklahoma to increase the number of people with disabilities who enter, re-enter, and remain in the work force, the state must develop and implement a strategic plan that focuses on the system as a whole. While state agencies might feel that progress toward integrated employment has been made, there are still large numbers of people with disabilities wanting jobs in the community.

A statewide conference and strategic planning workshop held in October 2003 produced the Interagency Strategic Plan – Olmstead Employment Section. The plan stresses the importance of interagency collaboration and the need for more effective matching of an individual's interests and strengths with quality jobs providing equitable pay and benefits. The following actions steps are taken from this plan.

Appendix E.1: Employment Services for People with Disabilities

Issue: Many individuals with disabilities need assistance in obtaining and maintaining employment services in the community.

Current Status in Oklahoma

- Oklahoma Department of Rehabilitation Services (DRS), the Oklahoma Department of Human Services (OKDHS) and Oklahoma Department of Mental Health and Substance Abuse Services (ODMHSAS) provide employment services such as:
    1. Job development;
    2. Job sampling;
    3. Job coaching;
    4. Assistive technology;
    5. Extended service; and
    6. Center-based employment.
- A statewide conference and strategic planning workshop was held in October 2003. This produced the Interagency Strategic Plan – Olmstead Employment Section that was included in Appendix D of the Second Annual Report.
- Programs such as the DRS transition summer camp are being developed in Oklahoma to enhance interagency transition planning and services from school to secondary education and/or work.

Barriers:

- Resources are extremely limited to people with disabilities, especially those who are not receiving home and community-based waiver services.
- There is inadequate funding for agencies that want to offer extended services to people with severe disabilities.
- People do not work because they fear losing their health care through Medicaid and other benefits.

Needed Changes and Supports

Policy:

- Strengthen the networks among state agencies, private agencies, organizations, advocacy groups, consumer groups and other stakeholders that result in effective, seamless employment service delivery.
- Educate the general public about the positive contributions, skills, and abilities of persons with disabilities along with the important and valuable economic impact of their contributions to the world of work.
- Establish a streamlined, uniform, and user-friendly service delivery system that is consistent among all agencies.
- People with disabilities must be included in all aspects of policy making.

Funding:

- Funding that is sufficient to meet the increased demand as more people move into the communities.
- Ensure funding that is flexible and follows the individual into the community, or wherever the individual chooses to live.
- Ensure funding is directed toward services selected and directed by the consumer.
- Create flexibility in supported employment services that allows for self-direction by consumers and for employer creativity in training and employment outcomes.
- Explore multiple funding streams and interagency collaboration to implement appropriate services during the transition process.

Supports / Advocacy:

- Coordinate advocacy efforts to eliminate barriers to full inclusion of people with disabilities in the work force.
- Educate the general public about the positive contributions, skills, and abilities of persons with disabilities along with the important and valuable economic impact of their contributions to the world of work.

Appendix E.2: Direct Care Work Force Crisis

Issue: Oklahoma has a serious shortage of qualified direct care workers. This work force includes personal care attendants, habilitation training specialists, home health aides and certified nursing aides.

Current Status in Oklahoma

* Position vacancies can exceed 25 percent and turnover rates often exceed 50 percent.
* Starting and average wages range from $13,520 to $17,680 annually ($6.50-$8.50 hourly).
* Most direct care workers do not have health insurance. Wages are not adequate to allow workers to purchase employee-sponsored health insurance where it is offered.
* Employers have high non-recoverable recruitment and training costs, making the costs of staffing with overtime financially challenging.
* Due to low wages, many direct care workers rely on public benefits to support their families. This dependency on assistance, such as food stamps, childcare, subsidized housing, etc., is an additional drain on local and state resources.

Barriers:

- Low wages make it difficult to afford health care benefits from their employer, if benefits are even available.
- There is a lack of recognition because society does not place a high value on direct care work.
- There are few opportunities for advancement.
- There are few opportunities for co-worker support, such as mentoring, peer training, and interpersonal relationships.
- Salaries are not commensurate with the training and responsibility required.
- For direct care workers in the community, work is often part time.

Needed Changes and Supports

Policy:

* Develop policy that encourages regular assessment of compensation to community direct care workers to ensure a realistic living wage as well as parity of comparable skilled providers regardless of employment setting.

- Study opportunities to increase incentives to encourage direct care workers to remain in the job.
- Build career opportunities for direct care workers by providing wage increases tied to training and longevity.

Funding:

- Provide funding for a living wage and adequate health coverage.
- Provide funding for on-going training for direct care workers.
- Provide funding for career development and staff networking opportunities.

Appendix E.3: Accessibility of Workforce Centers

Issue: The U.S. Department of Labor Workforce Centers, also known as One-Stops, or "the employment office," are not fully physically or programmatically accessible to persons with disabilities.

Current Status in Oklahoma

- Centers are mandated to serve anyone in the community, regardless of disability. They have a responsibility to ensure access to all job seekers. Section 188 of the Workforce Investment Act provides specific guidelines as to how full accessibility is to be achieved.
- There are 52 Workforce Centers throughout Oklahoma. Each center is locally governed and unique in that different federal, state, local, and tribal agencies and private organizations are partners.
- Workforce Centers are too often located in buildings that are not physically accessible to persons with disabilities. Most centers do not provide appropriate programmatic access such as interpreter services for people who are deaf, Braille literature for people who are blind, assistive technology and software for computer access, etc., to job seekers with disabilities.
- Only 12 out of the 52 Workforce Centers in Oklahoma have disability program navigators specifically trained to assist job seekers with disabilities. Serving people with disabilities does not appear to be a priority for most Workforce Centers.

Barriers:

- Workforce Centers do not emphasize their mandate to serve persons with disabilities and are not adequately trained to serve persons with disabilities.

- Not all resources within the Workforce Centers are accessible to persons with disabilities.
- Persons with disabilities frequently need more staff assistance to access resources than the Workforce Center is able to provide.
- Serving people with disabilities does not appear to be a priority for most Workforce Centers.
- Workforce Center Web sites are not accessible as required by federal and state law.

Because of diverse partnerships in Workforce Centers, no one will accept responsibility for accessibility.

Needed Changes and Supports

Policy:

- Enforce minimum standards of accessibility as provided for in Section 188 of the Workforce Investment Act and the Americans with Disabilities Act, Title II.
- Train agency personnel at the state and local level on the Workforce Center mandate to provide services to all job seekers, regardless of disability.
- Develop mutual understanding between partnering agencies in Workforce Centers to address the needs of all job seekers, regardless of disability.
- Require Local Workforce boards to develop and enforce interagency agreements between partners to address accessibility issues.
- Locate Workforce Centers in fully accessible buildings and locations.

Funding:

- Fund Workforce Centers for programmatic accessibility such as interpreter services, computer hardware and software, etc.

Supports / Advocacy:

- Promote Workforce Centers as essential partners in employment services for persons with disabilities.
- Encourage people with disabilities to serve as members of their local Workforce Center board to help ensure consumer input to enhance service delivery in the centers.

Appendix E.4: Quality Direct Care Work Force

Issue: Oklahoma has a serious shortage of qualified direct care workers. This work force includes personal care attendants, habilitation training specialists, home health aides and certified nursing aides.

Current Status in Oklahoma

- Position vacancies can exceed 25 percent and turnover rates often exceed 50 percent.
- Starting and average wages range from $13,520 to $17,680 annually ($6.50-$8.50 hourly).
- No standardized recruitment approach is used to attract and retain qualified direct care workers.
- Use of proven retention intervention strategies such as peer mentoring, support services, and high quality benefits is limited.
- Professional career advancement in the field of direct care is limited.
- Lack of recognition for direct care workers.
- Various governmentally appointed groups are working independently on studying and addressing the work force crisis, resulting in a splintered and inefficient approach to addressing the issue.

Barriers:

- Salaries are not commensurate with the training and responsibility required.
- The amount of money employers can devote directly to the wages of direct care employees is limited by the training and administrative requirements mandated by governing agencies.
- No organized approach to connect potential employers with employee candidates, resulting in money being devoted to recruiting costs instead of on wages.
- Few opportunities for co-worker support, such as mentoring, peer training, and interpersonal relationships.
- Screening procedures mandated by state agencies are ineffective in identifying ideal candidates for direct care positions. No specialized screening tool exists to identify ideal candidates for direct care positions.
- Transportability of experience and training, thus work opportunities between and among varied disability groups (developmental disabilities, physical disabilities, and elderly), is limited due to lack of certification or standardization of training requirements across direct care worker groups.
- A unified approach to addressing the work force crisis is difficult when the various "players" have differing motives, leadership and funding.

Needed Changes and Supports

Policy:

- Develop policy that encourages regular assessment of compensation to community direct care workers to ensure a realistic living wage as well as parity among comparably skilled workers regardless of employment setting.
- Develop policy that encourages a centralized information clearinghouse related to direct care position openings and direct care workers looking for positions.

Funding:

- Provide funding for a living wage and adequate health coverage.
- Provide funding for on-going training for direct care workers.
- Provide funding for career development and staff networking opportunities.

Supports / Advocacy:

- Support initiatives focused on studying the characteristics of successful direct care workers and developing tools to screen candidates to increase successful hiring practices.
- Study opportunities to increase incentives to encourage direct care workers to remain in the job, including direct care workers' professional associations.
- Build career opportunities for direct care workers by providing wage increases tied to training and longevity.
- Establish high-level state leadership to coordinate the efforts directed at solving the direct care labor crisis.

