

ARKANSAS DEPARTMENT OF HUMAN SERVICES

REPORT

OF

**THE ARKANSAS OLMSTEAD WORKING GROUP
FOR THE DEVELOPMENT OF A
COMPREHENSIVE, EFFECTIVELY WORKING PLAN
TO COMPLY WITH THE UNITED STATES SUPREME
COURT'S HOLDING IN *OLMSTEAD V. L.C.***

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EXECUTIVE SUMMARY

Life, for all of us, is a series of challenges. These challenges may be found in securing an education, employment that fulfills our needs, supporting a family or sometimes just coping with the daily grind. However, for tens of thousands of Arkansans, these challenges are immensely magnified by a physical or mental disability. Not until one has suffered the vicissitudes of aging, viewed life from a wheelchair, or seen the world from the standpoint of having a developmental disability or mental illness, made manageable with expensive medications and specialized services, can one truly appreciate the most challenging aspects of life.

The Americans With Disabilities Act (ADA), in part, provides that no state or local government may, because of an individual's disability, deny benefits to any person who meets the essential eligibility requirements to participate in governmental services, programs, or activities. As interpreted by the Supreme Court in the case of *Olmstead v. L.C.*, the ADA, and the ADA regulations, create a civil right for disabled persons to participate in government sponsored home and community-based services instead of government sponsored residential institutional services if:

- (1) The state's treatment professionals have determined that home or community-based placement is appropriate;
- (2) The transfer from institutional care to a less restrictive setting is not opposed by the affected person; and
- (3) The placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with similar disabilities.

At its heart, the U.S. Supreme Court's *Olmstead* decision is a reflection of the desire of persons with disabilities to experience life on their own terms to the extent their abilities will take them. Central to this desire is the chance to live in the most independent, least restrictive setting possible. Depending on a person's strengths and the extent of his or her disabilities, the

most appropriate setting can vary widely, from complete independence in one's home, to supported living in an apartment, to residence in a full-service institution. For this reason, states should offer a wide array of services, ranging from residential institutional care to minimal supports in the community.

Olmstead as a legal case and a terminology is very recent, but Arkansas' commitment to life in home and community based alternatives goes back a number of years. The record of these efforts contains much success and national recognition. A recent example, included with this report is an independent report from the Robert Wood Johnson Foundation on Arkansas' new *Independent Choices* program. This program, the first of its kind in the nation, allows approximately 2000 personal care clients the opportunity to exchange traditional personal care services for a cash allowance. Arkansas also became the first state in the nation to implement the Medicaid program for the Working Disabled under the federal Ticket to Work Initiative. For years, a major barrier to employment has been the fear of losing Medicaid eligibility due to increased earnings. People with disabilities might well want to work, but because their medical expenses are high and they are often uninsurable in the private market, gaining some income at the expense of losing all medical coverage was not a rational decision. However, the Department of Human Services has just taken a major step to remove this barrier. Earlier this year Arkansas became the first state in the nation to file a Medicaid State plan amendment to utilize the federal Ticket to Work program. Under this program, Medicaid recipients with disabilities will be able to earn up to 250% of the federal poverty level and continue to receive Medicaid coverage. For thousands of Arkansans, this option will realistically open the world of work.

Institutional care remains appropriate for some people with complex needs. Today, however, thousands of Arkansans with disabilities who would previously have had no other choice than receive care in an institution now live in the community with state assistance. In fact, despite the rapidly growing elderly and disabled populations in Arkansas, the number of people in nursing homes is steadily declining. Similarly, Arkansas' state hospital for mental illness is one of the country's smallest.

Despite these gains, Arkansas, like every other state, continues to struggle. Federal funding regulations contain an institutional bias. Those funds, which are the primary resource for serving people with disabilities, have been easily directed to institutional care. By contrast, funding home and community based services, has required exceptional efforts. For example, the income limit for people seeking Medicaid coverage for institutional care is generally three times the federal poverty level, far above the income limits allowed for other Medicaid services unless the state goes through the onerous process of getting a Medicaid "waiver". Consequently, while Arkansas has made steady progress, the state continues to serve many people with disabilities who are unable to live in the most appropriate and most integrated setting.

While Arkansas has made strides to offer persons with disabilities appropriate services, more could be done and barriers should be addressed and eliminated. Additionally, Arkansas has continued to lag behind other states in the quality of its services. By way of example, Kansas, a state with a population and economy that could be considered similar to Arkansas, provides a mix of services that is substantially different than that found in Arkansas. While the challenges each state faces are unique, examining this mix provides a pointed comparison. Kansas spends 47% of their long-term care dollars on home and community based services compared to Arkansas' 26%. Kansas also expends nearly twice the money – \$279,660,335 versus

\$140,186,686 – on home and community based care expenses. Arkansas should take steps to increase funding for home and community based services without neglecting the needs of those persons receiving services in a residential, institutional setting.

To accelerate Arkansas' progress and ensure compliance with *Olmstead*, Governor Mike Huckabee executed a proclamation directing the Department of Human Services to take the lead in developing this report on Arkansas' response to *Olmstead*. This report is intended to reflect Arkansas' goals when developing and implementing a comprehensive, effectively working state plan to provide services in the most integrated setting appropriate for a person with disabilities. To ensure broad input into the report, he further directed that an *Olmstead* Working Group be created to study the issues and recommend future actions. This report is the result of countless hours of effort by that Working Group and hundreds of other interested consumers, advocates and providers. There was, and is, much at stake and, as expected, emotions often ran high and consensus could not always be reached. However, the fact that so many diverse parties came to the table committed to working together to find solutions was, itself, a major achievement. Importantly, as evidenced by the attached mission statement and a Strategic Plan developed by the DDS Board and HDC Superintendents, many of the stakeholders have begun to see their roles much more broadly than before. This was also shown by the Focus 2000 report developed by the Arkansas Mental Health Planning Advisory Council, an entity of the Division of Mental Health Services. This bodes well as we continue to battle old stereotypes and seek innovative solutions.

The challenge of improving our service system is immense, and this report is only a beginning. Readers will find that along with a call for resources and action, central to the report is a call for further planning and further assessment of the needs and desires of people with

disabilities. The framework for conducting this planning and evaluation – including involvement from all stakeholders – is a critical component toward developing a comprehensive, effectively working state plan. While some may wish that this report included that plan, it is worth remembering the adage that “for every complicated problem there is a simple, but wrong, solution.” The Olmstead Working Group believed that a more thoughtful, deliberate approach was preferable to repeating the often-made mistake of acting in haste without understanding the consequences, especially when dealing with people’s lives.

The Health Care Financing Administration (HCFA) has announced a series of grant opportunities to assist states in long term care planning. One initiative, Real Choice System Change Grants, provides \$50 million nationally to promote the design and delivery of home and community-based services that support individuals with a disability or chronic illness to live and participate in their community. The Real Choice grants will be awarded through a competitive application. HCFA will issue Request for Proposals (RFP) in early Spring 2001 with an anticipated application dead line of July 2001. Arkansas will submit an application for the Real Choice grant to assist in formulating, developing and implementing an *Olmstead* plan. The grant must be developed in collaboration with a Consumer Task Force. DHS will recommend to the Governor that the Governor’s Integrated Services Taskforce serve as the Consumer Task Force as Olmstead issues are so closely related to goals of the Real Choice grants. Additionally, Arkansas should consider utilizing resources provided by the federal government, in the form of consultants, and other aid, to formulate a comprehensive, effectively working plan. Arkansas should further consider retaining the services of private consultants, apart from those offered by the federal government, to assist in this task.

Finally, the initial recommendations contained herein, are just that, “initial.” The needs and desires of people with disabilities continue to change, as do the resources and supports available to assist them. This report contains a template for where to go from here, not a set of commandments that should bind the state or the minds of the many people who will continue to address the issues raised here. If this report results in a better understanding of the challenges and opportunities we face, and serves to launch a number of initial improvements, then the Olmstead Working Group will have made a substantial contribution to the lives of people with disabilities. Stakeholders must remember that their work is not finished – it is only beginning. Their input will continue to be necessary, as it was in the Olmstead Working Group, for the development of a comprehensive, effectively working plan.

Implementing the *Olmstead* decision is an exciting opportunity for Arkansas to examine its existing care delivery models. With the cooperation of consumers, advocates, providers and applicable agencies, we can work toward providing appropriate care for all eligible Arkansans.

PRIMARY RECOMMENDATIONS

The Supreme Court, in *Olmstead*, indicated that states could develop a comprehensive, effectively working plan to allow citizens who so choose to make the transition from residential, institution-based care to home and community based treatment programs. The Olmstead Working Group found that although Arkansas has numerous and varied services for people with disabilities who wish to receive treatment in a home or community-based setting, these services are often difficult to access or are not widely available. In essence, there is not sufficient capacity in the health care delivery system to provide home and community based care to all those who could utilize it.

This report identifies numerous steps to build the capacity in Arkansas to provide home and community based services. Primary among these recommendations are the following:

1. State officials and other interested parties should examine existing programs, rules and regulations to identify potential changes which would improve access to home and community based services. This review should also include an analysis of federal laws and regulations and should result in recommendations for modifications at the federal level. Officials and interested parties should recommend legislation and funding priorities, at the state and federal levels, that promote development of community living options and seek to eliminate or modify legislation that conflicts with the intent of *Olmstead*.
2. Arkansas should seek to adequately fund existing Developmental Disability (DD) waiver programs. This will allow existing waiting lists to move at a reasonable pace. Fully funding the existing DD waiver will serve to build capacity for home and community based services as an outgrowth of an existing state program.

Building on an existing, proven, effective program will minimize any additional bureaucracies typically associated with new programs and will allow for more rapid implementation. Funding the DD waiver could also alleviate pressure on, reduce, or eliminate, the existing DD waiver waiting list. The Alternatives waiver and the Elderchoices waiver do not currently have waiting lists associated with these services. These should be monitored to determine if waiting lists develop to access these services and to determine whether the services offered under the waiver could be modified or expanded. Additionally, quality control and quality assurance mechanisms should be examined and maintained to ensure that care delivered – in all settings – is appropriate to a person’s needs.

