

Two-Year *Olmstead* Progress Report:

Disability Advocates Assess State Implementation of Mandate to Provide Community-Based Services to People with Disabilities

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The National Association of Protection and Advocacy Systems (NAPAS) is a membership organization for the Protection & Advocacy System. The System is a Federally-mandated nationwide network of disability rights agencies that provide legal representation and advocacy services to people with disabilities. The Advocacy Training and Technical Assistance Center (ATTAC) provides training and technical assistance to P&As and is housed within NAPAS. ATTAC is a federal interagency project of the Administration on Developmental Disabilities (ADD), the Center for Mental Health Services (CMHS), and the Rehabilitation Services Administration (RSA).

October 2001

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I. INTRODUCTION

It has been over two years since the Supreme Court issued its decision in *Olmstead v. L.C.*, a landmark ruling for people with disabilities. In *Olmstead*, the highest court in the land said that unnecessary segregation and institutionalization of people with disabilities constitutes discrimination and violates the Americans with Disabilities Act ("ADA"). The U.S. Department of Health and Human Services ("HHS") issued guidance to the states urging that they develop a plan for full compliance with *Olmstead* that follows certain key principles. Development of *Olmstead* plans is the lynchpin to compliance with the Court's decision -- and is the basis by which states are assessed in this progress report.

So, how are states performing? According to disability rights advocates, the vast majority of states are responding to the *Olmstead* decision by developing written reports that: document current service and support systems for people with disabilities; express an intent to comply with the decision's mandates; and recommend actions the state could take to increase access to services and supports. These reports aside, actual movement of people with disabilities from institutions to more appropriate integrated settings, when compared to the years prior to the *Olmstead* decision, is sluggish at best.

Why is it so important for States to make *Olmstead* implementation a top priority? The Supreme Court said it best in its *Olmstead* ruling:

[I]nstitutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life. . . .

[C]onfinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.

This report compiles data received from disability rights advocates across the country. Major trends among states regarding *Olmstead* compliance are identified, especially as related to state efforts to develop comprehensive, effectively working plans for supporting individuals with disabilities in the most integrated settings appropriate to their needs. Finally, the report highlights some seemingly effective strategies states are using to promote *Olmstead* compliance.

II BACKGROUND ON THIS REPORT

A. July 1999 - August 2001

With so much at stake, disability advocates quickly organized after the *Olmstead* decision came down and, with impressive uniformity, decided on a nationwide strategy for compelling *Olmstead* compliance. People with disabilities hoped that states would voluntarily comply with the Supreme Court ruling, as well as the federal directive. Disability advocates agreed to focus their efforts on demanding voluntary compliance from their Governors and state legislatures. People with disabilities also agreed that since they are the ones most affected by *Olmstead* plans, they would request meaningful input into state planning processes. After 12 months, people with disabilities would assess the level of compliance. If, after a year, states had not made significant efforts to develop an *Olmstead* Plan, disability advocates in those states would re-assess the voluntary compliance strategy and pursue more forceful means to gain compliance.

On July 25, 2000, exactly one year after the ruling in *Olmstead*, the National Association of Protection and Advocacy Systems (NAPAS) compiled a report entitled "*Olmstead* Progress Report: Disability Advocates Report on States' Progress After One Year." Using survey responses received from Protection and Advocacy Agencies (P&As), numerous state chapters of The ARC, and over a dozen state Developmental Disabilities Councils, last year's report found that while most states had taken at least preliminary steps to develop *Olmstead* plans, not one state had developed a plan that followed the principles for plan development recommended by the U.S. Department of Health and Human Services; additional funding for community supports and services had been minimal; states had not sought sufficient consumer input into the planning process; and those states that were starting to plan were focused primarily on individuals with developmental disabilities.

B. September 2001 - Present

In September 2001, NAPAS again distributed surveys to P&As and other disability advocates requesting information about state efforts to comply with the *Olmstead* decision. NAPAS received 54 responses from: 21 P&As, 3 independent living centers, 5 chapters of The Arc, 4 Developmental Disabilities Councils, 3 chapters of the Alliance for the Mentally Ill, 2 chapters of the Mental Health Association, 3 Associations for Persons in Supported Employment, 2 members of state mental health planning councils, 2 members of ADAPT, 1 member of the National Coalition for Self-Determination, and 8 consumer self advocates.