Appendix F: Mental Health Position Paper

Issue: Our nation's mental health care system is "fragmented and in disarray,"[4] leading to unnecessary and costly services, exacerbated disability, homelessness and/or limited options for living in the most integrated environment, underemployment, health care disparities, and incarceration.

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[4] New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America. Final Report*. DHHS Pub. No. SMA-03-3832. Rockville, MD: 2003.

Current Status in Oklahoma

Homelessness – The Oklahoma Department of Mental Health and Substance Abuse Services provided services to 38,066 Oklahoma citizens in FY05.[5] Of these people, 2,052 self-identified as homeless with 51 percent living in community shelters and 49 percent living on the street. At least two programs working on this issue are the Project for Assistance in Transitions from Homelessness (PATH) and the Governor's Interagency Council on Homelessness.

Employment – Among individuals receiving mental health services in FY05, 84 percent were either not employed or not in the labor force, 9 percent were employed full-time and 7 percent were employed part-time. Since full time employment is considered to be greater than or equal to 35 hours a week, some of the people considered full-time may not meet the traditional standard of 40 hours a week.

A possible explanation for low rates of employment is discrimination. Though the Americans with Disabilities Act (ADA) states that such discrimination is illegal, some employers are reluctant to hire people who experience psychiatric symptoms or, once hired, to advance them to positions of increased responsibility.

Health Care Disparities – The average person receiving mental health services has 4.2 appointments a month (between multiple agencies/providers). Many people with mental health problems have co-occurring issues such as diabetes, heart disease, traumatic brain injury, mental retardation/developmental disabilities, and other physical and/or sensory disabilities. Frequently mental health and substance abuse services are provided separately from one another resulting in increased cost and decreased effectiveness.

Discrimination against those with mental health problems may also result in inadequate insurance coverage. When mental illness is covered, coverage may be limited, inappropriate, or inadequate. Additional discrimination can occur because health care providers historically ignore or underrate reported medical symptoms experienced by people with psychiatric histories.

Criminal Justice System – Critical issues concerning the current status in this area include a lack of, or withheld, psychiatric and other medications, psychotherapy, peer support, housing upon release, and community reintegration upon release from prison. In a recently released report from

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[5] All Oklahoma specific statistics were provided by ODMHSAS Decision Support Services.

the Oklahoma Department of Corrections (DOC) 72 percent of female inmates and 32 percent of male inmates have mental illness.[6] Non-violent offenders make up 57 percent of those incarcerated with a mental illness.[7]

Children and Youth – Wraparound services, as part of an overall Systems of Care (SOC), is an evidence-based practice designed to meet the needs of children with serious emotional disturbance and their families. It is currently operational in 25 counties in Oklahoma. The core values of SOC are that all services are child centered and family driven, community-based, and culturally competent. Much of the effectiveness of SOC services is related to the coordination of multi-agency support and the involvement of SOC "graduates" in the support of current participants.

One study of 397 SOC participants found that after only six months of services there was a 31 percent reduction in total out-of-home placements, a 64 percent reduction in school detentions, a 65 percent reduction in self-harm attempts and a 54 percent reduction in arrests.[8]

Barriers:

Discrimination – The diagnosis of mental illness is often more disabling than the illness itself. There are myths and misinformation about mental illness that lead to an over-reliance on congregate housing and the isolation of people from the larger community. People living with mental illness have expressed their right and desire to live in communities of their choice, and to participate in the full range of community resources available to all citizens.

Institutional Bias – The primary barrier to community-based living is the strong institutional bias that demands a person be symptom free and medication compliant before receiving community integration services. This barrier crosses multiple service areas:

- housing and employment choices,
- access to adequate physical health care,
- increased incarceration,
- treatment of co-occurring addictions and trauma issues.

Transportation – Transportation also continues to be a barrier to full community integration. Many consumers of mental health services do not

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[6] http://www.doc.state.ok.us/Medical/April percent202005 percent20MH percent20Caseload percent20Lists percent20Data-BOC.xls

[7] http://www.doc.state.ok.us/Medical/Medical percent20Fact percent20Sheet percent2011-04.htm

[8] ODMHSAS Decision Support Services, 2005.

have the ability or access to transportation to be able to live independently.

Access to Care – Services are often delivered through a crisis driven medical model. People must qualify for services based on degree of illness rather than prevention of escalation of symptoms. Inconsistent admission criteria and provider self-referral following the assessment process limits access to care and decreases effectiveness. The lack of provider choice in rural areas can also be a deterrent to adequate care. A fear of the emergency detention process keeps people from seeking services.

Needed Changes and Supports

Policy:

- New "Recovery Home" criteria has been promulgated by ODMHSAS. It is recommended that a goal be set whereby all residential facilities contracted through the ODMHSAS meet Recovery Home initiative criteria.
- No ODMHSAS funding should go toward new congregate housing, and community specific plans should be developed to assure access to recovery-focused services for residents of congregate housing.
- Supported Employment, as an evidence-based practice, should be fully sustained with the new Memorandum of Understanding between the Department of Rehabilitation Services (DRS) and ODMHSAS.
- Expanded community-based mental health services that provide integrated care for people with co-occurring mental illness and addictions should be provided throughout the state.
- Housing and Urban Development (HUD) policy definitions should be revised regarding initial discharge placement, length of time to qualify for homeless status, and for convicted felon status when a person has mental illness and was incarcerated for a nonviolent crime.
- Mental health courts/jail diversion services should be expanded to provide statewide coverage. Alternatives should be found in the DOC for non-violent offenders with serious mental illness to qualify for early release upon proof of mental health diagnoses and evidence of participation in recovery-based programs.
- Increase the availability and use of peer support services in mental health settings. Peer support has been identified in the President's New Freedom Commission Report on Mental Health (2003) and by the Surgeon General's Report in Mental Health (1999) as being critical in creating a recovery-focused environment. Policies that support the hiring and training of people in recovery from mental illness are

needed. The adoption of reimbursable peer services will ensure the growth and sustainability of said services.

* Increase availability and use of family support and respite care.

Children and Community Integration Planning Issues

The needs of children at risk or in out-of-home placements differ from those of adults. Many of these children have been exposed to or are involved with violence, have co-occurring mental and substance abuse disorders, are in need of special education services, are high-risk infants and toddlers, or are older adolescents transitioning to adult services.[3]

When addressing the transition of children with mental illnesses from out-of-home placements to family settings, Olmstead plans and other state planning documents must include the following:[4]

* Providers need to be trained to recognize and to address the needs of these children.
* Use short-term home and family based intervention with children and their families, and strengths-based approaches that offer choice and flexibility to children and family members should be supported.
* The needs of children and families who live in rural and urban poverty areas must also be addressed. In urban areas, promoting availability of services at already frequented locations such as schools, churches and community centers helps to support children and families. In rural areas, providing transportation assistance and telemedicine services can be useful.
* The provision of transitional services for adolescents transitioning out of outpatient or residential treatment facilities and into adult services, such as vocational training and job support, is essential. These services should also be available for youth who do not meet the diagnostic criteria for being served in adult service systems.
* Attention must be given to young adults (≈16 to 25) who are experiencing emerging symptoms. Traditional services are not adequate to support the recovery of young adults as the focus tends to be on individuals who experience long-term symptoms.

Funding:

Funding to support these improvements should or could come from a number of sources including:

* Adoption of “money follows the person” practices
* Medicaid reimbursable peer services
* Systems of Care growth untied from federal funding
* The Transformation State Infrastructure Grant (T-SIG), a competitive grant recently received by ODMHSAS to develop cross-agency

coordination of mental health services and to develop recovery oriented, consumer driven care.

* Adequate funding is needed for evidence-based and emerging best practices from both Medicaid and state dollars. These practices currently include:
    - Program for Assertive Community Treatment (PACT);
    - Supported Employment;
    - Systems of Care/wraparound services;
    - Illness management and recovery;
    - Family psycho-education; and
    - Consumer run programs.

Supports / Advocacy:

Encouragement must be provided for the transition of children with serious emotional disturbance and adults with serious mental illness from institutional settings to the community setting of their choice. The supports and advocacy should include:

- Development of consumer run programs.
- Increased presence of advocacy organizations.
- Formation of an effective cross disability advocacy movement.
- Recovery oriented consumer driven infrastructure development.
- Maximization of technology including telemedicine, electronic records and other emerging technological advancements.
- Coalition building that addresses the social and political needs of people across the lifespan who experience psychiatric symptoms.

Appendix G: Transportation

* Funds from the Transportation Equity Act for the 21st century, Section 5310 program, can be used only for capital expenses and cannot be used for operating expenses. (Legislative Brief on Transportation, www.aucd.org)
* A lack of adequate transportation bars people with disabilities from employment. (Legislative Brief, www.aucd.org)

Through the home and community-based waivers and the in-home support waiver, 4,200 persons with disabilities may access Medicaid-funded transportation services to and from medical appointments, work or employment services, recreational activities, and other community activities within the number of miles authorized in their plan of care, and within the rules established by the Department of Human Services and the Oklahoma Health Care Authority.