3. Under *Olmstead*, a person who is subject to Title II of the ADA should receive a periodic assessment by a treatment specialist(s) upon whose opinion the state relies when making decisions regarding services. As part of that assessment, the treatment specialist(s) should recommend, from the array of services available, the treatment option most appropriate for that individual. This treatment plan must also be available with a reasonable modification to the state’s plan and be fair in relation to the needs of all Arkansans with disabilities. The person should then be afforded the opportunity to oppose, or not oppose, this treatment alternative. An assessment program should be developed to gauge a consumer’s choice of receiving these services. Arkansas proposes to measure this decision using an assessment program, to be that should be put into practice in two phases: a pilot program and an implementation phase. A pilot program should serve a two-fold purpose. First, it should test the assessment tool for effectiveness. Second, the

program should gather data to serve as the basis for future program modifications and budget requests. Without first establishing a statistically defensible baseline of the extent of the need for home and community based care, Arkansas could experience problems similar to those already faced by other states that have implemented broad programs to transition persons with a disability from residential, institutional settings before sufficient capacity or quality control and quality assurance mechanisms existed to offer appropriate services. The implementation phase of this program is intended to serve all Arkansans and allow them to make an informed choice about whether they oppose an indicated mode of care and help determine whether needed services can be adopted that would not be a fundamental alteration of the state's plan, taking into account the resources available to the state and the needs of other Arkansans with disabilities and would, instead, be a reasonable accommodation for that person's plan of care.

4. A transition team, or teams, if appropriate, should be organized that will attempt to assist persons making a transition between different modes of care. A transition team will attempt to ensure that persons with a disability receive appropriate care as they move from one mode of care to a different, presumably less restrictive, setting. This team, in conjunction with the person and the treatment specialist(s), should seek to determine whether the consumer is making an appropriate transition to home and community-based services and, if not, seek to integrate that person into a more appropriate setting.
5. An ongoing advisory task force, the Governor's Integrated Services Taskforce (GIST), comprised of persons with disabilities, guardians, advocates, providers

and representatives from applicable state agencies, should be appointed to continue the work of the Olmstead Working Group, assisting the state in the ongoing task of developing and implementing a comprehensive, effectively working plan, as referenced in *Olmstead*. The GIST should make proposals and offer advice on certain matters, including:

- Complete definitions for use in the Assessment program
- Review statistical data from the pilot assessment program
- Study the possibility and the feasibility of developing a single point of entry system for services and information and review methods to shorten or streamline waiting times and review prior authorization and gatekeeper functions
- Study methods to implement quality control and quality assurance procedures for expanded or revised home and community based capacity
- Review proposals made by the Olmstead Working Group for recommendation to appropriate state agencies and serve as an incubator to formulate new proposals
- Review existing state programs and review persons' needs assessments and evaluate community capacity in the context of these needs
- Review waiting lists to determine if needs can be met under other waiver services, subject to eligibility requirements
- Review existing waiver programs to determine methods to shorten or eliminate waiting periods; alternately, if no waiting lists exist, review program to determine if the offered services adequately meet needs
- Review staffing and employment issues as they impact the delivery of services, including methods to obtain, screen and train direct care workers
- Advise state agencies on methods of delivering services in the most integrated setting appropriate

- Work to identify barriers and methods to remove them
 - Work with appropriate state agencies to develop an overall state plan for transportation that can reasonable accommodate people with disabilities, building upon existing transportation systems
6. Arkansas should re-convene a Supported Housing Taskforce, including persons with disabilities. Because appropriate housing is central to community-based care, in contrast to the GIST, this Taskforce will focus solely on promoting the development of additional housing options.
 7. Arkansas should apply for a Real Choice grant to facilitate the development and implementation of a comprehensive, effectively working plan. DHS should coordinate this request with the GIST and complete the application process by the deadline imposed by the granting entity. Further, Arkansas should take steps to maximize funding for all services, including grants and federal funding mechanisms.

A comprehensive, effectively working state plan could take years to implement fully. Indeed, this report can only cover a small portion of the programs currently in place or that could be developed to provide Arkansans with a disability the opportunity to choose between different modes of care. The following is a timelines set forth challenging goals that the state – and stakeholders – should strive to meet in the development and implementation of this plan:

PROPOSED TIMELINE

<u>February 15, 2001:</u>	<i>Olmstead</i> Report submitted to Governor Huckabee.
<u>February-March 2001:</u>	Governor issues directives in response to <i>Olmstead</i> Report.
<u>February-September 2001:</u>	DHS and GIST should review draft plans for the development and implementation of comprehensive, effectively working <i>Olmstead</i> plans from other states to

	<p>identify best practices and determine the approach to adopt to develop Arkansas' Olmstead plan.</p> <p>Identify and federal resources to determine additional best practices.</p> <p>Identify and seek to retain independent consultant.</p>
<u>February-July 2001:</u>	DHS will develop and apply for Real Choice System Change Grant.
<u>April-June 2001:</u>	Begin implementation of Pilot Assessment Program (see below for further detail).
<u>March-June 2001:</u>	Organize GIST and other, related entities, including Supported Housing Taskforce and begin studying workforce issues as they relate to healthcare delivery in Arkansas.
<u>March-June 2001:</u>	Affected agencies should continue review of rule changes that could be implemented on expedited basis.
<u>March-November 2001:</u>	DHS should review waiver programs for potential modification to improve customer care (this should include a review of existing caps and limits on plans of care). Consider feasibility of waiver services for mental health needs.
<u>June-December 2001:</u>	Begin review and implementation of transition element.
<u>July-October 2001:</u>	Work on draft of comprehensive, effectively working plan.
<u>October-November 2001:</u>	Complete draft of plan.
<u>Ongoing:</u>	Review implementation of additional proposals.
<u>2002:</u>	Review assessment data and determine program modifications. Prepare proposed legislative agenda.
<u>2003:</u>	Next meeting of the Arkansas legislature. Propose legislation.

Implementing the *Olmstead* decision is an exciting opportunity for Arkansas to examine existing care delivery models for serving Arkansans. Through a partnership with consumers,

advocates, providers and applicable agencies, Arkansas can work toward providing appropriate care for all eligible Arkansans.

PURPOSE AND METHODOLOGY

Pursuant to a Proclamation issued by Gov. Mike Huckabee, the Arkansas Department of Human Services was directed to perform the following tasks:

1. The Arkansas Department of Human Services (DHS) is to develop a comprehensive review of all services and support systems available to people with disabilities in Arkansas, including availability, application, and efficacy of existing community-based services for people with disabilities. The review shall focus on identifying affected populations, improving the flow of information about support in the community, and improving opportunities for community placement. The review should examine these issues in light of the recent Supreme Court decision in *Olmstead v. L.C.*
2. The working group should not duplicate the effort of other related planning efforts, but will instead build upon their work, with a focus on *Olmstead*-related issues.
3. DHS should ensure the involvement of consumers, advocates, providers and relevant agency representatives in this review.
4. DHS will submit a comprehensive written report of its findings to the Governor no later than [February 15, 2001]. The report should include specific recommendations on how Arkansas can improve its programs for people with disabilities by legislative or administrative action.
5. All affected agencies and other public entities will cooperate fully with DHS's research, analysis, and production of the report. This report should be made available electronically.
6. As opportunities for system improvements are identified, DHS will use its programming and rule-making authority to effect appropriate changes.

(Proclamation, May 16, 2000 and Letter, December 20, 2000)

The *Olmstead* Working Group was composed of persons with a disability that were consumers of state services in both institutional settings and in a home or community based environment; parent or guardians of these persons with a disability; consumer advocates;¹ service

¹ While a complete list of all interested advocacy groups cannot be included, groups represented included the Disability Rights Council, ARC of Arkansas, the Assisted Living Council, NAMI, VOR and others. This list is not intended to be exhaustive and is illustrative only.

providers from the public and private sectors; interested representatives from affected Arkansas agencies; and representatives from the Department of Health and Human Services Office of Civil Rights.² After holding “big tent” meetings across Arkansas to provide information about the *Olmstead* decision, the Olmstead Working Group addressed specific issues regarding different modes of care offered to persons with a disability in Arkansas. Reports were drafted, and are included here as attachments, involving:

1. Assessments – determining methods for reviewing whether a consumer opposes a plan of care recommended by the applicable treatment specialist(s).
2. Transitions – determining how to assure the successful transition, when appropriate, of persons with a disability between alternate modes of care.
3. Employment – determining how to provide persons with a disability the opportunity to pursue gainful employment.
4. Public Awareness – determining how to provide the public with information about available services.
5. Staffing – determining how to attract, train and retain skilled healthcare workers.
6. Housing – determining how to provide, and adequate housing for Arkansans with disabilities.
7. Access and Eligibility – determining a more effective method for initial entry into the service delivery system.
8. Transportation – determining how to facilitate home and community based care choices for persons with a disability by examining transportation alternatives.

The recommendations generated by these sub-committees were reviewed by DHS senior staff and attorneys. These meetings served to identify methods, as suggested by the Olmstead Working Group, to comply with *Olmstead*. The resulting draft report was then provided to the Working Group for comments before being finalized for submission to Governor Huckabee.

² Special note should be made of the important contributions made by Ralph Rouse and Tony Records, representatives from the Department of Health and Human Services, Office of Civil Rights.

LEGAL BACKGROUND

The United States Supreme Court, in *Olmstead v. L.C.*, 527 U.S. 581 (1999) (“*Olmstead*”), reviewed a case wherein two women receiving care in an institutional setting in Georgia sued to be placed in an existing program to receive home or community-based services. Georgia’s treatment specialists recommended that the plaintiffs be placed in the existing program. Moreover, “open slots” were available for them to receive the recommended services. Nevertheless, Georgia refused to place these plaintiffs in that “less restrictive” care setting. These women sued, alleging violations of Title II of the Americans with Disabilities Act (“ADA”), 42 U.S.C. § 12132 and 28 C.F.R. § 35.130. They asserted that Georgia’s failure to place them in a less restrictive home or community-based treatment program, when the treatment specialists recommended placement in that program and space was available, was discrimination on the basis of their disability. The Court held that:

“[s]tates 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 reasonable accommodated, taking into account the resources available to the State and the needs of others with . . . disabilities.”