These advocates are from 39 states, the District of Columbia, and Puerto Rico. (States not represented include: Alaska, Hawaii, Idaho, Iowa, Maine, Nevada, New Hampshire, New Mexico, Oklahoma, Utah, and West Virginia.)

NAPAS cannot be certain that these surveys captured the full spectrum of state efforts to comply with *Olmstead*. However, we have done our best to report on those state efforts about which

advocates are aware. We encourage states and advocates to continue to send NAPAS information about *Olmstead* implementation. We will include this information in future *Olmstead* progress reports, likely to follow in coming years.

III BACKGROUND ON *OLMSTEAD* v. *L.C.*

The *Olmstead* decision interpreted Title II of the ADA and its implementing regulation, which oblige states to administer their services, programs, and activities “in the most integrated setting appropriate to the needs of qualified individuals with disabilities” (28 CFR 35.130(d)). In doing so, the Supreme Court answered the fundamental question of whether it is discrimination to deny people with disabilities services in the most integrated setting appropriate. The Court stated directly that “Unjustified isolation . . . is properly regarded as discrimination based on disability.”

Under the Court’s decision, states are required to provide community-based services for persons with disabilities who would otherwise be entitled to institutional services when: (a) the state’s treatment professionals reasonably determine that such placement is appropriate; (b) the affected persons do not oppose such treatment; and (c) the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others who are receiving state-supported disability services.

Significantly, the Court suggested that a state could establish compliance with Title II of the ADA if it demonstrates that it has:

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

On January 14, 2000, the U.S. Department of Health and Human Services (HHS) sent a letter to all state Medicaid directors regarding *Olmstead* and what states needed to do to comply with the decision. The enclosure to this letter offers some recommendations about key principles and practices for states to consider as they develop a comprehensive, effectively working plan for placing qualified persons with disabilities in less restrictive settings.

It strongly recommends that States:

1. Provide an opportunity for interested persons, including individuals with disabilities and their representatives, to be integral participants in plan development and follow-up;

2. Take steps to prevent or correct current and future unjustified institutionalization of individuals with disabilities;
3. Ensure the availability of community-integrated services;
4. Afford individuals with disabilities and their families the opportunity to make informed choices regarding how their needs can best be met in community or institutional settings;
5. Take steps to ensure that quality assurance, quality improvement and sound management support implementation of the plan.

IV UPDATE ON FEDERAL GOVERNMENT EFFORTS TO ASSIST STATE IMPLEMENTATION OF *OLMSTEAD*

The U.S. Department of Health and Human Services, Office of Civil Rights (HHS, OCR) is the branch of the federal government specifically charged with ensuring compliance with the ADA integration mandate. For two years, OCR has reached out to states and disability advocates to explain the HHS guidance on *Olmstead* plans and answer questions related to *Olmstead* compliance.

OCR has encouraged disability advocates and people with disabilities to file ADA complaints on behalf of individuals who are not receiving services in the most appropriate integrated settings. Between 1999 and August 2001, OCR received 423 *Olmstead* related complaints. Of those, OCR has resolved or closed 154, and has 269 still pending. The following excerpt is from a letter sent by the Georgia P&A, in coalition with several advocacy groups, to OCR Region Five, introducing complaints on behalf of 13 individuals and others similarly situated. It expresses the frustration felt by many P&As, advocates, and people with disabilities nationwide:

The Georgia Advocacy Office, along with other advocacy organizations, are greatly concerned with the pace of Georgia's formal compliance with the Supreme Court's decision in *Olmstead*... We are aware of a significant number of individuals with developmental disabilities living in state operated nursing homes and institutions . . . who meet *Olmstead* criteria. Yet for all, life beyond the institution continues to be an unfulfilled promise.

Twenty-eight states responded to the survey questions related to OCR enforcement of *Olmstead* complaints. Advocates in 15 of those 28 states have filed OCR *Olmstead* complaints. Out of those 15 states, advocates from 8 (Arkansas, Colorado, Indiana, Louisiana, Missouri, Montana, New York, and Texas) said they are satisfied with OCR's investigation of these complaints. Advocates from California said they were not satisfied. The remaining 6 states echoed similar concerns when asked if they were satisfied with OCR's responses, including:

- From Wisconsin: "nice and friendly, but they don't push the state. OCR is too liberal with accepting any state effort as movement toward *Olmstead* compliance. Advocates are growing frustrated at being asked to work together [with the state]".
- From Connecticut: "not sure yet, we are frustrated with the slow process. Follow up has focused more on how the state has progressed with plan development as opposed to substantiating allegations of rights violations."
- From Kentucky: "Not really. OCR proposed a voluntary compliance plan for the state without the knowledge or involvement of complainants; OCR declined to investigate complaints involving persons with state guardians unless state gave written authorization."
- From Delaware: "So far they watch state plan efforts and wait. It is time they stirred the pot and we have asked them to do so."
- From Rhode Island: "OCR is pleasant to work with but we have seen no increased effort by the state to work on a plan as a result of the investigation."
- From Georgia: "Somewhat. There has been little action so far because the investigator got sick and left OCR. The Commissioner says he is going to hire a new investigator, but it's discouraging."

OCR's enforcement is critical to state compliance. Complaints filed with OCR are used not only to identify individuals who are unnecessarily institutionalized or at risk, but also to call OCR's attention to *Olmstead* implementation concerns generally. Examples of issues brought to OCR's attention include concerns about a state's failure to address the assessment and consumer representation recommendations included in HHS' first *Olmstead* letter. Advocates have also encouraged OCR to establish clear time frames for *Olmstead* compliance reviews. Such written notice that OCR will review state implementation efforts would provide an added incentive for states to make *Olmstead* implementation a priority.

OCR is not the only division of HHS involved in *Olmstead* compliance efforts. For example, between January of 2000 and January 2001, OCR and the HHS Centers for Medicare and Medicaid Services (formerly the Health Care Financing Administration) jointly released five letters to state Medicaid Directors designed to support states' efforts to implement *Olmstead*. The first letter was discussed in the background section of this report. Letters 2-4 offer guidance on questions of common concern to states. *Olmstead* letter number 5 announced that HHS would make up to 70 million dollars in "real choice" grants available to states to promote community integration.

By June of 2001, 49 States obtained the first of these monies. Called "starter grants," these \$50,000 grants are to be used to: 1) develop plans for improving their long-term support systems

for community living; 2) include people with disabilities in the *Olmstead* planning processes; and 3) prepare for other forthcoming “new freedom” grant opportunities. The receipt of these grant funds was an important catalyst for states to involve people with disabilities and P&As in *Olmstead* planning, because consumer participation was a requirement for receipt of the funding and for future funding from the real choice grants.

In September 2001, HHS announced the recipients of the remainder of the “real choice” grant monies, approximately \$64 million dollars in new grants, to develop programs for people with disabilities or long term illnesses. The grants were awarded to the following states: Alaska, Alabama, Arkansas, Colorado, Connecticut, Delaware, Florida, Georgia, Guam, Hawaii, Idaho, Illinois, Indiana, Iowa, Kentucky, Maryland, Maine, Massachusetts, Michigan, Minnesota, Missouri, Montana, Nebraska, New Hampshire, New Jersey, Nevada, North Carolina, Oklahoma, Oregon, Rhode Island, South Carolina, Tennessee, Virginia, Vermont, Washington, Wisconsin and West Virginia.

The Center for Mental Health Services (CMHS) is another division of HHS seeking to help states comply with the *Olmstead* decision. In December 2000, CMHS announced a new initiative titled National and State-wide Coalitions to Promote Community-Based Care Under *Olmstead*. This initiative provides \$20,000 in annual financial support to mental health agencies in the 50 States and territories to ensure that State-wide *Olmstead* coalitions include representation from individuals with a diagnosis or history of mental illness.

On June 18, 2001, President Bush signed an executive order calling for “swift implementation of the *Olmstead* decision.” The order confirms that the “United States is committed to community-based alternatives for individuals with disabilities and recognizes that such services advance the best interests of Americans.” One of many important promises in the order was a request that:

within 120 days all [federal] agencies must evaluate the policies, programs, statutes, and regulations of their respective agencies to determine whether any should be revised or modified to improve the availability of community-based services for qualified individuals with disabilities. [Since that time, the deadline was extended to December 2, 2001.]