For thousands of Oklahomans, finding adequate transportation services is an ongoing struggle, and it is an even greater barrier for people with disabilities. There are four urban transit providers – Metro Transit (Oklahoma City), LATS (Lawton), CART (Norman), and Tulsa Transit – and there are twenty rural transit providers operating throughout the state.

In a study conducted by the Oklahoma Department of Transportation, more than eighty percent (80 percent) of the residents surveyed thought it was important for the state of Oklahoma to foster public transportation improvements at the city and county level, and almost half rated the availability of public transportation in their community as "poor."

Similarly, stakeholders who influence transportation decisions in the state were surveyed. Seventy-one percent of this group rated the availability of public transportation in their community as poor, and 87 percent thought that funding for public transportation should be increased during the next five years.

Voucher programs also exist (often through Medicaid funding) that are intended to service persons with disabilities and/or their families. Programs offer rides to hospital visits or reimburse those who use their own means of transportation for their driving expenses.

Though these programs can and do provide transportation to people in need of it, they have restrictions that prevent them from being a realistic option for many who need transportation services. For instance, services providing individual transportation to the hospital require that three days of advance notice must be given before the hospital visit takes place.

Furthermore, these programs carry the restriction that only one passenger is allowed to accompany the person requiring the transportation. Parents with more than one child who cannot find alternate care for their other children are unable to take advantage of these services.

The Department of Transportation has been concentrating its efforts on trying to create a viable transportation network. With more coordination of dollars and ideas, needed programs can be given a stronger footing and more statewide support. They are in agreement with the feelings expressed by many Oklahomans with disabilities who need reliable public transportation – strength in numbers is required to make lasting and noticeable change.

Workgroups and consumer advisory boards could play a vital role in coordinating transportation services throughout the state and tailoring those services to consumers' needs.

Before any of this can become a working reality, new and reliable funding sources must be established. Currently, the Oklahoma Department of Transportation administers funding from the government and from the Public Transit Revolving Fund – an allocated portion of the state's gasoline tax. The funds they receive now are inadequate to support the improvements that so many Oklahomans require.

The Oklahoma Transit Association is lobbying for an increase in the fuel tax directed to more funding for public transportation services. (Information from *Transportation and Oklahoma: Putting Residents with Disabilities on the Road to Success*)

Appendix G.1: Transportation Position Paper – Equal Access

Issue: Oklahoma lacks adequate transportation for people with disabilities to fully participate in work and community life.

Barriers:

- The biggest buyer of transportation services for people with disabilities is Medicaid. These services are primarily limited to transportation to medical appointments. People on home and community-based waivers may have more transportation options.
- The general population of Oklahoma values individual personal transportation.
- There is a lack of coordinated state and local funding to address multiple transportation services.
- There are transit service disconnects between metropolitan, suburban and rural areas.
- Demand for public transportation in Oklahoma is low possibly due to difficulty in making timely commutes to work, shopping and appointments. There are also a limited number of public transportation vehicles that are wheelchair accessible.

Needed Changes and Supports

Policy:

- Develop policy and procedure to encourage transportation providers to coordinate and interconnect their services with other transportation providers operating within their service area.

- Identify ways to combine transportation funds from different sources including Medicaid waivers, Department of Transportation, etc., into a single seamless, coordinated transportation network, accessible for all.
- Utilize and strengthen the role of the consumer council in transportation with meaningful involvement of people with disabilities and their advocates to monitor national and local transportation funding streams and to oversee use of public transportation funds and implementation of local, state and federal transportation policies.

Funding:

- Establish a dedicated fuel tax that would fund public transportation initiatives.
- Offer tax incentives for use of public transportation.
- Maximize Oklahoma's access to federal and state monies available for transportation services.

Supports / Advocacy:

- Create a statewide marketing program to increase the public's awareness of transportation issues.
- Establish a more effective consumer grievance process.
- Create and coordinate transportation systems and procedures that allow persons with disabilities to participate in their communities. This will require expanding and enhancing community transportation throughout the state.

Appendix H: Housing

* 71 percent of people without disabilities own homes, but fewer than 10 percent of those with disabilities do.
* Nationally, approximately 750,000 people with developmental disabilities live with aging parents. (www.aucd.org, Legislative Brief on Housing)
* For the first time ever, the national average rent was greater than the amount of income received by 3.7 million Americans with disabilities who rely on a monthly Supplemental Security Income (SSI) of $545 to pay for all their basic needs. (*Priced Out in 2002*)
* In 2002, of the nation's 2,702 housing market areas, there was not one single area where modestly priced rental units were affordable to people with disabilities. (*Priced Out in 2002*)
* The 1992, "elderly only" designation law allowed owners of federally subsidized housing to restrict or exclude non-elderly people with

disabilities from moving into HUD funded public and assisted housing. (www.aucd.org, Legislative Brief on Housing)

* Nationally, more than 400,000 units (out of 1 million) are designated exclusively for people older than age 62. (www.aucd.org, Legislative Brief on Housing)

People with disabilities are often very limited in the housing options available to them. Factors that contribute to these limited options are described below:

- Many people with disabilities must rely on Social Security disability payments as their only source of funds. This payment is approximately $564 per month in 2004, which is not enough money to pay rent and other living expenses unless the person on Social Security chooses to live with other individuals who may share the rent and living expenses. If they exceed the income limits to qualify for Medicaid they will lose health care coverage.
- Housing often is not accessible for people who use wheelchairs or other forms of mobility assistance. Frequently the bathrooms do not have grab bars and doorways are not wide enough to permit wheelchairs to get through. Additionally, most landlords are not willing to make modifications.
- Some people with disabilities choose to live with members of their family and do not have any out-of-pocket expenses for rent or living expenses.

Therefore, many Oklahomans with disabilities look to programs that provide housing assistance. The Housing and Urban Development (HUD) Section 8 program provides housing assistance payments through rental certificates, vouchers, or payments to participating property owners. However, there are drawbacks to this type of housing. The most crucial and common issues raised by persons with disabilities were the concerns about:

- Physical accessibility;
- Affordability – difficulty finding housing within their means;
- Safety of HUD Section 8 housing – housing is often located in undesirable areas, causing concern for peoples' safety and ability to become fully participating members of their community;
- Waiting lists make it difficult to time an individual's exit from a nursing home, or an individual may have to live in a nursing home waiting for housing vouchers; and
- Funding sources for owning one's own home.

Appendix H.1: Housing Challenges Position Paper

Issue: Oklahomans with disabilities lack access to safe, accessible, affordable, and integrated housing.

Barriers:

- No coordinated statewide planning effort addressing homelessness and housing for people with disabilities.
- People who have experienced housing discrimination lack effective legal representation.
- Individual choice and community integration is limited due to over-reliance and/or segregated congregate housing.
- The lack of safe, accessible, affordable, and integrated housing makes it difficult for people with disabilities to: 1) leave institutions; and 2) to maintain residency in their community of choice.
- The process of finding and securing subsidized housing is unnecessarily complex.
- The present proposed decrease in federal appropriations for housing initiatives will severely limit the intent of the President's New Freedom initiatives.

Needed Changes and Supports

Policy:

- Utilize the Governor's Task Force on Homelessness and Housing as the organizing body for coordinated statewide planning. Members of this organizing task force should include the Olmstead Strategic Planning Committee, Home of Your Own, Public Housing Authorities, Oklahoma Housing Finance Agency, and other appropriate housing groups as identified. Representation by individuals seeking or accessing housing services must be included in the task force.
- State policies and contracts should be reviewed to insure consistency with informed choice and community integration.
- Promote a capacity building initiative between the public housing authorities and community and state based organizations to develop creative housing options for serving people with disabilities in the most integrated setting.
- Study way to simplify the housing application process to make it more user-friendly.

Funding:

- The New Freedom Commission Report identified important goals for systems change and those goals should influence fiscal appropriations. Education and advocacy should focus on making the goals a reality through appropriate funding.

Supports / Advocacy:

- Establish an interim study to examine the effectiveness of the protection and advocacy for people with significant disabilities.

Appendix I: Assistive Technology

* U.S. Census Bureau statistics estimate that 20 percent of Oklahomans, more than a half million people, have a disabling condition(s). Some disabilities will be life long; others may be temporary. Whether permanent or temporary, however, provision of necessary adaptive equipment is essential for increasing function, decreasing complications, and promoting the psychological well being of individuals with disabilities.

Technology makes things *easier* for people without disabilities, but for people with disabilities, assistive technology makes things *possible*. The purpose of assistive technology devices and services, regardless of the type of device or service, is to:

- Improve or maintain functional abilities.
- Prevent the development of secondary impairments and disabilities.
- Increase independent living.
- Decrease or eliminate the need for caregivers.
- Facilitate entrance into or return to work, school, or living situation.
- Enable full access to, and participation in, the opportunities afforded the non-disabled citizens of Oklahoma.
- Empower persons with disabilities to compete with persons without disabilities within their capabilities.

Technology – having it and being able to use it – has become a necessity of daily life. This reality applies to all, and affects everyone’s quality of life. Technology has become one of the primary engines for economic activity, education and innovation in this nation, and throughout the world. Commitment to the development and utilization of technology is one of the main factors underlying the strength and vibrancy of the economy.