Olmstead, 527 U.S. at 607. The modifications to treatment plans required under *Olmstead* are not boundless and the state must make only those reasonable modifications that do not entail a fundamental alteration of the state’s services and programs. *Id.* at 603 (citing 28 C.F.R. § 35.130(b)(7) (1998)). The Court further recognized that institutions play a vital role in the array of services a state may offer. *Id.* at 597. Indeed, the Court noted that neither the ADA nor “its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings.” *Id.* at 601-02. The Court recognized the

“fundamental-alteration” defense to a claim for discrimination on the basis of a disability when clients did not receive available care, as recommended by the treatment specialists, when a state develops a “comprehensive, effectively working plan for placing qualified persons with . . . disabilities in less restrictive settings, and a waiting list that moved at a reasonable pace not controlled by the State’s endeavors to keep its institutions fully populated” *Id.* In response to the *Olmstead* decision, the Department of Health and Human Services (HHS), the Health Care Financing Administration (HCFA) and HCFA’s Office of Civil Rights (OCR) offered guidance to implement the decision as each state works to craft a comprehensive, effectively working plan to offer persons with a disability the opportunity to oppose services recommended by the applicable treatment specialist(s) and identify reasonable modifications that might allow that person to live in a more integrated setting.

Arkansas provides residential services in residential, institutional settings. Examples of these settings could be the Hot Springs Rehabilitation Center, the School for the Blind, the School for the Deaf, the Human Development Centers located across Arkansas, and the Benton Services Center. In addition, the Department of Human Services (DHS) funds institutional care at hospitals, nursing facilities, and intermediate care facilities for the mentally retarded. The Health Department, through the Bureau of Alcohol and Drug Abuse Prevention, funds residential substance abuse treatment programs. Some or all of these governmental services may be deemed residential institutional services under state or federal law. As such, *Olmstead* will impact the manner that care is delivered in these environments.

In certain circumstances, the state may be required to offer home and community based services to persons with a disability that fall within the purview of Title II of the ADA and that are currently receiving services in a residential, institutional environment. The *Olmstead*

Working Group, formed at the behest of a gubernatorial proclamation, reviewed numerous proposals that could ultimately affect a person's ability to receive home or community based services. These proposals merit additional review to identify modifications that could be made to existing programs to deliver services in the most integrated, least restrictive manner appropriate to the needs of persons with a disability receiving residential, institutional services and subject to Title II of the ADA. *Olmstead* can be read to require a state to review the manner in which it delivers services and this report focuses on the changes Arkansas intends to implement to comply with the holding in that case or that will allow persons with a disability to experience greater success when receiving home and community based services. Additional modifications should be addressed, as suggested by the Olmstead Working Group, by a continuing, advisory body, selected by the Governor. The proposed Governor's Integrated Services Taskforce should continue the efforts already put forth by the Olmstead Working Group and review data and proposals to ensure that Arkansas is, and remains, compliant with the Supreme Court's holding in *Olmstead v. L.C.*

EXISTING HOME AND COMMUNITY BASED SERVICES

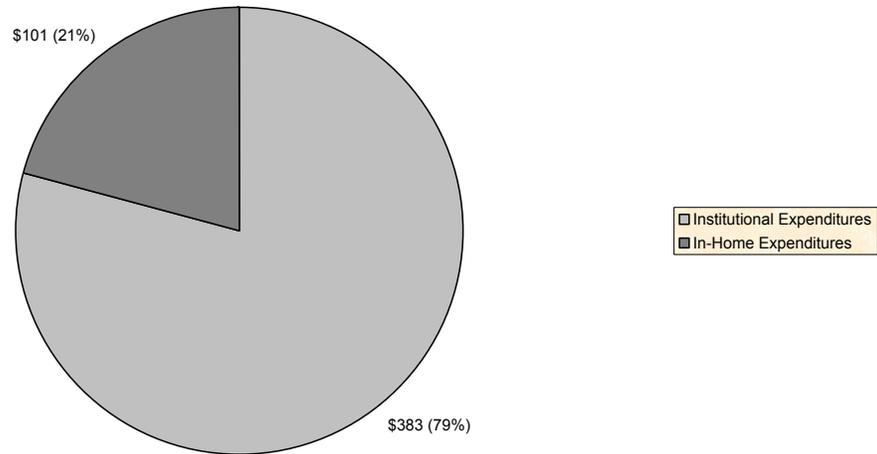
To offset the institutional bias inherent in existing federal Medicaid law, Arkansas has historically requested waivers of those regulations to provide services in home and community based settings. For example, Arkansas' aging population can receive services through the Elderchoices program, adults aged 22 to 64 with a physical disability can receive services through the Alternatives waiver, and persons with developmental disabilities can apply for home and community based services through the DD waiver. Arkansas intends not only to retain these programs, but also to improve them so that Arkansans receive services in an efficient, effective manner and in the least restrictive manner appropriate for their needs.

Arkansas offers many other programs to assist persons with a disability make a choice between residential, institutional care, if appropriate, and care in a home or community based environment when that setting is the most appropriate, least restrictive setting. Each of the following, existing initiatives are designed to expand services or to offer choice to Arkansans with disabilities that will allow them to live in the most integrated environment.

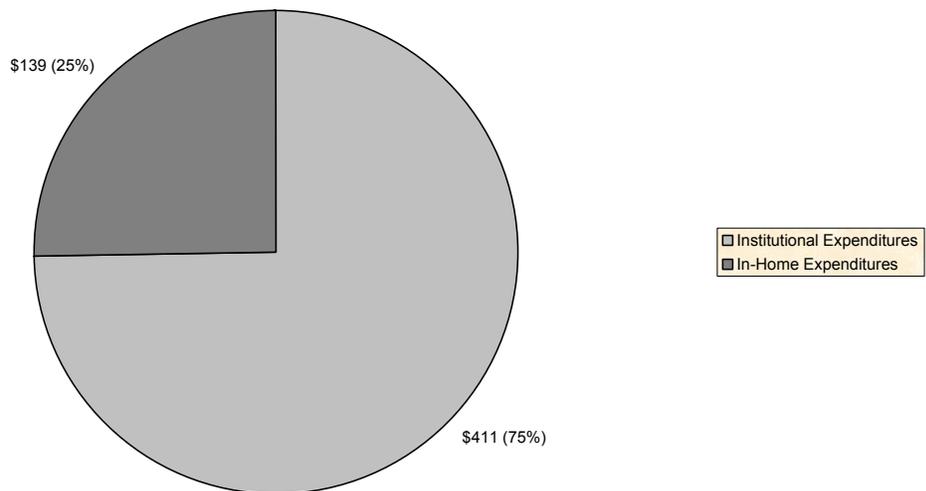
Arkansas currently provides residential, institutional care – or funds this care in facilities not owned by the state – for more than 22,000 Arkansans at a cost of approximately four hundred eleven million dollars (\$411,000,000.00). Conversely, over thirty thousand Arkansans receive services in a home or community based setting at a cost of approximately one hundred thirty-nine million dollars (\$139,000,000.00). The differences in spending between home and community based services and residential, institutional services and the number of persons using these services are represented graphically below³:

³ The assistance of the Division of Medical Services and the Division of Aging and Adult Services was vital in obtaining and verifying this data.

1996 Expenditures (millions)

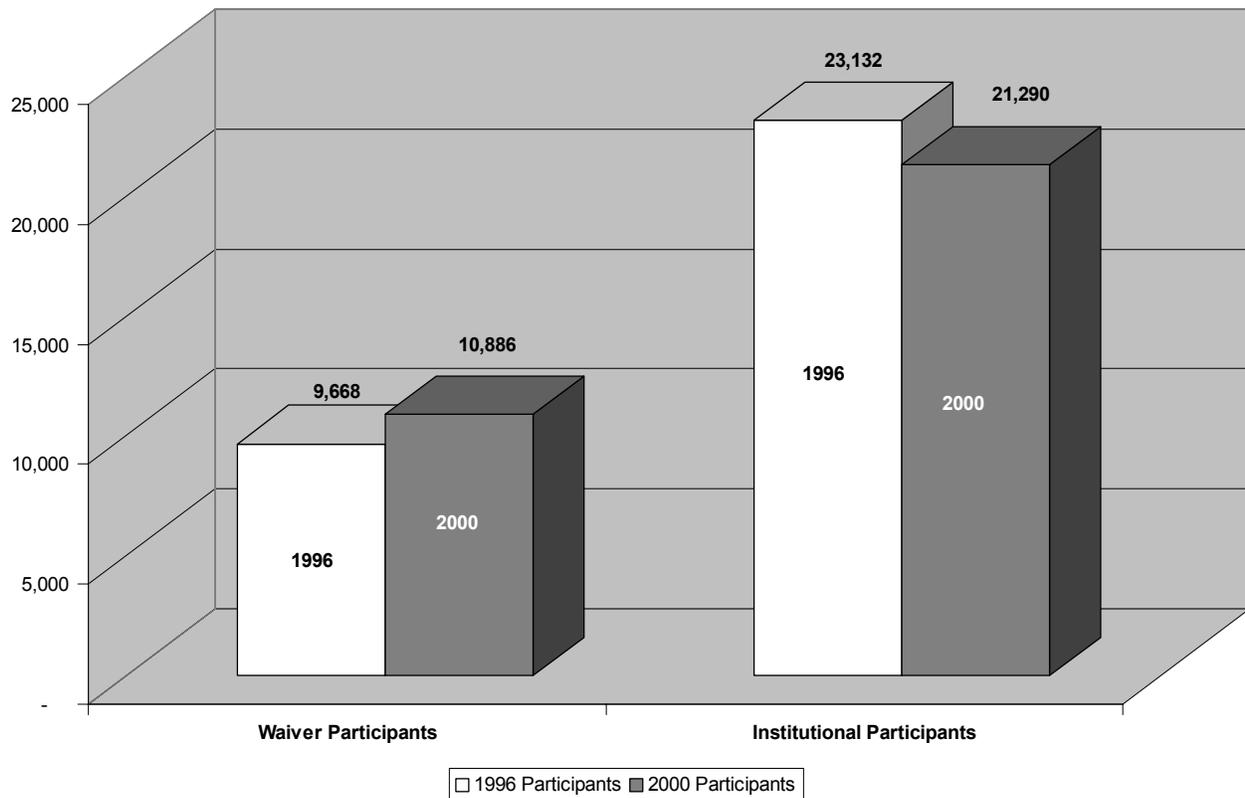


2000 Expenditures (millions)



While the total amount of funding for home and community based services has increased since 1996, as have the total number of participants, the total amount of funding for residential, institutional care has also increased, all at a time when the total usage for these services has been decreasing. Using waiver participants only, this is shown graphically here:

Participants by Year



Each of the following, existing, initiatives are designed to expand services and offer choices to Arkansans with disabilities, and those persons in the aging and adult communities, that will allow them to live in the most integrated environment.