Most importantly, the review is required to “ensure the involvement of consumers, advocacy organizations, providers, and relevant agency representatives.” NAPAS, P&As and several dozen disability advocacy groups used this opportunity to recommend actions the federal government could take to increase access to community services and reduce institutionalization of people with disabilities. Advocates’ recommendations covered many topics, including: housing, employment, transportation, provider access, informed choice, assessment standards, ADA enforcement and health care. Below are just a few of the recommendations supported by P&As and NAPAS:

- From the Michigan P&A - The Centers for Medicaid and Medicare Services should modify its rules and regulations to make mandatory Home and Community Based Services and make institutional services an optional state plan service.
- From the South Carolina P&A - There is a necessity for strict enforcement of Federal requirements to screen and assess individuals for appropriate living situations, both new admissions and people currently in nursing homes. All who can be served in alternative settings should be diverted rather than institutionalized. Training for those administering these requirements needs to be increased and must include the impact of the *Olmstead* decision. The screening criteria needs to be amended to include people with head and spinal cord injuries.
- From NAPAS - Increase support for enforcement of the Americans with Disabilities Act, the Fair Housing Amendments Act (FHAA) of 1988, and Section 504 of the Rehabilitation Act of 1973, and the federal regulations thereunder. This should include support for the U.S. Department of Housing and Urban Development, the U.S. Department of Justice, the HHS Office of Civil Rights (OCR), and the Protection and Advocacy for Individual Rights (PAIR) program.

V ANALYSIS OF STATE PROGRESS IMPLEMENTING *OLMSTEAD*

A. Less than One-Half of Reporting States have Increased the Percentage of Individuals Moving out of Institutions into the Community when Compared to the Years Immediately Prior to the *Olmstead* Ruling

Advocates representing 32 states and Puerto Rico answered the following survey question: “Does it appear that the percentage of unnecessarily institutionalized persons who have moved out of institutions or off of waiting lists has increased in the past two years when compared to the years prior to the *Olmstead* ruling?” Twelve states and Puerto Rico have increased percentages. Three states are likely to increase percentages as a result of recent litigation, legislation, or budget appropriations. Seventeen states have not seen increased percentages.

Many states reported that increases were not across the board, but rather had been experienced in specific institutions or by specific populations. For this reason, many advocates reported percentage increases for one disability population and no increases for other disability populations.

Many advocates provided specific reasons why percentages have increased, for example: 4 states and Puerto Rico cited a recent court order or court settlement requiring increased movement to the community; 2 states cited resolution of OCR complaints; 2 states cited state integration plans developed prior to the *Olmstead* decision; and 1 state cited a statutory change which lowered the rates Medicaid would pay for nursing facility care.

B. Thirty-eight States and the District of Columbia have *Olmstead* Task Forces that are Preparing Written Reports in Response to the *Olmstead* Decision

Advocates representing 39 states, Puerto Rico and the District of Columbia answered the question “Is your state working on a comprehensive, effectively working *Olmstead* plan?” Advocates from all but eleven states answered “yes”. Those states not working on an *Olmstead* plan include: California, Kansas, Michigan, Minnesota, Nebraska, New York, Oregon, Rhode Island, South Dakota, Tennessee, Vermont, and Virginia. A large number of advocates from states developing plans took pains to clarify that the written report that their state is developing could not be considered a “comprehensive, effectively working *Olmstead* Plan”. However, for convenience sake, references to “*Olmstead* plans” in this report are intended to include any state *Olmstead* reports, regardless of whether they should, in fact, be considered a comprehensive, effectively working plan for supporting individuals with disabilities in appropriate community settings.

In August and September, 2001, the National Conference of State Legislatures (NCSL) surveyed state officials from all fifty states and the District of Columbia about state *Olmstead* implementation efforts.. The results of this survey will be published by NCSL in December 2001 and will update an earlier NCSL report published in March 2001 entitled “The States’ Response to the *Olmstead* Decision: A Status Report.” However, preliminary survey results, announced by NCSL to Virginia advocates and state officials in October 2001, show that 40 states and the District of Columbia have task forces that are developing *Olmstead* plans. The 10 states not developing plans include: Michigan, Minnesota, Nebraska, New York, Oregon, Rhode Island, South Dakota, Tennessee, Vermont and Virginia. NCSL’s findings are consistent with what disability advocates reported on the NAPAS survey, with the exception of California and Kansas.

The Kansas P&A, as well as the Kansas Developmental Disabilities Council, report that Kansas is not developing an *Olmstead* plan. The Kansas Department of Social and Rehabilitation Services did form a committee in February of 2001 to develop a report on Kansas efforts since 1990 to include people with disabilities in the community and to develop a process for identifying people with disabilities who want to leave institutions. Also, the state is working on a 5 year plan for provision of community mental health services. However, none of these efforts are coordinated and there is no overarching agency assigned to develop a plan. The P&A and the Developmental Disabilities Council do not believe that these reports constitute meaningful *Olmstead* implementation planning. The Committee is simply releasing a report on progress made to expand services. It will not identify gaps in services or recommendations for future community infrastructure.