No development in mainstream technology can be imagined that would not have profound implications for Oklahomans with disabilities. Hence, the concept of assistive technology is not just a device or a service. It requires systems working together in a coordinated effort to keep the needs of individuals with disabilities for access to technology as a central component of decision making related to the development, use, and availability of technology in both the public and private sectors.

The Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) of 1998 was passed by Congress to increase access to, availability of, and funding for assistive technology through state efforts and national initiatives. With the passage of the Tech Act, children, youth and adults with disabilities and their families and advocates were given a clear and expanded set of expectations that assistive technology devices and services would be more available, accessible, and responsive to consumer needs.

To develop these comprehensive changes will require the involvement of individuals with disabilities, family members, providers, professionals, technology manufacturers and dealers, insurers, federal and state agencies, and members of the Oklahoma Legislature.

Appendix I.1: Assistive Technology Position Paper

Assistive technology device means any item, piece of equipment, or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.
Assistive technology service is any service that directly assists an individual with a disability in the selection, acquisition, or use of an assistive technology device.

Issue: Oklahomans with disabilities have inadequate access to, and an inability to acquire needed assistive technology. Contributing factors include:

1. Lack of resources to pay for assistive technology devices and services;
2. Lack of trained personnel and qualified vendors to assist individuals with disabilities to select, use and maintain such devices;
3. Lack of information among individuals with disabilities, their family members and professionals about the availability and potential benefit of technology for individuals with disabilities;
4. Lack of outreach to underrepresented and rural populations;
5. Lack of systems that ensure timely acquisition and delivery of assistive technology devices and services;

6. Lack of pre-service and in-service training for students and professionals in the use of assistive technology;
7. Lack of coordination among state human services programs and private entities, particularly with respect to transitions between such programs; and
8. Lack of capacity in such programs to provide the necessary technology-related assistance.

Current Status in Oklahoma

1. Twenty percent of Oklahomans have a disabling condition (U.S. Census Bureau, 2001). Assistive technology can benefit individuals with any type of disability, of all ages, in all arenas of life such as education, employment, and/or community living.
2. Due to advances in health care, increasing numbers of individuals are living with permanent functional limitations that require assistive technology for independence and productivity. Yet, the health care system continues to classify assistive technology as durable medical equipment (DME) and health insurance provides inadequate or no DME benefits. Many assistive technology devices have not been classified as DME.
3. Many Oklahomans who need AT devices cannot afford them and do not qualify for public funding unless they ‘spend down’ income and assets. In addition, access to public/private funding of assistive technology is tied to specific eligibility factors that include a person’s age, type of disability and/or income. Most Oklahomans do not meet any of the eligibility criteria requiring them to utilize their limited resources.
4. Public funding sources responsible for providing assistive technology, all too often shift the responsibility from system to system by claiming they are the “payer of last resort.” This places both the burden of payment and the knowledge of complicated systems on individuals with disabilities and their family members.
5. Many third party payers impose arbitrary restrictions on equipment covered and the frequency of purchase regardless of need. Each individual is unique; therefore, their assistive technology needs are unique.

Barriers:

For the purposes of this report, assistive technology barriers will focus only on issues that prevent a person transitioning from an institutional setting to the community or those that force a person from a community setting to an institutional setting.

1. Oklahoma Health Care Authority (OHCA) reimburses nursing homes on a per patient day rate that is inclusive of all custodial care including DME.

Nursing home residents can not access DME on an individual needs basis and individuals who reside in an intermediate care facility for the mentally retarded can only access DME if it is specifically customized for their individual needs. Individuals who want to leave a nursing home can't move out without proper equipment such as wheelchairs, walkers, and bath and toilet aids.

2. Public/private funding sources (i.e. Medicaid State Plan, ADvantage waiver, home and community-based waivers, Community Care, Blue Cross Blue Shield, etc.) rely on a broadly written policy to determine the approval of DME payment. All too often, DME payment is left to the payer's policy interpretation, frequently creating practice that is inconsistently applied. Organizational practices that do not follow policy create a subjective and ever moving target of device approval criteria. This information is frequently not made available to recipients or providers resulting in an inconsistent provision of DME to persons with disabilities. (Examples: augmentative alternative communication (AAC) device (Medicaid State Plan) or vehicle lift equipment (HCBW))
3. Individuals on the ADvantage waiver who are denied DME through Medicare often do not know they can request the equipment through the ADvantage waiver and often do not receive equipment through the waiver in a timely manner. Yet, one of the listed services provided by the ADvantage home and community-based waiver is (317:35-17-3 (c)(5) specialized medical equipment and supplies.
4. Current OHCA policy (317:30-5-211 (a)(1)(D)(iii) that provides for bath and toilet aids, imposes automatic restrictions that not only limit a person to the home, but also confine them to their beds. CMS (formerly Health Care Finance Administration) provided state Medicaid directors clarification on Medicaid regulations in a letter dated Sept. 4, 1998, that states, "…. A state may not impose arbitrary limitation on mandatory services, such as home health services based solely on diagnosis, type of illness, or condition (42C.F.R. § 440.230(c))." The letter goes on to explain that, "A medical equipment policy that provides no reasonable and meaningful procedure for requesting items that do not appear on a state's pre-approved list, is inconsistent with the federal law …"
5. A state's Medicaid program is allowed to have greater flexibility than the Medicare program through the Medicaid State Plan. The OHCA in both practice and policy (317:30-5-211 (a)(1)(D)(iii) restricts the provision of DME, medical supplies and prosthetic devices to be equivalent or less than what Medicare can provide their beneficiaries.
6. Many uninsured or underinsured Oklahomans go without needed DME and could benefit by accessing used DME from a reutilization program. OHCA DME policy (317:30-5-211 (a)(1)(B) states, "All durable medical equipment purchased with Oklahoma Medicaid funds becomes the property of the Oklahoma Health Care Authority to be used by the

recipient until no longer needed." If the OHCA implemented a program to collect DME that is no longer needed it could redistribute the equipment to Oklahomans who otherwise would not be able to get the equipment.

7. State Medicaid policy does not outline the procedures for needed repairs to DME in policy 317:30-5-211; therefore, it is difficult to determine if and when a repair is covered by Medicaid. Whereas, in the Medicare Benefits Policy §110.2, Repairs Maintenance, Replacement and Delivery explains the procedure for Medicare to repair DME.

Policy Recommendations:

1. OHCA should develop objective instructions to staff for DME provision so that health care providers, suppliers of durable medical equipment and individuals with disabilities could clearly understand both the criteria and documentation necessary to determine payment.
2. The Long-Term Care Authority needs to provide ADvantage case managers with uniform training on how to access medically necessary specialized equipment that is not provided by Medicare or the state plan.
3. Bath and toilet aids should be considered medical equipment and therefore a mandatory service of Medicaid in 42 C.F.R. §440.70. Bath and toilet aids should be considered DME, within the OHCA DME definition 317:30-5-211 (1)(A), "… is equipment that can withstand repeated use, is used to serve a medical purpose, is not useful to a person in the absence of an illness or injury, and is used in the most appropriate setting including the home or workplace."
4. The OHCA needs to change DME policy 317:30-5-211 to be reflective of the state Medicaid director's policy clarification in the Olmstead Update No. 3, July 25, 2000, which explains that the state Medicaid agency may not arbitrarily deny or reduce the amount, duration and scope of required service through 42 C.F.R. Section 440.210 (i.e. medical equipment through home health services) to an otherwise eligible recipient solely because of the diagnosis, type of illness, or condition.
5. OHCA needs to create and maintain an effective DME inventory listing and retrieval mechanism. At a minimum, policy should include: inventory and bar code items at the time of payment, time frames and reasons for repossession of equipment from Medicaid recipients, additional manpower and warehouse space to store equipment, contracts with appropriate vendors to refurbish and maintain equipment, policy for recycle or reuse to others, and identification of persons eligible to benefit from the used equipment.
6. The OHCA needs to establish objective policy on the provision of repair and maintenance of DME.
7. Establish a policy that provides a fee-for-service system for credentialed assistive technology professionals (ATPs).

Funding:

Each funding recommendation has a parenthetical number listed beside it that directly references the above outlined barrier**.**

- The Quality of Care revolving fund needs to provide funding for nursing home residents to be able to access needed DME on an individual basis while they reside in the institutional setting. As the individual transitions to community living, so should the equipment.

Supports / Advocacy:

- Statewide training through partnerships would be provided to individuals with disabilities, their family members and support personnel on how to request appropriate DME, how to track that request to ensure timely delivery and how to appeal denials.
- With the passage of the Assistive Technology Act of 1998 as amended in October 2004 (ATA), Congress mandated state ATA programs to administer activities that assist individuals with disabilities to access or acquire needed assistive technology.

Appendix J: Advocacy

Individual advocacy enables people to have a voice in the decision-making process, especially when those decisions affect their quality of life. Advocacy means helping someone by speaking or acting in his/her best interest.

Whereas many individuals with disabilities are able to self-advocate, there is also a need for advocates who work on behalf of individuals who cannot advocate for themselves. They must take the individual's perspective in trying to resolve the problem. If the individual can represent themselves, the advocate may assume a mediator role to ensure that the individual's views are heard and that everyone participates in determining the resolution. When advocating for another, objectivity is required to determine the validity of the complaints. Sufficient information must be gathered to have an accurate understanding of the problem and to plan a resolution strategy.