- Personal Care – Medicaid State Plan Service providing in-home support to Arkansans with disabilities. In 1990, personal care services were provided to over 5000 persons. In SFY 2001, over 15,000 persons will be served costing approximately \$56.4 million dollars.
- Older Americans Act, Social Services Block Grant and State Funding including cigarette tax provides an alternative to nursing home services to over 18,300 older Arkansans at an approximate cost of 25 million dollars.
- Alternatives – A home and community based services Medicaid waiver serving over 500 persons with disabilities by offering one of the few consumer directed attendant care and environmental adaptation programs in the nation. The projected expenditure for 2001 is 9 million dollars.

- Independent Choices – A Medicaid Demonstration Waiver offering Medicaid personal care clients the opportunity to exchange traditional personal care services for a cash allowance. Approximately 2000 Arkansans participate in this program and it is one of the first of its kind in the nation. This program was singled out for recognition by the PBS news broadcast “NewsHour” with Jim Lehrer in January 2000.
- Coming Home – DHS is a finalist with the Robert Wood Johnson Foundation to receive a grant to develop affordable assisted living. In conjunction with the grant opportunity, DHS is submitting a Medicaid Home and Community Based Services waiver application to the Health Care Financing Administration to develop a reimbursement method for assisted living services.
- ElderChoices – A Medicaid Home and Community Based Services Waiver providing in-home support services to elderly Arkansans who are at risk of institutionalization. Over 6,500 participants received services for an approximate total of 25 million dollars for SFY 2001.
- Passages – In October 2000, DHS was chosen by the Health Care Finance Administration to receive five hundred thousand dollars to develop, implement and evaluate a program specifically designed to provide support for nursing home residents to return to the community. This grant is expected to assist 80 persons currently residing in nursing homes to return to their homes and communities.
- Alzheimer’s Grant – In July 2000, DHS was awarded a million dollar grant from the Administration on Aging to expand respite and adult day care services for Arkansans diagnosed with Alzheimer’s or related dementia diseases.
- Joint UAMS-DHS Alzheimer’s Project – this joint project between the Department of Human Services and the University of Arkansas for Medical Science will seek to make life better for Arkansans with a disability suffering from Alzheimer’s related dementia diseases.
- Working Disabled Category – DHS has submitted to the Health Care Financing Administration a Medicaid State Plan amendment that, if approved, will allow a new Medicaid category for persons with physical disabilities that allow them to seek employment without losing Medicaid benefits.
- DD Waiver – A Medicaid Home and Community Based Services waiver with an approximate annual cost of \$38 million dollars serving approximately 2,344 persons with developmental disabilities who are at risk of institutionalization. From January 1999 until the spring of 2000, approximately 1,744 persons were addressed on the DD waiver and either began receiving home and community-based services or were found be ineligible.

In addition to offering services to persons with physical disabilities, Arkansas has taken strides to offer services to persons with mental illness. Some of these programs and accomplishments are listed here:

- Arkansas has one of the lowest rates in the country of people in state mental health institutions. Specifically, Arkansas' rate of persons per 100,000 hospitalized annually in a state mental institution is less than 50.
- Arkansas Community Mental Health Centers (CMHCs) and other providers have created hundreds of supported housing units for people with mental illness. In SFY 2000, 1397 seriously mentally ill persons received supported housing through the auspices of CMHCs.
- CMHCs and other mental health providers have collaborated with private residential care facilities (RCFs) around the state to ensure that RCF residents receive appropriate services.
- The Greater Assistance for those In Need (GAIN) program operates a nationally recognized Assertive Community Treatment program in Central and Northwest Arkansas for people who otherwise would frequently cycle in and out of acute hospitalization. Gain served 247 clients in SFY 2000.
- Arkansas makes extensive use of the optional Medicaid program "Rehabilitation Services for People with Mental Illness" to assist people with serious mental illness in staying in the community. During the first 6 months of SFY 2001, 8,263 seriously mentally ill adults had received RSPMI services.
- Birch Tree Communities, Inc. provides a group home (or homes), supported living and/or intensive day treatment to nearly 260 seriously mentally ill people who otherwise would cycle in and out of acute hospitalization.
- Small Group Work Therapy provides supported living, case management and/or intensive day treatment to approximately 150 persons with chronic mental illness in SFY 2000 whose circumstances are similar to those in the Birch and GAIN programs.
- The Research and Training Institute of the Division of Mental Health Services implemented an initiative to provide "cross-training" to the staff of mental health and substance abuse treatment providers to enable them to care more effectively for those with the co-occurring disorders of mental illness and substance abuse. Over the past five years, this Institute has trained approximately 150 mental health and substance abuse treatment professionals in the effective treatment and care of persons with co-occurring substance and mental health problems.

- The Medical Staff of the Division of Mental Health Services works closely with the Office of Long Term Care, Division of Medical Services, to assure that residents of nursing homes with psychiatric symptoms receive proper diagnostic services and medications.

Arkansas also offers specific methods to assist persons with a disability transition from institutional care to home and community based services – or avoid institutionalization – through programs developed and implemented by the Division of Developmental Services. These programs or initiatives include:

Transition From Institutional Care Settings: These activities are team decisions with input from the person with a disability and, if applicable, from the person’s parent or guardian. The decision to make this transition is made as part of a person’s annual review or upon request.

- From Human Development Centers to Group Homes. The Human Development Centers (six large state-operated facilities for persons with a disability with significant levels of need in three of five functional areas that include: self-care; understanding and use of language; learning; mobility; self direction; and capacity for independent living) may transition persons to private non-profit organizations, Developmental Day Treatment Clinic Services (DDTCS), that operate group homes operating in the community. These group homes are available for disabled adults who desire to reside in the community with other DDS eligible persons in a small group setting of 10-15. These clients reside in a group home where they participate in recreation activities, cook, and go out to work or other programs and services.
- Permitting persons with a disability to transfer from a Human Development Center in one area of the state to one closest to the person’s home.
- From Human Development Centers to the ACS Home and Community Based Medicaid Waiver. The waiver allows the person with a disability to remain in a home or community based setting and receive “wraparound services” such as personal care, transportation, and integrated services.
- Transition from a Human Development Center back to the residence of the person with a disability.
- “Follow along” services are provided from a Human Development Center when an individual transitions from the institution to other services. This service provides

technical assistance and helps insure success of the person's transition to a less restrictive setting.

Alternative Programs – Receiving Services in a Community Setting:

- ACS Home and Community Based Medicaid Waiver. Providing services through the DD waiver allows persons with a disability to receive care in a home or community based setting.
- Integrated Supports Programs (CASSP, ACT 911, Integrated). These programs provide “wraparound” services with a dual diagnosis or multiple needs. These programs often provide a method for providing services to persons that may not be purchased through any other source within DHS.
- Together We Can (Interdepartmental program that includes Departments of Education, Health, and Human Services). This program allows a child or adolescent remain home, or return home from an institutional setting, with needed wraparound services in place to support a person with a disability that results in the ability to remain in the community rather than receive services in a residential, institutional setting. This program integrates services offered by numerous state agencies, based on local teams. Counties must request to become part of the program. Currently there are 22 such local teams located across the state.
- Community Group Homes.
- Adult Day Habilitation. Located in DDTCS' around the state, this service option is designed to work with persons with a disability in need of learning skills that result in an increase in independence.
- Early Intervention Services for children with a disability aged 0-36 months. This is a federal program implemented by DHS. Under this program, developmental services such as speech, physical therapy, occupational therapy and parent training are offered in a home or community based setting. It is designed to reduce the possibility of special education and institutional placement later in life.
- Pre-school services. Under this federal program for children ages 3-5, these center based services prepare children with disabilities for participation in school. Upon reaching age five referrals are made to public schools for services through the Department of Education.
- Assisted Living Apartments. These facilities allow persons with a disability to reside independently with minimal support in their community.

- Case Management. This service is necessary to help persons with a disability access service and make referrals. This service helps people remain in a home or community environment.
- Job Skills Training. Through this program, private providers work with persons with a disability to deliver job training. These providers may also contract with businesses to provide them with products that help persons with a disability develop work skills.
- HDC Community Outreach. This initiative encourages HDC staff to provide technical assistance and services to and for persons with a disability within the community. HDC Staff may also provide in-service training, wheel-chair repair, emergency residential placement, respite care, in-home training, crisis intervention, parent training, teacher training and CPR training, among other services.
- The COP program is available on a short-term basis for people whose behaviors must be brought under control for them to remain in the community. A team within the HDC works with the person with a disability and the person's parents or guardians to gain control of behaviors so that the person may return to the community or remain in the community.