The California P&A and the California office of the National Senior Citizens Law Center both report that California is not developing an *Olmstead* plan. The Long Term Care Council, which was identified to NCSL as an *Olmstead* Task Force, has in fact not been given a directive to develop an *Olmstead* plan. The LTC Council’s only written document is a vision and mission

statement supporting the provision of quality long-term care. This document does not mention the *Olmstead* decision and its structure does not directly involve consumers of long-term care services or their advocates.

The following is an excerpt from a letter sent to the Governor by over 20 organizations representing people with disabilities and senior citizens expressing several concerns about California's lack of *Olmstead* enforcement:

The Coalition of Californians for *Olmstead* (COCO) was referred to the statewide Long Term Care Council (LTCC) as the body that would be coordinating California's *Olmstead* efforts and as a forum where COCO's expertise and commitment could be utilized. Unfortunately, after over a year of our efforts [to work with this group], the LTCC has failed to identify itself as the body coordinating *Olmstead* planning and therefore there is confusion and disagreement about its goals and mission. The efforts of the Council's workgroups do not focus on *Olmstead* planning. The LTCC and its workgroups have failed to incorporate or address the majority of issues and concerns raised by COCO and its members, including the lack of meaningful participation by consumers . . . although federal grant money was available for Real Choice System Change Grants to states for *Olmstead* implementation, the LTCC failed to [apply for this grant].

C. Advocates in a Majority of States are not Satisfied with the Level of Consumer Input into Plan Design; An Even Larger Majority of Advocates are Concerned that Consumer Input will not be Sufficient During Plan Implementation

Advocates representing 29 states responded to the question: "Are you satisfied with the level of input and involvement of persons with disabilities in the plan development and implementation process?" Advocates in the following 7 states answered "yes": Alabama, Arkansas, Connecticut, Indiana, Massachusetts, Montana, and Texas. Advocates from 14 states answered "no," including: Arizona, California, Colorado, Delaware, Florida, Georgia, Kentucky, Louisiana, North Dakota, Ohio, Tennessee, Pennsylvania, Washington, and Wisconsin. "No" responses were also received from states who are not working on *Olmstead* plans, including: Nebraska, New York and Rhode Island.

Advocates from Illinois, Maryland, and Missouri responded that they are "somewhat" satisfied. Advocates in all three states explained that, on the positive side, the state asked a broad range of advocates for input and received comments on plan development from a wide scope of stakeholders. On the negative side, the state included elements in the plan without making sufficient efforts to gain consensus among stakeholders and without responding to many of the concerns raised by people with disabilities. This lack of effort appears to fall short of HHS recommendations, which indicates that "states should consider the level of awareness and agreement among stakeholders and decision-makers regarding the elements needed to create an

effective system, and how this foundation can be strengthened.”

Some common state practices are cited by advocates who are satisfied with consumer input, including: obtaining input from a broad range of stakeholders; having a clear, written structure for providing input; and development of draft plans/recommendations by stakeholders themselves. In addition to the common characteristics mentioned above, several advocates recommend that state legislators also be represented on Olmstead task forces. Legislators will be asked to fund or enact many of the recommendations included in state plans and involvement up front could smooth the process.

Advocates from Alabama say they are happy with consumer input. While Alabama has not gotten very far with actual plan development, it has practiced the steps mentioned above. For example: Alabama has a steering committee charged with developing an Olmstead plan, whose representation is broad and structured, including from top to bottom: the Governor, the Commissioner of Health and Human Services, and the Alabama Mental Health Planning Council. Under these entities are four equally important subcommittees covering mental illness, developmental disabilities, providers/administrators, and substance abuse. Each of the four subcommittees includes: 2 consumers, 2 family members, 2 mental health advocates, a representative from the HHS Commissioner’s office, a representative from the community services division, 2 DD facility representatives, 2 community service providers, and representatives from several advocacy groups.