"Families and self-advocates have a body of information and experience that is needed by service providers, policy makers and people in education. Yet, their individual voices are often a whisper in the noise of systemic change." (Center for Learning and Leadership training initiative project, non-competing renewal application) Advocates work in a variety of ways to improve quality of life for individuals with a disability as defined in Olmstead.

People in the disability advocacy community must become more visible and cross the line to become *ability* advocates. A good example of an advocacy spectrum is the Oklahoma Long Term Care Ombudsman Advocacy Spectrum, which encompasses:

- Empowering residents and community citizens;
- Getting necessary system-wide changes;
- Extending community resources to residents;
- Making overall changes in the facility environment (community); and
- Working to resolve resident's individual and group problems.

Pockets of advocacy across the state of Oklahoma do not have the same impact as one unified voice speaking for all people with differing abilities and health care needs. Olmstead advocacy efforts must be addressed by persons with disabilities as a group, not just those who provide services to persons with disabilities.

Appendix K: Self-Directed Services Position Paper

Issue: People with disabilities want more control of their lives and how services are delivered.

Current Status in Oklahoma

- Oklahoma has the ability to implement self-directed service options through the Medicaid home and community-based waivers administered through the Department of Human Services Aging Services Division and Developmental Disabilities Services Division.
- The Tulsa Long-Term Care Authority is currently implementing a self-directed model through a Medicaid grant.
- Consumers and families have expressed a willingness to participate in a self-directed services model.
- Federal Medicaid regulations not only allow but encourage states to implement self-directed service systems.

Barriers:

- Every state that receives Medicaid must provide nursing home and institutional services, but community-based services are optional.
- No agency in the state of Oklahoma has applied for federal funding to implement self-directed services.

- Additional state dollars may be needed to expand services to people who do not have mental retardation, or are younger than age 60.
- Societal attitudes and perceptions focus on the limitations and not the abilities of people with disabilities.
- Need a way to pay for transition expenses when a person leaves a nursing facility or institution, such as deposits for utilities, rent, household supplies, etc.

Needed Changes and Supports

Policy:

- Develop and implement state Medicaid programs that have self-directed options.
- Require state agencies that provide services to people with disabilities to develop and implement self-directed service options.
- Develop and implement a system of financial management assistance or fiscal intermediaries for people who choose self-directed services but need some assistance with planning, budgeting, payroll, insurance or taxes.
- Work with the Oklahoma Health Care Authority to change the Centers for Medicare and Medicaid Services (CMS) Medicaid provider agreement requirement to allow flexibility needed for self-directed services. CMS currently requires that Medicaid agencies execute a Medicaid provider agreement with every provider and vendor that receives Medicaid funds.
- Establish the budget levels that will be available to the individual for services and a procedure to resolve underspending or overspending individuals' accounts.

Funding:

- Develop self-directed policies, training and payment procedures.
- Develop flexible funding mechanisms that allow consumers more control of how those funds are spent.
- Determine who will be served and calculate what it will cost.
- Find a funding source and mechanism to pay for transition expenses.
- Claim federal matching funds for the financial manager or fiscal intermediary function.

Supports / Advocacy:

- Develop a way to balance an individuals' desire for choice and control of their services and workers, and the reality of regulatory compliance, program accountability, liability and program participants' health and safety.

- Obtain a commitment from service providers and funding sources to change how they construct, deliver, and monitor supports to people with disabilities.
- Develop a quality assurance process to monitor health, quality of life and individual/representative noncompliance.
- Develop a way to determine individuals' and/or representatives' ability and desire to manage employer-related tasks.

Appendix L: Transition to Community-Based Services for Persons Inappropriately Placed in Institutions

Issue: There are people with disabilities who are inappropriately placed in institutions because of attitudinal barriers, inadequate community supports and institutional bias.

Barriers:

- The Medicaid structure favors nursing home and institutional placement above the provision of community-based services.
- It often takes a long time between the applying for and receiving of community-based services, which can prevent people from leaving institutions and/or cause premature entry into institutions.
- Once an individual enters an institution such as a nursing home, residential care home, or private intermediate care facility for mentally retarded, there is no formal process in place to help them transition back into the community.
- There is inconsistent and inadequate assessment for access to community-based services.
- There is a lack of interagency service coordination for person-centered diversion and transition planning.
- There is a lack of coordination with the community-based agencies and the medical community to prevent institutional placement.
- Medicare policy is problematic concerning the purchase of equipment that can be transitioned with the individual from institutional settings into community settings.
- There is no mechanism or funding for community organizations to provide service coordination for people transitioning out of institutions.
- It is the perception of many people with disabilities that the appeals process favors the agency policy writers and not the individual's choice.

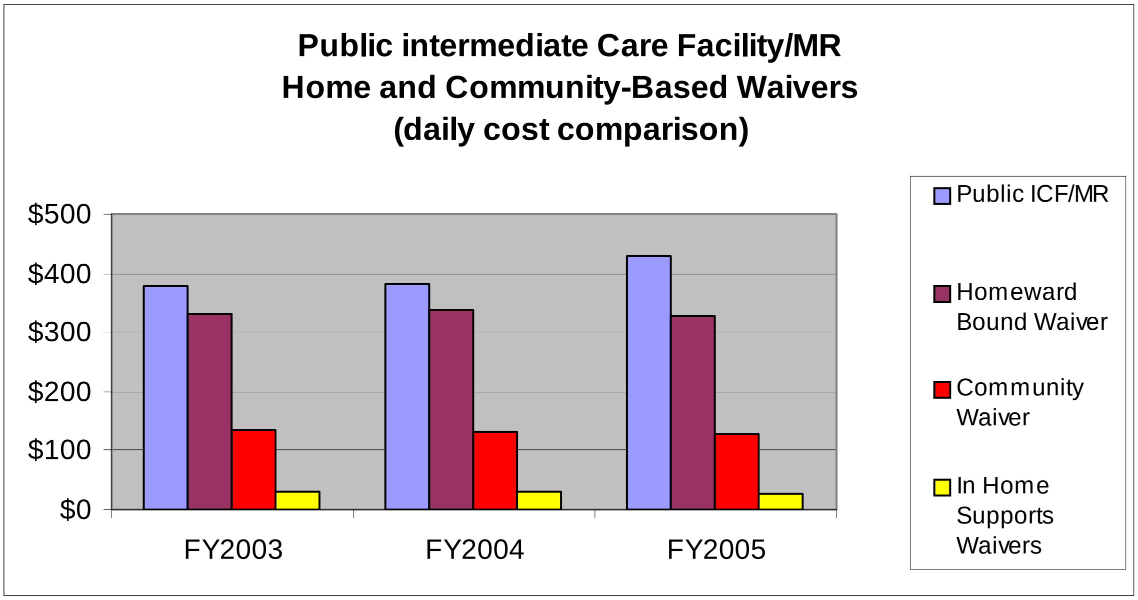
Needed Changes and Supports

Policy:

- Create incentives to reduce the waiting time between application and receipt of community-based services.
- Make medical equipment available to residents in advance of placement in the community (e.g. arranging for manufacturers and durable medical equipment vendors to make the equipment available for a trial period prior to community placement or utilizing waivers).
- Develop data sharing capability between federal and state agencies and providers to aid in the identification of individuals who have indicated a preference for community-based services.
- Create interagency agreements to help people get out of and stay out of institutions.
- Make it easy and profitable for public and private agencies to provide diversion and transition services.
- Review assessment tools and how they are being used.
- Make sure people are evaluated fairly and expediently.
- Develop and implement systems that provide intervention points that are critical to the placement of persons into institutions (e.g. hospital discharge, expiration of Medicare skilled nursing days, discharge from an acute rehabilitation setting).
- The selection of hearing officers and the hearing process should be independent of the state agency.

Funding:

- Persons who are currently inappropriately placed in institutions can be funded through allowing the dollars to follow them from institution budgets into community-based services budgets as legislated by SB 1015.
- Find additional ways to fund one-time expenditures to assist a person moving into his/her own home.
- Create funding for transition services to coordinate the move into community-based services.


Public intermediate Care Facility/MR
Home and Community-Based Waivers
(daily cost comparison)

Supports / Advocacy:

- Develop an effective and person-centered quality assurance process to monitor health and quality of life for persons who have been transitioned from institutions into the community.
- Continued advocacy efforts for individual choice and services in the most integrated setting.
- Support outreach and education of diverse disability groups on state and federal policies to support community-based services.

Appendix M: Quality Assurance Principles

Quality assurance should encourage the delivery and improvement of supports consistent with the preferences and needs of individuals receiving services by assessing, providing feedback, encouraging quality improvement and providing follow up.

QA systems will:

Assure partnerships that actively include individuals who are receiving services and/or their families.

- Are recipients and/or families included in all aspects of planning, developing and implementing programs, policies, and quality assurance?

- Do systems policies and funding support and train the person and/or families in understanding how to contribute to the process and inform policy makers of their ideas?