Arkansas Rehabilitation Services (ARS) serves Arkansans with mental, physical and sensory disabilities in obtaining and keeping meaningful jobs. Arkansas Rehabilitation Services served nearly 18,000 persons with mental, physical and sensory disabilities in Arkansas in SFY 1999. Through 20 field offices and the Hot Springs Rehabilitation Center, ARS provides an array of comprehensive services designed to place people with disabilities into competitive employment. Services include counseling and evaluation to ensure a client's strengths are identified and maximized; physical restoration and medical services to prepare clients physically; academic and vocational training to obtain high quality jobs commensurate with their aspirations and abilities; and the equipment to ensure clients are adequately prepared to enter the workplace. Other programs or initiatives undertaken by ARS are listed below:

- The Association of Rehabilitation, Industry and Business, an important part of the ARS team, provides job placement support.
- In FY 1999, 2,426 Arkansans with disabilities completed their rehabilitation programs and met Arkansas Rehabilitation Services' rigid standards necessary to be considered

successfully employed. Of significance is the fact that 90.8% of these success stories were persons with complex needs.

- The vast majority (85.9%) of the state's citizens with disabilities who received rehabilitation services last year reported some type of assistance as their primary source of income with very few gainfully employed. Once these customers completed their rehabilitation program, only 7.9% of them remained on assistance. The average weekly income of those successfully rehabilitated was \$310.36.
- 94% of ARS' clients finding jobs were placed into competitive employment. ARS' supported employment programs are effective in this regard, with 75-80% of the recipients successfully completing their program, and 90% finding and maintaining long term, competitive, integrated employment at or above the minimum wage. Supported employment is a contemporary rehabilitation option designed to maximize the employment opportunities for those persons who have traditionally been excluded from participating in integrated competitive employment situations. In this model, ongoing, on-the-job coaching is provided at the work site and is available, intermittently, for the long term.
- ARS has been awarded a federal special demonstration grant of \$1,375,000.00 over five years to provide transportation services to people with disabilities in the Mississippi River delta region in Arkansas. The program, which involves a wide coalition of community organizations, will assist individuals to prepare for, obtain, and maintain employment. It is an innovative model that will effectively address this most challenging barrier to employment and independence for people with disabilities.
- The Hot Springs Rehabilitation Center (HSRC), a unique facility offering a range of comprehensive services to Arkansans with disabilities, offers two core programs: the Arkansas Career Training Institute and the Hot Springs Rehabilitation Hospital.
- In HSRC's vocational preparation programs, a community component is included. Students who have completed a core curriculum are placed at internship sites in the community with employers who agree to put the "finishing touches" on the person's skill training. These internship sites are in competitive employment settings, and often lead to offers of regular, full-time employment. HSRC's job placement efforts emphasize competitive employment. "Sheltered" employment is considered only when the person prefers this type of employment. More than 90% of all placements are in competitive, community settings.
- Another successful HSRC program is a cooperative program between HSRC and the local community college. In this program, students with disabilities live at the Hot Springs Rehabilitation Center and attend classes at the local community college. The Center provides housing, meals, counseling, attendant care, ancillary medical care, psychological services, transportation, and any other support services the person needs to attend college. When the student has completed the community college program,

assistance is available to transfer to a four-year college when appropriate. The program serves approximately 40 students per year.

- HSRC's hospital program provides inpatient rehabilitation services and has a strong record of enabling persons with severe physical disabilities to return to the community. Medicaid cost containment has resulted in a "cap" on the number of days a person may receive in-patient hospital benefits. In the cases of spinal cord injury, traumatic brain injury, and stroke, often the cap is reached before physical medicine/rehabilitation can be completed. In a special arrangement with Medicaid, the Rehabilitation of Severe Physical Disabilities (RSPD) program allows an additional period of in-patient hospitalization at HSRC to avoid the patient being placed in a long-term institutional setting. The program has been very successful, with almost 85% of patients returning to the community who otherwise would have been placed in nursing homes or other institutions.
- The Deaf Outreach Center Program provides mental health counseling (geographically limited), technical assistance/community liaison and training for those who are deaf or hearing impaired.
- The Disability Management Program provides disability management services to state agencies and, for a fee, to private businesses. The service addresses both the prevention of on the job entities and the early return of those who are injured.
- The Telecommunications Access Program provides access to telecommunications equipment to eligible deaf, hard of hearing, deaf-blind and speech impaired residents of Arkansas.
- The Deaf-Blind Program provides a variety of services to people who are deaf-blind to include information/referral, environmental modifications, and intervention/support services. This program also provides training and support for family members, training and supervision for Intervention/Support Service Providers, and consultation to other agencies regarding deaf-blindness.
- The Rehabilitation Initial Diagnosis and Assessment for Clients (RIDAC) provides the following services for ARS and, for a fee, other state agencies: psychological evaluation, vocational evaluation, mental health assessment, and general medical assessments.
- The Increasing Capabilities Access Network (ICAN) provides activities that assist the State in maintaining and strengthening a permanent, comprehensive statewide program of technology-related assistance for people with disabilities of all ages. Services include capacity building, advocacy, information/referral, outreach, public awareness, training, demonstrations, and used equipment exchange and equipment loan programs.

Arkansas currently offers an extensive array of services for persons with a disability seeking to make a transition from residential, institutional care to a home or community based setting. These services could be offered in a more integrated fashion and this report focuses on procedures the state could consider to improve the care delivery system for all eligible Arkansans. These barriers to offering care in the most integrated manner appropriate for the person's needs should be addressed.

RECOMMENDATIONS

Assessments

Transition

Access to Services and Information

Staffing

Employment

Public Awareness

Housing

Transportation

ASSESSMENTS

Arkansans who receive benefits or services on account of a disability should receive an assessment of the nature and extent of their need on, at least, an annual basis. As part of this assessment, the treatment specialist(s) makes recommendations for the care that a person should receive that can be funded by the state within it's Medicaid plan. What may be missing from this annual "functional" assessment are the wishes of that person or their guardian. This section offers a proposal to correct this omission and provide a method to ensure that person with a disability are afforded the opportunity to make an informed choice among service options appropriate to their need for services. While certain persons are currently informed of service options, Arkansas, through the adoption of a program to assess whether a person opposes a treatment professional's determination that they should receive services in a specific mode of care, hopes to provide for a more uniform method for providing persons, or their guardian, with that informed choice. This section addressed this proposal. A valid assessment of a person's informed choice is the only component addressed here and is not intended to – and could not by itself – usurp the role of a person's annual, functional assessment.

A choice assessment program should be implemented in two phases. The first phase should be a pilot program to test the effectiveness of the tool and determine the scope of the need for home and community based services. The second phase is the actual implementation of a choice component to a person's plan of care.

Before any existing program to assist Arkansans make a transition from a residential, institutional setting to home and community based care can be evaluated in a meaningful fashion, baseline data must be collected to determine the scope of the need for those services. The pilot assessment program will assess a random sample of persons with disabilities who

receive – or are waiting to receive – state services. This assessment will be made to determine the services that these consumers want and will help avoid the development of services that do not meet consumers needs. The second basis for conducting a pilot assessment program will be to test the validity of the choice assessment tool and provide for sufficient time to train staff to administer this program.

A number of hurdles must be overcome before such a project can be implemented. Arkansas has already taken steps to address certain of these obstacles. First, definitions of persons with a disability who fall within the bounds of the *Olmstead* decision should be developed – this will be necessary primarily in the context of the implementation of the statewide program and should be addressed by the GIST as soon as possible. This sample population should be constructed to include all persons with a disability receiving government services, or who are at risk of needing government services. Second, the population to be sampled should be defined – this should be overcome by assessing all persons with a disability receiving or applying to receive state services. Third, an assessment tool should be developed or purchased to perform the assessments and people should be trained to use and interpret the information gathered during these assessments – DHS is currently in the process of selecting this tool and setting parameters for this training. Fourth, public awareness programs should be undertaken before the program reaches the implementation phase to provide the public with sufficient information about the program – this hurdle should be overcome during the implementation of the assessment program and will involve advising persons with disabilities of their rights and their ability to challenge the assessment of the treatment specialist(s) and of their ability to seek alternate placement.

The Olmstead Working Group indicated that greater emphasis should be placed on a person's wishes – or the wishes of that person's guardian – than may currently exist. The method for obtaining a record of this expression of choice was the subject of great debate within the Olmstead Working Group. This group also grappled with the identity of the applicable treatment specialist(s) and the timing of assessments. This pilot program will seek to determine the effectiveness of an assessment tool to determine a person's choice and correct difficulties before an assessment of choice becomes a part of a person's functional assessment.

Because the Olmstead Working Group has devoted such extensive effort to develop a pilot assessment program and a proposed implementation phase of this assessment program, the material in this report is intended to offer a brief overview. For further details of this program, review the attached report. The components for the implementation of the assessment program require additional effort on the part of DHS and the GIST. These bodies should begin work to complete this component as soon as possible. However, completion of the final phase of the assessment program should not delay the implementation of the pilot assessment program.

Steps should also be to ensure that persons conducting these assessments use an objective set of criteria when making these assessments.

For the assessment program to be successful substantial work must be done before any assessments are performed. The following is a proposed calendar setting forth expected dates for milestones to be achieved. These dates are predicated upon acquiring an appropriate assessment tool and completion of training. All dates are given in relation to time after acquisition of the assessment tool:

Pilot Phase

(1) Within two months after acquisition: Train pilot project assessment team members as certified trainers. The team members should include treatment professionals and consumer advocates.

(2) Beginning one month after the acquisition and extending until the first of the third month following acquisition: Select persons to be assessed using a statistically valid process.

(3) The third month after acquisition: Obtain and review assessments and evaluations as determined necessary by the team leader, to include at a minimum all existing evaluations and assessments prepared within the sixty (60) months preceding the assessment.

(4) Beginning in the fourth month after acquisition and lasting fifteen months: Conduct initial assessments and evaluate assessment tool and process.

(5) Determine a schedule for follow-up contacts that, in the opinion of the assessment team leader, will be sufficient to determine the accuracy of the original assessment, and if the person's placement changes, the degree to which the services delivered in subsequent placements are appropriate and sufficient to meet the person's needs.

(6) After the pilot assessment program has been concluded, the results should be examined by independent statisticians to determine the estimated number of persons with a disability that could be expected to utilize transition assistance services. Beginning in the twentieth month of the Pilot Program, approximately September 2002, the pilot project assessors and trainers should train additional staff in the use of the assessment tool. At the conclusion of the training, trainees will become assessors. Staff ratios and composition will be set after the results of the pilot assessment program have been analyzed.