D. Most States Require Plans to be Completed Within a Specific Time Frame

Advocates from 23 states responded to the question “When will the plan be ready?” Of those, 22 states have a specific plan due date. Within those, Alabama, Colorado, and Delaware reported that the due date has come and gone without a completed plan; Arizona, Illinois, Indiana, Maryland, Missouri, North Carolina, Ohio, South Carolina, Texas, Washington and Wyoming have already distributed plans or “draft” plans (still subject to comments); and plans from Connecticut and Arkansas are due by the end of October, 2001. Although surveys were not received from these states, NAPAS is aware of plans released from Iowa and Oklahoma.

E. Most Plans Include a Requirement that States Complete Preliminary Assessments of Individuals who may be Unnecessarily Institutionalized

Advocates from 20 states responded to the question “Are there time lines for completion of preliminary assessments of individuals who may be unnecessarily institutionalized or at risk?” (“At risk” refers to individuals who are not currently institutionalized, but are at risk of institutionalization because the community services they are receiving are not appropriate to their needs, are insufficient, or are about to end.) It is important that an *Olmstead* plan include details on how individuals will be assessed for community service needs. Assessments will likely form the basis for identifying what services the state needs to develop or expand. Identification of what services need to be developed will form the basis of budgets included in

assessments will drive so much of what states must plan for, it is important for a plan to establish time frames for preliminary assessments.

Out of twenty states, eleven included specific time frames for preliminary assessments to be completed. Alabama and Illinois indicated that deadlines included in the state plan have already passed and the assessments have not been completed. Moreover, the eleven states that included time frames reported that time frames are attached to specific institutions or waiting lists. Assessment time frames are not established for individuals who are at risk of unnecessary institutionalization.

F. Plans do not Include Specific Time Frames by which Substantial Percentages of Unnecessarily Institutionalized Persons will Receive Services in Appropriate Community Settings

Advocates from 20 states answered the question "Are there time lines for substantial placements of unnecessarily institutionalized persons into more integrated settings?" Only 4 states answered "yes": Texas, Missouri, New Jersey, and Ohio. In each of these states, time frames are specific to particular institutions or Medicaid waiver waiting lists.

G. States are not Linking State Plan Recommendations to Specific Legislative or Budgetary Proposals

Most *Olmstead* plans include recommendations for changes that can be made at the legislative level or recommend an increase in funding for certain programs. This is consistent with the HHS principle for *Olmstead* implementation, which recommends that:

The State reviews what funding sources are available (both Medicaid and other funding sources) to increase the availability of community-based services. It also considers what efforts are under way to coordinate access to these services. Planners assess the extent to which these funding sources can be organized into a coherent system of long term care which affords people with reasonable, timely access to community-based services.

Advocates were asked the following questions: 1) "Has your state passed, or sought to pass, legislation related to *Olmstead*?" and 2) "Has your state prepared budget requests that specifically mention *Olmstead* implementation?" These questions were asked in recognition that a comprehensive plan for supporting individuals in appropriate community settings will require appropriation of new resources and legislative action. Access to community services can and must be enhanced through administrative action. However, efforts should not stop at the administrative level.

Of the advocates representing 30 states that responded to the first question advocates from 13 states answered "yes." Of those, Alabama, Arkansas, Connecticut, Texas, Louisiana, Illinois,

Kentucky, Massachusetts and Maryland enacted legislation specifically calling for development of an *Olmstead* plan. It is important to clarify that the legislation calls for plan development but does not require that the recommendations made in these plans be implemented or funded. However, passage of legislation does suggest that the legislature is informed about *Olmstead* planning efforts. This awareness could potentially lead to more legislative involvement in state plan development, and such involvement could make it easier to obtain funding or statutory changes to implement plan recommendations. California, Washington, Missouri and North Carolina all tried but were not yet able to pass legislation calling for *Olmstead* planning efforts.

Advocates representing 30 states responded to the second question, "Has your state prepared budget requests that specifically mention *Olmstead* implementation?" Advocates from 17 states responded "yes", and of those states: California indicated that the budget request was not appropriated; Alabama, Florida, Louisiana, Illinois, Oregon, and Washington State appropriated funds primarily to comply with court orders or settlements that called for institutional closure or wait list reduction; Delaware appropriated some funds specifically for plan development; Rhode Island appropriated funds to study elimination of barriers to community integration for children residing in residential treatment centers; and the remaining states obtained funding or have requested funding to implement plan recommendations.