Honor the Expertise of Individuals and/or Families

- Is the person with a disability and/or families given the same respect as the service provider or health care provider?
- Are people with disabilities and/or their family members valued at the table?
- Are people with disabilities and/or their families involved in determining what information needs to be gathered?
- Do we inform them of why we are gathering information?
- How is this information used and distributed?
- Do people with disabilities and/or families feel the providers have really listened to them and acted upon their input? Is the expertise of people with disabilities and/or their families honored when evaluating the information?
- Are all team members trained on how the expertise of people with disabilities and/or their families should be valued, respected and considered?
- Are all team members trained on how people with disabilities and/or their families are to be informed and included in the evaluation of information?

Respect and Accept Their Values

- Are cultural/ethnic differences and personal values respected and accepted?
- Are safeguards in place to protect against negative assumptions based on culture, life style, economic status and religious beliefs?
- Are people with disabilities and/or families given a chance to articulate their values?
- Are people with disabilities and/or families treated with dignity?
- Is training provided to service providers regarding cultural values, issues, biases and preferences being considered when determinations are being made?

Focus on Entire Family

- When a child is living with family, is the impact on the whole family assessed?
- When a recipient is living in his/her own home, is the impact on his/her natural support system assessed?
- How will an assessment evaluate preferences when the recipient and family may not agree on services or risks?

- Are we providing training to service providers, case management and monitors on family dynamics that includes cultural issues?

Promote Flexible Service and Funding

- Do people with disabilities and/or families have control of who, what, when, where and how supports are provided?
- Are people with disabilities and/or families given an opportunity to state their preferences, needs and how they want services delivered?
- Are services restricted due to lack of funding or lack of flexibility of funding?
- Do policies restrict a recipient's ability to direct how services are delivered, and access to needed funding?
- How are services coordinated when multiple agencies are involved? Is it a seamless system or a nightmare?
- Are community/natural resources accessed to fill gaps in services? How are community supports evaluated?
- Are people with disabilities and/or families given sufficient information to make informed and beneficial choices?
- Are they trusted to make decisions for themselves, including decisions that may include some risks?

Affirm Lifespan Planning

- Is the system flexible enough to respond to current needs and preferences and still plan for the future?
- Is the person with a disability and/or family involved in planning for the future?
- Is the system seamless so that services do not drastically change when a person reaches a certain age or there is a change in needs?
- Is information shared between systems so that vital information and the history of the person is not lost during the transition period?
- Is training provided on lifespan issues from birth to aging?
- Will the services be beneficial across the lifespan?

Practice Open Communication

- Are people with disabilities and/or their families given information in various ways and formats, and given time to assess and understand the information?
- Was information provided in a way that people from all cultural, educational and ethnic backgrounds could understand?
- Are policies clear?
- Are policies available in different formats and languages?
- Are interpreters provided when needed?

- Do service providers communicate and collaborate to assure all vital information is exchanged?
- Are service providers and agency personnel trained in communication skills, including “I-messages” and reflective listening techniques?
- Are persons with disabilities, families and service providers given the opportunity to be jointly trained in policies, resources and funding?

Recognize the Importance of Community

- Based on the person’s preferences, is integration into the community a valued component of the support system?
- Is community integration supported by policies and practices, or do people with disabilities have to live where services are located?
- Are service providers and public agency personnel trained regarding the value of living in the community and the policies that support community integration?

Measure things that make a positive difference in the lives of people with disabilities.

- Are individual outcomes measured?
- Is there a reason to gather the information?
- Are people with disabilities and/or families included in determining what information is needed and how the information is gathered?
- Are monitors trained to be respectful of the recipient and/or family?
- Are monitors sensitive to the needs of the recipient and are visits scheduled at the convenience of the recipient?
- What is the purpose of evaluating a program or system?
- What information is needed to effect system change?
- What do we do with the information gathered?
- How do we share the information?
- Are monitors trained in how to gather information, evaluate it and include the family in determining the results?

Appendix N: Appeals Process Principles

A consumer who is denied services should be afforded an opportunity to appeal the denial. The appeals process should be sufficiently formal to ensure that consumers similarly situated receive equal treatment, but should not be so formal as to intimidate the consumer or the consumer’s lay representative. In order to protect both consumers and the integrity of the service delivery system, the following guiding principles should be employed by agencies when implementing the appeals process.

1. The hearing officer must be impartial in the conduct of the proceeding and disinterested in the outcome.

In order to ensure impartiality, the hearing officer must be independent. Hearing officers who are employees of the agency must have the security of knowing that they will not suffer an adverse personnel action if they rule against the agency. The organization of the agency should be structured in a way that shields the hearing officer from any such adverse action.

The same principle should apply to hearing officers who are independent contractors. The decision to renew or terminate a contract should not be based on whether the hearing officer ruled against the agency but on the hearing officer's skill and proficiency in conducting impartial and non-intimidating proceedings.

2. The formal structure of the hearing should not intimidate the consumer or lay representative.

A formal structure is necessary to ensure that consumers are treated in an equal and uniform manner. However, the structure should not be so rigidly applied that consumers and their lay representative feel overwhelmed by the process. The hearing officer should be flexible in the conduct of the hearing. For example, testimony that does not follow a strict examination/cross-examination methodology should be permitted. The consumer's presentation of the case should not be undercut by procedural technicalities.

The conduct of the hearing should be consistent with the ultimate goal of admitting all relevant evidence into the record. Although the hearing is technically an adversarial proceeding, it should not be viewed as an instance of "dueling lawyers." The hearing officer should not serve merely as a passive referee, but should actively engage the parties to ensure that all relevant evidence is admitted into the record. The hearing officer should question witnesses when necessary. When appropriate, the record should be left open for a reasonable time so that the consumer can submit further information for the hearing officer to consider.

3. The hearing officer should not be reluctant to facilitate a settlement prior to hearing.

If the hearing officer believes that the dispute can be resolved without the expense and burden of a hearing, he/she should encourage the parties to reach a settlement. Experienced hearings officers may be able to identify the core issues early in the proceedings and assist the parties in reaching an agreement.

4. The notice of the hearing should be in plain language.

The notice of the hearing should be in clear, easily understandable language. Formal legal language should be kept to a minimum. Pre-hearing dates and requirements should be clearly indicated.

5. The consumer should receive all relevant documents in a timely manner prior to the hearing. The pre-hearing schedule should ensure that the consumer receives all documents that the agency is going to submit as exhibits prior to the hearing. The consumer should receive the documents long enough in advance to prepare for the hearing. Timely exchange of information not only provides for a more thorough hearing, but also assists in a possible resolution of the dispute prior to the hearing.

6. The agency should administer a questionnaire following the hearing.
The agency should provide the consumer with a questionnaire that gives the consumer an opportunity to comment on the proceeding. The questionnaire can assist the agency is devising an appeals process that is not only fair but is perceived as fair by the consumer.

7. All consumers should receive a brochure on the appeals process.
The agency should provide consumers with a brochure written in simple, easy-to-understand language, which they can use as a guide to the appeals process. The brochure should include contact information for the client assistance program used by the agency.

8. The agency's protocol should be clearly explained to the consumer.
The consumer should understand why services requested have been denied. The agency should provide the consumer with an explanation of the agency's triage protocol and the reason for denying the consumer's request.

9. The consumer should have access to advocacy counseling other than the caseworker.
Consumers should have access to client advocacy programs that operate independently of the case management program. Consumers may be reluctant to question caseworkers and service providers about advocacy issues for fear of repercussions. Even though the prospect for adverse repercussions may be remote, the fear of such adverse action can prevent consumers from voicing concerns that can lead to more productive services.

10. Agencies should promote the employment and retention of well-trained, experienced advocates.
The state should promote and fund self-advocacy groups and organizations with demonstrated expertise in representing persons with disabilities in administrative proceedings.

Well-trained, experienced advocates benefit the entire appeals process. An experienced advocate can contribute to a smoother, more efficient proceeding. The experienced advocate can identify weaknesses in the consumer's case and counsel the consumer accordingly. Likewise, the advocate can identify strengths in the case and communicate those to the agency in an attempt to reach a resolution prior to the hearing. An experienced advocate can present the consumer's case more thoroughly in the hearing.

Agencies should not only train advocates well, but should also adopt employment practices that retain advocates once they become experienced.

11. Hearing officers should receive uniform training and orientation.

In order to ensure that similarly situated consumers are treated alike, all hearing officers used by a particular agency should receive uniform training in disability-related issues. They should also be trained and oriented in conducting appeals in a manner consistent with these guiding principles.

12. The hearing should be accessible.

The physical location of the hearing should be accessible to persons with disabilities. Moreover, the proceeding itself should be accessible. For example, a consumer who is hard-of-hearing should be provided an interpreter.

Summary

The ultimate purpose of the appeals process is not only to ensure that consumers are treated fairly but also that they perceive that they have been treated fairly. Consumers and their lay advocates should not be intimidated by the process. Consumers should be given clear explanations of the process and have access to well-trained experienced advocates.

The structure of the proceedings should be flexible. Hearing officers should actively engage the parties and liberally admit evidence into the record. No consumer's case should be undercut by procedural technicalities. Hearing officers should not hesitate to facilitate a settlement prior to the hearing.