Projected pilot costs: It is expected that training for the pilot project should be approximately \$60,000. Funds for this training should be available within the existing DHS budget structure. Additional funds for the pilot phase of this program have been discussed and will be revisited once training has commenced.

Implementation Phase

(7) By January 2003, appropriate schedules and procedures should be in place for the implementation of assessments for appropriate persons. Also by this time, and using the data gathered during the pilot assessment program, and in conjunction with the GIST, appropriate measures should be developed to retain suitably qualified and competent trainers and trainees, maintain the independence of the assessment teams, provide sufficient funding for training and continued implementation; and provide for adequate quality assurance and quality control. Using the data gathered during the assessment phase, affected state agencies, providers and consumers should also have developed budget requests for the legislature to fund existing, or possible additional, programs.

TRANSITION

The “transition” element of a comprehensive, effectively working plan to allow person with a disability to choose between residential, institutional care and home and community based services will center on three elements. These elements include, first, organizing a Governor’s Integrated Services Taskforce. Second, Arkansas should adequately funding existing waiver programs to provide for Arkansans currently on the DD waiting list. This funding should allow the waiting list to be processed at a reasonable pace, without regard to any desire to maintain full institutions. The third element to accomplish this “transition” will be to provide for methods of moving people from institutional care to home and community based services. To do this effectively, it will be necessary to organize a transition team to monitor consumer satisfaction and establish effective quality assurance and quality control procedures.

Background

Community supports, like institutional supports, cost money. Like all other states, Arkansas has limited resources to provide those supports. The challenge, then, is to maximize what can be done within available resources. Most states, including Arkansas, have opted to provide services through a mix of funding streams with a heavy reliance on Medicaid to target spending and specialized services to particular disability populations.

The Arkansas Medicaid State Plan offers an array of medically necessary services for persons with a disability, including augmentative communications, electric mobility items, custom seating systems, orthotics and prosthetics. Arkansas also offers home and community based services through three waivers, the Alternatives Waiver, Elderchoices waiver and the DD waiver. These are but a few examples of programs instituted in Arkansas in the last 15 years that are not available in all other states.

SECTION I. PROCESS AND SAFEGUARDS

Some people currently residing in institutions need only a few supports to reside successfully in the community. Others have complex needs and are at high risk for neglect and abuse if mechanisms are not in place to protect them.

The Governor should appoint an Integrated Services Taskforce (GIST) to guide and advise state agencies on transition activities. The GIST will also review statistical information gathered during the assessment pilot program and provide guidance in Arkansas' continuing efforts to assist Arkansans move successfully between different modes of care. The GIST should then work and advise DHS regarding further efforts to comply with the Supreme Court's holding in *Olmstead*.

Once the decision is made by the applicable treatment specialist(s) that an individual can move into a less restrictive setting, and if the person with a disability does not oppose this transition, a "team" should be formed, composed of the person with a disability, a family member or other legal guardian if available and appropriate, an advocate and a case manager. The team will develop a plan of care that is consistent with the treatment specialist(s)'s recommendations and the choices of the person. The case manager, as part of the planning process, should complete all administrative actions associated with eligibility and funding. After placement, the team should monitor the placement and provide periodic reports. The waiting list should also be monitored to assure even-handed treatment and satisfactory progress. It is understood that DDS currently offers a service like that referred to in this paragraph. This model should be reviewed to determine whether it can be improved and whether it could be applied in other settings.

While quality control and quality assurance mechanisms are currently in place to monitor existing home and community based programs and residential, institutional care, additional problems associated with quality of care could develop if persons with a disability make a transition to an alternate mode of care too quickly. Specifically, quality review programs currently focus on care given in residential, institutional settings but can also monitor care given for existing waiver levels. As more persons with a disability receive care in home or community based settings, existing quality control and quality assurance programs must be reviewed and strengthened to ensure that recipients receive the level of care required.

It must be noted that not all placements to a less restrictive setting will be successful and that the option to return to a more restrictive setting without a delay should be available. Thus, it may be necessary to maintain some unused capacity in residential, institutional facilities during a client's transition period to home and community based care.

SECTION II. WAITING LISTS

Two principle issues are involved in the waiting list issue. First, waiting lists should move at a reasonable pace, not dictated by a desire to maintain a given level of utilization in a given setting. Currently, there exists in Arkansas, a waiting list to receive services in certain residential, institutional placements, a waiting list to leave these settings to receive services through a home and community based waiver and, finally, waiting lists for persons already living in the community who wish to receive services through a home and community based waiver. These issues are often associated with services supplied by the DD waiver and the large increase in requests for services encountered during the previous twelve to twenty-four months. The second issue involving waiting lists is less obvious. While Arkansas delivers services through

waiver services administered by the Division of Aging and Adult Services – the Elderchoices and Alternatives waivers – there are, currently, no waiting lists associated with these services.

Arkansas has identified funding the DD waiver as a primary recommendation. This could help alleviate pressure on this waiting list, which is currently capable of processing as many fifty applications per month, and should also serve to increase capacity for home and community based services. The second issue is more problematic and will require additional review to determine the basis for the lack of waiting lists for these services. Reasons for the lack of a waiting list for these services could include overly restrictive criteria for eligibility to receive these services imposed by the federal government, marketing issues, the number of people the waivers were designed to serve are receiving services or any number of other reasons that have not yet been identified. This issue deserves further attention.

Until the analysis referenced above is completed, for those in institutional placements who are seeking transition, their place on the waiting list should generally be the order in which they have made the choice to move to a home or community based setting. Moving those who have less severe disabilities first was rejected as the Olmstead Working Group felt that this approach was discrimination based on disability. Other groups indicated that it might be possible to perform a form of “triage” and allow those individuals with less complex needs to receive services more quickly. Still other groups indicated that existing waiting lists should be broken into segments – one segment for persons receiving residential, institutional services, one segment for those waiting to receive residential, institutional care and a third segment for those living in the community and who apply for services. The only real consensus that arose from this discussion fell into two areas: first, that waiting lists are an important issue in Arkansas and require substantial, additional attention and; second, that funding was required to administer the

existing DD waiver waiting list to provide services and help build capacity for home and community based services.

SECTION III. COMMUNITY PROGRAMS

Before high-need people seeking transition can be moved from institutional care to home and community based placements, appropriate supports must be in place to provide a probability of success. Arkansas operates three home and community based waivers: Elderchoices for Arkansas' aging population, Alternatives for adults with physical disabilities aged 21-64, and the DD waiver for persons with a developmental disability. All three waivers require the individual to meet institutional level of care criteria, be eligible for Medicaid (under waiver rules), and meet eligibility requirements for the population that the waiver is designed to serve. All three provide a range of support services considered adequate to support the intended population. All three must meet HCFA standards for cost effectiveness.

HCFA Cost Efficiency Measures

HCFA rules require states to measure the cost effectiveness of waivers by either capping each plan of care at the institutional average or by an aggregate comparison of program costs. That is, costs for home and community based services cannot, by any measure, exceed the projected costs of institutional care for the same population.

Aging and Adult Services Waivers

Currently, there are no waiting lists for adults with physical disabilities under the Alternatives Waiver or under the Elderchoices Waiver for seniors; both waivers must cost less than twenty-nine thousand dollars (\$29,000) per year, per person, to meet HCFA requirements for cost effectiveness. Cost efficiency on these waivers is maintained using benefit limits on technology and services. Additionally, clients requiring more than eight hours a day of services

cannot be placed into the community using these waivers as their sole source of supports. Transition is possible with the use of natural supports or with a minor cash supplement to purchase services, as directed by the person with a disability.

Developmental Disabilities Services Waiver

The DD waiver is capped at \$160 a day for direct services, or \$58,000 annually; however, HDCs are reimbursed on a cost basis for all services and range from \$173 to \$225 per day with total expenditure limited by state appropriation. Although the average DD waiver plan of care cost is \$82 a day because of the cap, certain high need clients cannot be served by the waiver without natural supports or other funding to supplement the waiver. This limit has been in place for at least six years with no adjustments for inflation. The limit is not the average Medicaid reimbursement rate for an HDC or the average HDC cost using the HCFA formula – it is lower than both. It is important to remember that the benefit limit on direct care services under the DD waiver is not a cap on the plan of care: it limits only that portion of the plan that is funded through the waiver. Plans of care can be supplemented with Medicaid State Plan Services or other state general revenue to enable certain people receive home or community based services.

Another issue related to the DD waiver is the waiting list to receive services at an HDC. There are also people receiving services in HDC's that are also on a waiting list for discharge to the DD waiver. There are over one thousand persons with disabilities in the community that are on the waiting list for the DD waiver. The *Olmstead* decision held that waiting lists must move at a reasonable pace and that the pace cannot be dictated by a state's desire to ensure that institutional beds were filled.

DDS's experience with waiting lists would indicate the likelihood of three things: (1) a substantial number of the people on the waiting list will be found to be not eligible or will have

changed their minds, (2) new applicants will continue to sign up for waiting list slots, and, (3) the waiver system can only process approximately 50 people per month onto the waiver. Additional funds will be needed to implement more fully the existing DD waiver. Funding the waiver accomplishes at least two goals. First, it provides a mechanism that allows persons to receive services in a less restrictive setting. Second, funding the waiver builds capacity in the home and community based health care delivery system, allowing for more community placement without developing new, untried programs.

Mental Health Programs

Arkansas has an estimated 1,000 people with mental health diagnoses currently living in residential care facilities (RCF's). These facilities are licensed by the State, but are not funded with public dollars, with the exception of Medicaid personal care reimbursements. Clients are generally required to pay over to the RCF all but \$30 of their supplemental security income (SSI) checks. Some RCF's provide personal care to eligible applicants and bill Medicaid for reimbursement. Single Resident Occupancy apartments (SRO's) are available in some regions of the State. This is not a core service of the mental health providers under contract, but can be offered as an option. While it is currently unclear what role these facilities may have in the context of an *Olmstead* plan, clearly, the needs of people with mental health diagnoses are important to Arkansas. To that end, further investigation should be performed by DHS and the GIST to determine how to better, and more effectively, serve the needs of mental health clients and study the feasibility of including RCF's and SRO's in the pilot assessment program to better understand the needs of developing a sufficient community infrastructure.