In particular, Texas stands out for the efforts of advocates in that state to tie legislative proposals to specific recommendations contained in its *Olmstead* plan. Examples from the proposed Texas legislation include:

- Development of a housing assistance program to assist persons with disabilities in moving from institutional housing to integrated housing, depending upon availability of funds
- Re-allocation of funds to the community care services portion of DHS' budget whenever Texans relocate from a Medicaid-funded nursing facility bed into a community-based long-term living arrangement
- Development of a "mid-range" waiver to serve persons with mental retardation who do not need out-of-home care, and thus have a lower cost per client than in many of the existing waivers
- Reporting to the Legislature comparing the per-client costs in the various community care waivers and the different types of institutional settings, including a comparison of state-owned and non-state operated facilities
- Implementation of a single functional assessment tool for all disability services, which was an existing role for HHSC

- Provision of waiver funds and waiver slots for transitional services, access to immediate housing and transportation service; or development of family based alternatives for children leaving institutions
- H. State *Olmstead* Compliance Efforts have Focused Primarily on Individuals in Development Disability Centers, Mental Health Facilities, Nursing Facilities and on Medicaid Waiver Waiting Lists**

Advocates from 16 states responded to the question: “Which of the following ‘populations’ does the plan address: individuals in state hospitals, nursing facility residents, children soon to leave the school system, children in the foster care system, children soon to leave the juvenile justice system, adults soon to leave detention centers, persons who reside in the community and are at risk for institutionalization, individuals in developmental disability centers, children in residential treatment centers, individuals in veterans hospitals, individuals in homeless centers, and individuals in substance abuse programs?”

The low number of states responding is a reflection of state plans that are either in such early planning stages that planners have not determined which settings are covered, or are so short on details that the plan does not specify which populations are covered under the plan.

Of the 16 state plans surveyed: 15 cover individuals in state hospitals, 14 cover individuals in nursing facilities, 16 cover individuals in ICF/DD centers, 2 cover individuals in veterans hospitals, and 12 cover individuals at risk of institutionalization. Breaking out the “at risk” population more specifically, 2 cover individuals about to leave detention centers, 3 cover individuals in substance abuse treatment centers, and 2 cover individuals living in homeless shelters.

I. Populations At Risk of Institutionalization are Likely to be Missed -- Particularly, Children and Individuals with Mental Health Needs

The U.S. Department of Health and Human Services confirmed in guidance to states that the mandate of the *Olmstead* decision applies to individuals at risk of institutionalization as well as individuals who are unnecessarily institutionalized. Mechanisms for identifying individuals at risk should be outlined in state *Olmstead* plans.

The most common methods identified in state plans for identifying “at risk” populations are: 1) all individuals who have applied and been found eligible for Medicaid in the past two years, and, even more prevalent, 2) individuals who have been found eligible for Medicaid waiver services and placed on a waiting list. Because of the limits on Medicaid coverage for mental health treatment, individuals with mental illness are less likely than individuals with physical or developmental disabilities, brain injuries, or elderly persons to have received Medicaid services. Therefore, using the identification methods above, people with a diagnosis or history of mental illness are particularly likely to be missed in state efforts to identify the “at risk” populations.

Even plans that cover individuals in state hospitals are likely to miss large percentages of individuals with mental illness at risk of institutionalization. Many people with psychiatric disabilities are only admitted to state hospitals for short periods of time. Often, individuals are discharged from state hospitals without sufficient community supports and follow up services, resulting in high rates of return to institutions. Therefore, a plan that truly hopes to reach individuals at risk of institutionalization would, for example, require identification of individuals who have been institutionalized more than once over a two year period.

Additionally, responses to several questions in the survey regarding *Olmstead* planning for children at risk of institutionalization indicate that children are also likely to be missed in state efforts to identify "at risk" populations. Specifically, out of 18 states surveyed, only Indiana, Maryland, South Carolina and Wisconsin use a needs assessment program specifically designed for children; only Colorado, Indiana and Texas are including children soon to leave the school in planning efforts; only Indiana, Maryland and Wisconsin cover children in foster care in their plans; and not a single advocate responded that their state's plan addresses children soon to leave the juvenile justice system. Furthermore, although not related to children "at risk," out of 18 states reporting, only Alabama, Georgia, Indiana, Maryland, Missouri, South Carolina, Texas, Washington and Wisconsin have a plan that specifically covers children in residential treatment centers.

VI PROMISING RECOMMENDATIONS INCLUDED IN STATE PLANS

This section highlights language from State *Olmstead* plans that suggest effective methods of increasing home and community-based services. The language quoted below is not provided as a model for states; it is offered simply as some of the more thought provoking examples currently proposed in plans.