Appendix O: OLMSTEAD MARKETING PLAN

A. Definition

The Olmstead decision, in the words of the Supreme Court, says that services to persons with disabilities must be provided, "in the most integrated setting possible." However, many individuals with disabilities and their families have yet to fully appreciate the implications of the Olmstead decision, and are unaware of the full range of community services that are available as alternatives to institutionalization. The decision challenges federal, state, and local governments to develop more opportunities for individuals with disabilities through accessible systems of cost-effective community-based services.
— PACER Center, Parent Advocacy Coalition for Educational Rights, Minnesota

B. Goal of the Marketing Plan

The goal is for people to understand that all Oklahomans with disabilities, as well as those in the aging population, have the right to live, work and play where they choose.

C. Target Markets

The <u>primary</u> target market is all Oklahomans with disabilities, or who are aging, who are at risk for out-of-home placement, and families who need support to keep their family member at home or in their own community.

<u>Secondary</u> target markets include:

- Providers of Services
- State Agency Directors
- State Elected Officials
- Oklahoma Legislature
- Oklahoma U.S. Congressional Delegation
- Educators
- Social Workers
- Chambers of Commerce
- Employers
- Faith-based Groups
- Medical Professionals
- First Responders
- News Media
- General Public

D. Objectives | Strategies | Accountability / Oversight

This document is a work in progress. Implementation timelines (incremental to June 30, 2007), costs and sources of funding are in development. Full names for acronyms and abbreviations are listed at the end of this plan.

Objective	Strategy	Accountability/Oversight
1. People with disabilities will have telephone access to quality community-based services and supports for all types of disabilities.	Identify and educate providers and public on available referral systems – Oklahoma 2-1-1, OASIS, etc. Develop/publicize <u>statewide</u> 2-1-1 warm-call capacity and access to persons with disabilities. Train 2-1-1 workers and other Information and Referral staff to ensure they have correct/current information on services and supports available to persons with disabilities and their families.	+ OKDHS (DRS, DDSD) + Oklahoma 2-1-1 Advisory committee + OASIS + JOIN + Ultimately, all I and R agencies and services
	Reinforce other campaigns for general awareness that people with disabilities have the right to community-based services and support; model People First Language. Create and revise materials with a consistent message through the Olmstead Training Grant as needs are identified.	+ OKDHS (DRS, DDSD) + ODDC + PI + CLL
	Develop/update fact sheets, brochures, Web pages, etc., for easy dissemination of basic information (non-specialized to improve shelf life) about state service systems. Make available in multiple formats.	+ OKDHS (DRS, DDSD) + All agencies that provide direct services.

	Develop a one or two page "common application" for state agencies that provide direct services and as part of that, intake worker cross-training (watch HIPAA regulations).	Coordinated effort among multiple groups including but not limited to: + OKDHS (DRS, DDSD, DMS) + Oklahoma Department of Health + OHCA + Olmstead Legislative committee
	Review eligibility criteria at each state agency that provides direct services; assure consistency in materials/forms.	+ OKDHS (DRS, DDSD) + Other state agencies + Private service providers + Olmstead Task Force
Objective	Strategy	Accountability/Oversight
2. People with disabilities will be empowered and supported to live where they choose.	Create or reinforce other campaigns for general awareness that people with disabilities have the right to community-based services and support. Support existing training programs and public forums that go out into the community to provide information about Olmstead decision. Expand Progressive Independence's "Opening Doors to the Community" program.	+ OKDHS (DRS, DDSD) + CLL + Centers for Independent Living + Oklahoma Association of Community Action Agencies + PI
Objective	Strategy	Accountability/Oversight
3. People with disabilities will understand and exercise their rights and responsibilities.	Promote advocacy training programs like PIP (Partners in Policymaking), YLF (Youth Leadership Forum), PEA (Partners in Education Advocacy), etc. Use/update brochures already available. Use media, newsletters, and Web sites.	+ OKDHS (DRS, DDSD) + Olmstead Marketing/Public Relations committee + CLL + ODDC + SILC + Centers for Independent Living + Education Advocates + ODLC + Oklahoma People First

Objective	Strategy	Accountability/Oversight
4. Improve attitudes and perceptions in the community.	Work to help elect people with disabilities to public office and make them high profile, positive role models and champions of disabilities issues addressed by the Olmstead decision. Write and produce public service announcements on inclusion, for example the "Count Us In" campaign, for electronic media. Blitz community access radio and TV shows with a message about the abilities of people with disabilities.	+ OKDHS (DRS, DDSD) + Olmstead Task Force + Olmstead Marketing/Public Relations committee + ODDC + CLL + SILC + TARC + Oklahoma Department of Mental Health and Substance Abuse
Objective	Strategy	Accountability/Oversight
5. People with disabilities will have and know about accessible and affordable transportation and housing through more funding to make these supports more socially acceptable and safe.	Create materials as needs are identified such as fact sheets for transportation and housing officials.	Transportation: + OKDHS (DRS, DDSD) "United We Ride," etc. + Mass Transit Authorities Housing: + OKACIL + PI
Objective	Strategy	Accountability/Oversight
6. Demonstrate that community services are more cost effective and people have a better quality of life because of the Olmstead decision.	Distribute media releases with success, quality of life, and cost savings stories related to changes brought about by the Olmstead decision (for example, Texas' "Money Follows the Person").	+ OKDHS (DRS, DDSD) + Olmstead Marketing/Public Relations committee + ODDC

E. Communication Materials to be Developed/Updated

Brochures
Print and Broadcast PSAs
News Releases
Speakers Bureau and PR Scripts for target markets
Training and Education Materials

F. Agencies/Organizations with Access to Primary Target Market and Potential Ability to Help Implement Marketing Plan Goal

OKDHS DDSD – Oklahoma Department of Human Services, Developmental Disabilities Services Division
DRS – Department of Rehabilitative Services,
OSDH – Oklahoma State Department of Health
ODMHSAS – Oklahoma Department of Mental Health and Substance Abuse Services
CLL – Center for Learning and Leadership, UCEDD University of Oklahoma Health Sciences Center, College of Medicine
ODDC – Oklahoma Developmental Disabilities Council
Oklahoma 2-1-1 – phone access to health and human services
OASIS – Oklahoma Areawide Services Information System
JOIN – Joint Oklahoma Information Network
SILC – Statewide Independent Living Council
OKACIL – Oklahoma Association of Centers on Independent Living
Progressive Independence (**PI**), Norman
Ability Resources Inc., Tulsa
Green Country Independent Living Center, Bartlesville
Sandra Beasley Independent Living Center, Enid
Oklahomans for Independent Living, McAlester
OHCA – Oklahoma Health Care Authority-Opportunities for Living Life Division
Oklahoma Community-based Providers
Oklahoma Association of Community Action Agencies
Oklahoma Department of Mental Health and Substance Abuse
Oklahoma Department of Education
Oklahoma Department of Libraries
ODLC – Oklahoma Disability Law Center
ABLE Tech

TARC – Tulsa Alliance for People with Developmental Disabilities
Tulsa Area Alliance on Disabilities
Case Workers/Social Workers/Social Work Students
Legislative Administrative Assistants
Human Services Centers
Youth and Family Services
Mass Transit Authorities
Non-profits

Appendix P: Glossary and Abbreviations Related to Disabilities

ABLE Tech – Mission is to help individuals with disabilities gain access to assistive technology so they can achieve their greatest potential. Thousands of Oklahomans with disabilities depend on assistive technology such as wheelchairs, communication tools, and other resources that help accommodate the challenges of living with a disability.

ADvantage Waiver – The ADvantage program is a Medicaid home and community-based waiver used to finance non-institutional long-term care services for elderly and a targeted group of adults with physical disabilities who meet Medicaid eligibility for care in a nursing facility. ADvantage program recipients must be Medicaid eligible and must not reside in an institution, room and board, licensed residential care facility, or licensed assisted living facility.

Assistive Technology – Assistive technology (AT) services, also called adaptive equipment services, provide for evaluation, purchase, rental, customization, maintenance, and repair of specialized equipment for eligible persons, contingent on availability of resources.

Cash and Counseling Waiver – Participants receive a monthly cash allowance, in lieu of the traditional Medicaid service, for personal care. A personal budget is developed that reflects the participant's personal needs. The participant purchases his or her own personal care eliminating state purchased services and the traditional community-based residential service provider. The participant assumes the role of employer, hiring and paying personal care aides.

Centers for Independent Living – Centers for Independent Living (CILs) provide the four core services of peer support and counseling, advocacy, independent living skills training, and information and referral. Additionally, centers are locally governed to respond to community needs. Centers for Independent Living are governed, staffed and run by individuals with disabilities (at least 51 percent) and are non-profit community-based entities. Centers for Independent Living provide high-impact, individualized services to assist people with disabilities to live in the community and contribute to the local economy.

Early and Periodic Screening Diagnosis and Treatment (EPSDT) – A preventive health program that provides for comprehensive medical services to children younger than age 21 who are eligible for Medicaid. The purpose of the EPSDT program is to identify and treat physical, mental or emotional illnesses or conditions. Children younger than age 21 who receive EPSDT screenings are eligible for all necessary follow-up care as prescribed by a physician, which meets the medical necessity criteria. These follow-up services include physical therapy, speech therapy, occupational therapy, assistive technology, adaptive equipment, etc.

Family Support Assistance Program – Provides a cash payment to families who have children younger than age 18 with severe developmental disabilities. These children must reside in their family homes and the parents' income cannot exceed $45,000 annually.