Inpatient and residential treatment is provided at the Arkansas State Hospital, Benton Services Center and (for children) at private rehabilitation hospitals. Once the patient is

discharged, treatment is provided through regional mental health providers under contract to the state. Core services such as after care, day programming and case management are provided at all community mental health centers, and other services, such as housing support, may be offered.

Funding of ongoing treatment is an issue. While the Division of Mental Health Services (DMHS) does not have a “managed care” program, Medicaid requires prior approval for most services. Fewer services may be authorized than was recommended by regional providers. When this occurs, Medicaid pays for that portion of the treatment that is pre-approved, and if the provider chooses to provide additional services, the remainder is funded through the contracts with regional mental health providers through general revenue or block grant funds.

Obtaining medicine is a problem in some instances as new drugs are often very expensive and sometimes not listed as approved medication by Medicaid. Further, these medicines are extremely effective for some clients and would decrease the need for other services.

DHS should consider including the DMHS as a part of existing waiver programs to provide services, including non-medical transportation, transition services, and assistance with the cost of medications.

Other

The Medicaid State Plan and Children’s Medical Services (CMS) provide the support system for children with complex needs, with the majority of waiver recipients being adults. Upon reaching age 21, however, not all adults with complex needs have access to a waiver. When the CMS case must be closed other Medicaid State plan services become more restrictive. Arkansas waivers provide community supports for citizens who are aged, physically disabled, or developmentally disabled. Waiver services are not available for those with a severe mental

disability having an age of onset after their 22nd birthday. While Medicaid and DHS have provided supports for this population, there can be pressure for institutionalization. DHS should consider waivers for those who are catastrophically injured or disabled after their 22nd birthday and who are not otherwise eligible to receive services.

SECTION IV. INSTITUTIONAL ISSUES

A deceptively simple place to begin any analysis of institutional issues is to examine the definition of an “institution.” Interestingly, these definitions vary under state and federal law. Persons who receive services in a residential, institutional setting, or who, without certain home and community based services, could have no alternative but that receive services in a residential, institutional care setting, and who are subject to Title II of the ADA fall within the purview of *Olmstead*. This could include persons in many care settings in Arkansas who are provided services by the state at those facilities. Arkansas should continue working to identify all care settings where persons reside that fall under Title II of the ADA.

Institutional providers face many challenges in moving into the community an individual for whom a transition is appropriate. Even after an individual has been identified for placement in a community program, the discharge planner may face challenges finding an appropriate placement. Another barrier to community placement is waiting lists. Community providers often have their own waiting lists for services such as a 10 bed ICF/MR or larger facility. Residential, institutional providers offer a wide array of specialized services and operate with a very high percentage of their total costs being fixed. A funding floor should be examined in an effort support clients and keep the operation functioning efficiently. Additionally, more effort should be taken to identify those issues involving the delivery of care in a residential, institutional setting that could preclude persons from making a transition to home and

community based services, if recommended by the treatment specialist(s) and that would not be a fundamental alteration to the state's plan and would be fair to other receiving services.

SECTION V. CONCLUSION

Arkansas can, and does, assist persons with a disability make a transition to home and community based care, when appropriate and available. More could be done to facilitate this process and remove barriers to the delivery of home and community based services. These recommendations have been divided into issues that could be considered under Arkansas' *Olmstead* plan while other should be considered to allow for more effective care delivery. The latter proposals are, and will remain, laudable goals to which Arkansas can strive and they will be reviewed as, and when, appropriate.

RECOMMENDATIONS

1. Arkansas should increase funding for the DD waiver.
2. The Governor should develop an ongoing body, the Governor's Integrated Service Taskforce, whose task it would be to review programs and proposals for the continuing development of a comprehensive, effectively working state plan to assist persons with a disability make a transition to home and community based services. This body would advise DHS on ways to comply with the Supreme Court's holding in *Olmstead* in a way similar to that of the Olmstead Working Group.
3. DHS should consider existing caps within existing waivers to determine whether these amounts will be revised or eliminated. These caps must also comply with relevant federal law.
4. As people are assessed in the assessment pilot program, the existing waiting list order should be honored.

OTHER RECOMMENDATIONS IDENTIFIED BY THE OLMSTEAD WORKING GROUP

The Olmstead Working Group – when addressing the transition issue – identified additional considerations that could be addressed either in Arkansas or with federal entities to serve Arkansans more equitably. Certain of those proposals are listed here.

1. Arkansas should address cost efficiency measures with HCFA and propose an alternative measure that removes institutional bias.

2. DHS should continue reviewing procedures in effect for prior authorization of mental health services to ensure that authorization levels are appropriate.

3. Arkansas should consider a waiver program similar to the DDS program for persons with mental health issues.

4. Arkansas should consider waivers for those who become disabled or are catastrophically injured and are not otherwise eligible for existing community long term care programs. By way of example, persons who experience an acquired brain injury or a stroke after their 22nd birthday may require additional support not currently provided under existing programs.

ACCESS TO SERVICES AND INFORMATION

Arkansas has continually sought to provide health care services to persons with a disability in the setting most appropriate to each person's needs. However, in certain instances, there may be services available for that person about which neither the person's caseworker or other state facilitator, nor the person with a disability, is aware. Often the arm of state government attempting to deliver services, and the person with a disability attempting to maximize service eligibility, face the difficult task of identifying all state service programs for which a disabled person could be eligible. This can result in an inability to deliver all services for which the person with a disability is eligible. This barrier is regrettable, and could be alleviated if additional information were made available to the person with a disability and to the state government representative assisting that person. Access to all services provided by federal, state, public and private entities should be user friendly and readily available to the consumer. Applications, information and referral, and direct services should be available on a timely basis and in formats that facilitate easy communication. All eligible persons should have access to a range of service options to enable them to secure or maintain residence in the most appropriate, least restrictive setting. No individual should have to elect to receive services in a manner that person opposes due to barriers to alternatives, delays, or resource deficiencies.

Access to information regarding services provided by the state should be user friendly and readily available to the consumer. Additionally, applications for services should be handled with reasonable promptness and information regarding state services should be available in accessible formats.

Additionally, many Arkansans could more easily transition from institutional care to home or community based services if a person with a disability was able to receive Medicaid

reimbursement for services provided from non-traditional sources such as family members, friends or other non-licensed personnel. Arkansas should consider adopting proposals providing for reimbursement to these natural supports, when appropriate. Under the Nurse Practice Act, personal care attendants can have certain functions delegated to them that would allow for greater assistance in a home and community based environment.

RECOMMENDATIONS

1. Arkansas should consider the development of a single point of entry information center should be developed. This information should be available through the Internet and through existing state “help” lines.

2. Arkansas should ensure that training for case managers is adequate to make them aware of programs for which a person with a disability could be eligible.

3. Licensing rules for medical professionals could be modified to allow certain, skilled procedures that cannot currently be delegated by licensed personnel to be provided by non-licensed personnel if sufficient quality control and quality assurance is available and training specific to the person’s need is provided.

STAFFING

There is an unprecedented shortage of direct care workers both in Arkansas and in the nation. This includes professionals (nurses) and paraprofessionals, the “hands-on” caregivers (certified nursing assistants, home health aides, homemakers, personal care attendants, and mental health case managers). Under *Olmstead*, it may be necessary for providers to increase staffing levels as part of Arkansas’ comprehensive, effectively working plan to provide a basis to move persons with a disability from institutional care to home and community based care. This is particularly true for providers offering home or community based treatment. Final decisions about necessary staffing levels can be made only after the assessment pilot program has been completed and the existing waiver has been fully funded. Only after implementing these two steps will it be possible to make any reasonable analysis of the needs to be addressed with respect to staffing issues. While staffing is an important factor, it is a long-term problem with no short-term solution.

At the national level, nursing school enrollments have declined by 15%.⁴ More nurses will retire as the nursing workforce ages (the average age increased from 40.3 years in 1980 to 44.3 years in 1996).⁵ Nationwide, long-term care providers report high numbers of vacancies and annual paraprofessional turnover rates of 40-60% in home care agencies and 70-100% in nursing homes. No accurate figures are available for current vacancies, either individually or collectively, in nursing homes, home health agencies, and residential care and mental health facilities.

⁴ American Association of Colleges of Nursing, Washington, D.C.

⁵ *The Registered Nurse Population, March 1996 Findings from the National Sample Survey of Registered Nurses*, U.S. Dept. of Health and Human Services, Health Resources and Services Administration, Bureau of Health Professions, Division of Nursing, Tables 38 and 39.

The U.S. Bureau of Labor projects that between 1996 and 2006, direct care workers will be among the top ten occupations having the largest job growth. The demand for direct care services exceeds the supply of caregivers and is growing as the population ages due to:

- Slow growth in the labor force and the shrinking number of the traditional providers of direct care.
- Heated competition for employees willing to accept relatively unattractive jobs caused by low unemployment rates.
- A long-standing assumption among health care providers that there is an endless supply of low-income paraprofessionals willing to accept existing low wages, benefits, and working conditions.
- A combination of third-party payment policies and industry practices that restrict the ability or willingness of health care providers to improve wages, benefits and working conditions.

RECOMMENDATIONS

To address staffing issues, the following should be considered:

1. Steps should be taken for the appropriate state agencies to review and examine measures to attract and retain staff to care for persons with disabilities. This function should include input from affected state agencies; health care providers and consumers; unions; and researchers with expertise in health care and low-wage employment. This task should be undertaken with the following goals in mind:

- ✓ Encourage cooperation between state agencies on a statewide plan to monitor health care consumption and worker availability;
- ✓ Recommend changes to address long-term direct care workforce needs over time; and
- ✓ Gather baseline employment and staffing information in the health care field.
- ✓ Identify and reward quality programs.
- ✓ Continue and expand study of work force needs in the health care sector in Arkansas.

2. Evaluate existing data and collect further information on the health care market in general and, specifically, with respect to the direct caregiver labor market. Policy makers need a coordinated, inter-agency system of data collection to estimate current, and project future, needs for workers.

3. Review methods to enhance nurse and paraprofessional wage and benefit levels.

4. Examine incentives to recruit caregivers.

5. Develop methods to tap a new pool of direct-care workers. This should include efforts to make long-term care the gateway to employment for new workers and encourage efforts to hire mature, disabled or disadvantaged workers in caregiving jobs.

6. Support and encourage family caregivers. A 1997 National Alliance for Caregiving and AARP survey estimated the national economic value of informal caregiving at \$196 billion, compared to national spending for formal home health care at \$32 billion and nursing home care at \$83 billion. To balance work and family roles, many caregivers reduce their hours or quit altogether to care for family members at home. To encourage family caregivers, these recommendations should be considered:

- Request that HCFA expand provisions for Medicaid payments to family members who provide care.
- Take steps to provide a single entry point for access needed information.
- Provide respite care for the caregiver.
- Access the services to be provided by the National Family Caregivers Support Program.

EMPLOYMENT

Arkansas enjoys unemployment rates lower than the national average. Being at nearly full employment can create a more difficult environment for providing quality services for Arkansans with a disability in that skilled, motivated workers needed to perform difficult, labor intensive services for persons with a disability may be difficult to locate. However, a worker shortage can provide persons with a disability the opportunity to benefit from employment in the private sector that might otherwise have been excluded from consideration. In this way, persons with a disability might have the opportunity to find meaningful work experience. This work experience could make it easier to achieve a person's treatment goals and makes a person's transition from residential, institutional care to home and community based services more successful.

As persons with a disability who can and will choose to do so make a transition from institutional care to home and community based treatment, many of these citizens could, and should, seek employment opportunities. Many persons with a disability in Arkansas could benefit from employment services. However, for many of these Arkansans, becoming employed and being self-sufficient, productive citizens has been difficult and, for some, not possible.

Arkansas offers a wide range of rehabilitation and employment services to our citizens through the Arkansas Rehabilitation Services and Arkansas Employment Security Division. However, these services alone may not meet the total service needs of persons with a disability. Different approaches are being implemented in Arkansas and around the country, such as collaborative programs combining the resources of human service agencies and rehabilitation and employment services agencies to develop services providing persons with a disability employment opportunities. In Arkansas, the Division of Developmental Disabilities and the

Arkansas Rehabilitation Services developed collaborative efforts to provide rehabilitation and training services to persons with a disability. This collaboration offers a range of services to increase the likelihood that a disabled person's entry into the job market is successful. A similar collaborative program between the Arkansas Rehabilitative Services and a nonprofit community organization called Greater Assistance to those In Need (GAIN) has been formed to provide training and employment services to another segment of the disabled population. This combination of services provides greater opportunity for success.

Arkansas has also become the first state in the nation to implement the Ticket to Work program that allows persons with disabilities to work, earn up to 250% of the federal poverty level and continue to receive Medicaid coverage. For thousands of Arkansans, this option will realistically open the world of work and open many opportunities to gain valuable vocational experience and become citizens that are even more productive.

As more individuals with complex needs make a transition into home and community based services because of *Olmstead*, the state vocational rehabilitation program will be required to serve their more intensive needs. This will result in a higher cost per client. When couple with the increased number of persons with disabilities now graduating through Special Education programs, a severe strain on existing resource levels will be created. Increased federal financial support of the state vocational rehabilitation program is essential to their effectively addressing the needs of this fundamentally changed client population.

Persons with a disability seeking employment assistance should use existing services already offered in Arkansas. Moreover, employment opportunities for persons with a disability will continue to be the subject of further review by the Governor's Integrated Services Taskforce.

RECOMMENDATIONS

1. Develop and review flexible service models designed to assist persons with a disability that provide opportunities to develop work skills and provide work experiences and educational or training programs, if necessary.
2. A person's treatment plan or service plan should include a vocation evaluation to determine that person's employability and identify the appropriate setting to gain vocational experience.
3. The Department of Human Services agencies should seek to collaborate further with appropriate state and federal agencies providing resources or support to promote work skills, education, training, rehabilitation, and work experience, and provide a public awareness program, emphasizing the abilities of persons with a disability.
4. Federal financial support of the State Vocational Rehabilitation Program should be increased to effectively support the increasingly intensive needs of the population they serve.
5. Work to increase involvement in the Ticket to Work program.

PUBLIC AWARENESS

The public awareness subcommittee examined existing policies, procedures and practices of the Arkansas Department of Human Services (“DHS”) communications office to inform the public about consumer choice and to make recommendations for revision of any policies, procedures or practices to comply with the *Olmstead* decision. The Olmstead Working Group concluded that the media historically have failed to portray the needs of people with disabilities accurately, noting that the media’s interest in disability issues typically centers on telethons or stories about people with disabilities who accomplish extraordinary physical feats, ignoring important substantive issues, such as attempts to eliminate work disincentives.

The Olmstead Working Group found no existing channels open for news about the *Olmstead* decision. It found that newspapers were not interested in publishing messages about the decision. Olmstead Working Group Members perceived that the media considers the effort to develop a comprehensive, effectively working plan to comply with the Supreme Court’s decision in *Olmstead v. L.C.* a process rather than an event, and until something happens, such as the plan’s implementation, the media will do little or nothing to cover the topic.

Informing Arkansans of the potential impact that the *Olmstead* plan could have on their lives will be challenging. The commitment to inform Arkansans of the effect of this plan must be made if people with disabilities are to have a real choice about where and how to live. The communications office of all affected state agencies should play a significant role in this process.

RECOMMENDATIONS

1. Arkansas’ report for the development of a comprehensive, effectively working state plan should be presented to the public, possible through regional “Big Tent Meetings”. Additionally, the public should be apprised of the development of the plan. Once the plan has been completed – in both draft and final form – public input should be gathered in a similar fashion.

2. Arkansas should consider developing awareness newsletters to specific groups concerning the development and the implementation of Arkansas' Olmstead Plan.

3. The DHS web site should be expanded to include information regarding the Plan and information should be added in an easily identified manner.

4. Examine the development of public awareness programs to make persons with unmet service needs aware of available programs.

HOUSING

Traditional housing choices range from apartments, condominiums, and single-family manufactured and conventionally built homes. Many Arkansans live in the same community all their lives, others follow jobs to other regions of the state, and others seek opportunities outside Arkansas. However, many persons with a disability living in Arkansas may have few appropriate, adequate choices as to the place they call home. Even for those persons who can make a choice, the market for housing adapted to persons with physical, mental and other disabilities is limited. The principal issues surrounding housing involve:

- Options
- Accessibility
- Informed Choices
- Location
- Affordability
- Supportive Services

A 1990 survey conducted by Central Arkansas Screening and Assessment Center reported that 80,000 low-income Arkansans with disabilities and the elderly lived in housing that was inaccessible, substandard, or both; or in nursing homes, or on the streets. This survey, which was based primarily on anecdotal reports and self-reported conditions, has been our “benchmark” for the past ten years. Community-based housing agencies and service providers throughout the state need current, in-depth, accurate data to justify the expenditure of taxpayer funds on the range of social service and housing programs. As such, further information on the current need for housing – for all persons with disabilities – should be obtained.

RECOMMENDATIONS

1. Governor Huckabee should be asked to re-convene the Arkansas Supported Housing Taskforce to work with the Governor’ Commission on Integrated Services to review, study and find solutions to housing issues facing Arkansans with a disability. This Taskforce should include representatives from relevant stakeholder groups.

2. Governor Huckabee should continue his work with the Southern Governors Association and seek to address affordable housing issues.

3. Arkansas should promote partnerships between public housing authorities, state agencies and nonprofit organizations to increase the supply of creative, innovative housing options for Arkansans with disabilities.

4. Arkansas should encourage cooperation between federal and state entities such as HUD and ADFA to encourage development of housing alternatives and encourage funding maximization.

5. Arkansas should methods to increase public awareness of Arkansans with a disability regarding housing alternatives.

6. Arkansas should consider performing a longitudinal study to determine the housing needs of persons with disabilities.

TRANSPORTATION

Transportation is an important requirement for all Arkansans. This is particularly true when a person with a disability moves to a home or community based treatment setting from a residential, institutional case setting. Arkansas currently provides non-emergency medical transportation to eligible Arkansans through a brokerage system; however, this program may not meet all the needs for all qualified persons with a disability. While recognizing that further study must be done, the following components should be considered a part of a comprehensive, effectively working state plan to provide persons moving to home and community based care transportation alternatives and opportunities.

RECOMMENDATIONS

1. The GIST should work with appropriate state agencies to develop an overall state plan for transportation that can reasonably accommodate people with disabilities, building upon existing transportation systems.
2. Arkansas should examine and seek to address the need for transportation other than non-emergency medical care.
3. Transportation programs should address the need for an aide or assistant for fragile people.
4. Reimbursement methodologies should recognize the costs for training and testing of drivers, aides, or both, to meet the needs of specialized groups who may require enhanced communications or physical transfer skills.

BUDGET

Waiver Funding. Arkansas should fully fund the DD waiver program. These funds should be identified during the current legislative session.

Assessment. The assessment pilot program should cost less than one hundred thousand dollars. Funds can be allocated from existing DHS programs to fund this project.

Task Forces. It is expected that task forces recommended by this Report will require some nominal level of funding. This is particularly true for the Governor's Integrated Services Taskforce and the Arkansas Supported Housing Taskforce. While it is not expected that substantial funds will be needed, funds for payment of members travel expenses, postage and related expenses should be considered.

ATTACHMENTS

Documents referenced in this report are attached here. Also attached are the reports generated by the Olmstead Working Group that formed the basis for this report.

INDEPENDENT CHOICES REPORT

DDS STRATEGIC PLAN

DDS MISSION STATEMENT

ASSESSMENTS

TRANSITION

ACCESS & ELIGIBILITY

STAFFING

EMPLOYMENT

PUBLIC AWARENESS

HOUSING

TRANSPORTATION