Home and Community-Based Waiver – Offers certain home and community-based services to categorically needy individuals who, without such services, would be eligible for care in a facility for the mentally retarded. Individuals with mental retardation are eligible for Medicaid as categorically needy through the HCBW/MR program when income and resources are within the standards; the individual meets the SSA test for disability; the individual requires a level of care provided in a public or private intermediate care facility for the mentally retarded; has an IQ score of 75 or below; it is appropriate to provide care outside the ICF/MR; the average cost of providing care outside the ICF/MR does not exceed the cost of providing institutional care.

HUD Section 8 – The Housing and Urban Development (HUD) Section 8 program provides housing assistance payments through rental certificates, vouchers, or payments to participating property owners.

Institution (includes SORC, NORCE, private ICF-MR and nursing homes) – A privately or publicly run facility in which people with disabilities reside and receive personal care.

ICF-MR – Intermediate Care Facility for the Mentally Retarded

In-Home Supports Waivers for Children and Adults – Provide services to those determined to have a disability, with a diagnosis of mental retardation, by the Social Security Administration or the Oklahoma Health Care Authority, Level of Care Evaluation Unit; be three years of age or older; be determined by the Oklahoma Health Care Authority, Level of Care Evaluation Unit, to meet the ICF/MR Institutional Level of Care requirements; reside in the home of a family member or friend, his or her own home, a DHS Children and Family Services Division (CFSD) foster home, or a CFSD group home; and have critical support needs that can be met through a combination of non-paid, non-waiver, and state plan resources available to the individual, and within the annual per capita waiver limit agreed between the state of Oklahoma and the Centers for Medicare and Medicaid Services (CMS).

Institutional Bias – In 1965, Medicare and Medicaid legislation was passed that provided strong financial incentives to provide long term care in nursing homes. Medicare and Medicaid legislation came to guarantee public payment for institutional services. Institutional care in the United States is an entitlement, which means any person who is eligible for nursing home or ICF-MR services cannot be denied that service if there is a bed available. Services delivered in the community do not have such entitlement status. "There is still a strong institutional bias in federal and state policies that provide funding for long-term services." (Center for an Accessible Society, The "Institutional Bias" in Long-term Care Policy, Funded by the National Institute on Disability and Rehabilitation Research)

Job Coach – An individual who holds a department approved job coach certification and provides ongoing support services to eligible persons in supported employment placements. Services directly support the service recipient's work activity including marketing and job development, job and work site assessment, training and worker assessment, job matching procedures, development of co-worker natural and paid supports, and teaching job skills.

Medicaid Buy-In – Medicaid Buy-In, when fully funded by the tobacco tax, is a program that allows people with disabilities to return to work by purchasing health care services from the state Medicaid program. This program will increase the income level in which people with disabilities are eligible for Medicaid. As a person's income increases, the person pays a bigger portion of the monthly Medicaid premium.

NORCE – Northern Oklahoma Resource Center, a state-run ICF-MR in Enid, Okla.

O-EPIC Premium Assistance – The program is Medicaid compensable and state share funding comes from the tobacco tax. The purpose of the program is to provide health care to uninsured and underinsured individuals who are working for small businesses, self-employed or seeking re-employment. For this population the individual has a higher participation or buy-in that is limited to 5 percent of income.

OK 2-1-1 – An easy to remember telephone number that connects people with important community services and volunteer opportunities. While services that are offered through 2-1-1 vary from community to community, 2-1-1 provides callers with information about and referrals to human services for everyday needs and in times of crisis.

Oklahoma Respite Resource Network (ORRN) – A collaboration of 34 partners who have designed and implemented a respite voucher program. Caregivers hire the person they choose to care for their loved one, set the rate of pay for the provider and train the provider.

Program for Assertive Community Treatment (PACT) – PACT is a service-delivery model that provides comprehensive, locally based treatment to people with serious and persistent mental illnesses. Unlike other community-based programs, PACT is not a linkage or brokerage case-management program that connects individuals to mental health, housing, or rehabilitation agencies or services. Rather, it provides highly individualized services directly to consumers. PACT recipients receive the multidisciplinary, round-the-clock staffing of a psychiatric unit, but within the comfort of their own home and community. To have the competencies and skills to meet a client's multiple treatment, rehabilitation, and support needs, PACT team members are trained in the areas of psychiatry, social work, nursing, substance abuse, and vocational rehabilitation.

Poverty Level – The Federal Poverty Level is a set of poverty guidelines developed by the Department of Health and Human Services used in determining financial eligibility for certain federal programs. Some states have chosen to use a percentage multiple of the Federal Poverty Level for their own programs.

Recovery Home – A special designation for residential care facilities (RCF) that contract with the Oklahoma Department of Mental Health and Substance Abuse Services, and meet additional quality standards that emphasize consumer choice, community integration and recovery principles.

SoonerCare – SoonerCare is a managed care program that provides services primarily to low-income children and pregnant women. Additionally, SoonerCare covers people with disabilities who are not dually eligible for Medicare and Medicaid, and who do not meet the level of care criteria for institutional care. SoonerCare covers primary care, inpatient and outpatient hospital services, prescription drugs, behavioral health care, transportation, family planning and limited dental care.

SORC – Southern Oklahoma Resource Center, a state-run ICF-MR in Pauls Valley, Okla.

SSI-Disabled Children's Program (SSI-DCP) – Provides services and equipment to children younger than age 18 who meet the Social Security Administration's definition of disability and are receiving at least $1 of Supplemental Security Income (SSI). The child with a disability must live at home or be away at school, returning home occasionally, and under parental control. SSI-DCP provides therapeutic equipment and appliances, speech and hearing services, developmental aides, child-care services, and diapers (age 3-18). These services are available only after Medicaid has denied authorization or the services are not covered through Medicaid.

Systems of Care – Systems of Care is an individualized “wraparound” approach to providing mental health services. Wraparound is a process that helps a family develop and carry out their own treatment plan, which focuses on the needs of the child, youth and the family. Wraparound gives the family a choice about the services they receive and a voice in the manner in which they receive them.

Ticket to Work – The Ticket to Work and Work Incentives Act (P.L.106-170) permits states to establish their own income and resource standards. The law creates a new eligibility group, termed the Medical Improvement Group. Individuals with disabilities who qualify for the Medicaid Buy-in program through this eligibility category must have a medical condition that has improved to the point that SSA determines he or she is no longer disabled within the SSA definition.

Tulsa Area Alliance on Disabilities – Tulsa Area Alliance on Disabilities’ mission is to ensure full participation of people with disabilities in all aspects of community life. The alliance, with more than 100 members, is an innovative program within the Community Service Council of Greater Tulsa, providing local leadership and an ongoing structure through which concerned people and organizations can plan and act together at the community level to fulfill the alliance's mission

Waiver Services – Waiver services, when utilized with services normally covered by Medicaid, provide for health and developmental needs of individuals who otherwise would not be able to live in a home or community setting. Any waiver service should be appropriate to the client's needs and must be written on the client's individual plan (IP).

Abbreviations Related to Disabilities

ADA – Americans with Disabilities Act

ASD – Aging Services Division

AT – Assistive Technology

ATP – Assistive Technology Professional

BIA-OK – Brain Injury Association of Oklahoma

CD-Pass – Consumer-Directed Personal Assistance Services

CIL – Center for Independent Living

CLL – Center for Learning and Leadership, UCEDD University of Oklahoma Health Sciences Center, College of Medicine

CMS – Centers for Medicare and Medicaid Services

DDSD – Developmental Disabilities Services Division

DME – Durable Medical Equipment

DRS – Department of Rehabilitation Services

DSP – Direct Support Professionals (caregivers)

EPSDT – Early and Periodic Screening, Diagnosis and Treatment

HHS – Health and Human Services

HIFA – Health Insurance Flexibility Act

HTS – Habilitation Training Specialist (caregiver)

HUD – Housing and Urban Development

ICF-MR – Intermediate Care Facility for the Mentally Retarded

IDEA – Individuals with Disabilities Education Act

IEP – Individual Education Program

IPE – Individualized Plan for Employment

JOIN – Joint Oklahoma Information Network

LTCA – Long-Term Care Authority

MDS – Minimum Data Set

MOU – Memorandum of Understanding

NAMI – National Alliance on Mental Illness

NF – Nursing Facility

NORCE – Northern Oklahoma Resource Center at Enid

OASIS – Oklahoma Areawide Services Information System

ODDC – Oklahoma Developmental Disabilities Council

ODLC – Oklahoma Disabilities Law Center

OMHCC – Oklahoma Mental Health Consumer Council

ODMHSAS – Oklahoma Department of Mental Health and Substance Abuse Services

ODOT – Oklahoma Department of Transportation

OHCA – Oklahoma Health Care Authority

OKDHS – Oklahoma Department of Human Services

OKACIL – Oklahoma Association of Councils on Independent Living

OKHRA – Oklahoma Health Care Recovery Act

OTA – Oklahoma Transportation Authority

PI – Progressive Independence

SILC – Statewide Independent Living Council

SORC – Southern Oklahoma Resource Center, Pauls Valley

SSDI – Social Security Disability Insurance

SSI – Supplemental Security Income

TARC – Tulsa Alliance for People with Developmental Disabilities

TEFRA – Tax Equity and Fiscal Responsibility Act of 1982

TWWIIA – The Ticket to Work and Work Incentives Improvement Act

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