- A. Improving Access to Qualified Community based Providers** (South Carolina *Olmstead* Report Recommendation): Amend the Nurse Practice Act in order to implement medication administration technician certification, as well as to authorize the delegation of other specific routine procedures to specially trained direct care staff -- time line: 1 year. Create an exception from the definition of nursing for self-directed attendant care services provided in the community. Home health agencies and other professional providers must be carefully monitored for screening, training and quality assurance. Consumers must have safe and effective mechanisms to register complaints. Sanctions should be imposed against agencies that persist in failing to honor service contracts or deliver quality services. Individuals should have prompt and effective remedies if injured or forced to spend out of pocket because of agency failures.
- B. Enhancing Transportation Options for People with Disabilities and Seniors** (Arkansas *Olmstead* Report Recommendation): Develop an overall state plan for transportation that can reasonably accommodate people with disabilities, building upon

existing transportation systems. Address the need for transportation other than non-emergency medical care. Transportation programs should address the need for an aide or assistant for fragile people. 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.

- C. **Ensuring that Individuals Receive Appropriate Services to Facilitate Transition from Institutions into the Community** (Arizona Olmstead Report Recommendation): Determine the financial impact and submit a waiver request to CMS to allow payment for community services from the time an applicant applies for services rather than the day the individual is found eligible; provide Medicaid funding to assist people to transition from institutions into their own homes, including deposit funds for rentals/utilities, and start up funding for household items and furniture. Establish transition planning guidelines.
- D. **Furthering Coordination between Various State Agencies Serving People with Disabilities** (Missouri Olmstead Report Recommendation): Develop inter-agency agreements and a budget item for information systems to complete the following recommendations: data linkages and shared information systems among agencies; plan to determine who is the lead agency/primary services coordinator when multiple agencies are involved with a person; service coordinator training to learn about all services in the person-centered plan, not just those that the service coordinator's agency funds; development of a central phone number that individuals can call and get information about community services; development of a universal application form for all community-based services; development of a comprehensive chart of what community services are available and what the criteria for each program are.
- E. **Expanding Services for Children with Mental Health Needs** (Indiana Olmstead Report): A recent analysis of *Olmstead* plans by the Bazelon Center for Mental Health Law finds that Indiana's planning document is exemplary in recognizing the importance of choice for families of young children with mental health needs. Indiana's plan recognizes that parents have almost no choice in institutional placements, which are geographically determined by region of residence. They also have had limited choice of community services because services were also allocated by geographic area - called catchment areas - and provided by a local community mental health center. Indiana has broken down these geographic boundaries, added providers outside the mental health centers and allowed consumers to choose other providers. The state is also taking specific action to ensure that families are aware of the choice they have available to them and to ensure that they have the information they need to participate in their own treatment and recovery, and the Mental Health Division is entering into an agreement for Consumer Counseling services. This counselor will be responsible for providing information and choice to all consumers of community based services.

VII NEXT STEPS FOR PEOPLE WITH DISABILITIES AND ADVOCATES

A. Continue to Work in Coalition to Urge States to Implement the *Olmstead* Decision

Disability rights advocates have been most successful when they have worked in coalition. Advocates should continue working with their colleagues and should put pressure on those states that are not aggressively implementing *Olmstead*. Examples of potential coalition goals include:

- Seek additional support for the immediate creation of additional community services;
- Inform State legislators how best to prioritize the numerous recommendations included in state plans;
- Oversee state progress implementing the programs and systems change states promised to provide if they obtained “real choice” grants. In order to apply for the “real choice” grant, states had to involve people with disabilities in the application process. Therefore, it is likely that the programs recommended in the real choice grant applications are supported by consumers with disabilities.

Even if a state did not receive “real choice” grant monies, advocates may still support the ideas in the application and may wish to encourage states to implement the ideas with other funding sources. Advocates also need to be on guard for states that restrict *Olmstead* implementation to only those projects funded under the “real choice” grants. The funding is just one of many opportunities states must identify to move beyond simply planning to move individuals into appropriate setting and into actual development of community services.

- Continue to provide input on how state plans can be more comprehensive or effective. Identify weak portions of plans that fail to meet the HHS guidance to states on what an *Olmstead* plan should include. The following is an example of such input from the Washington P&A and Washington Legal Aid program to the state Mental Health Director:

This plan fails to provide any guidance regarding who can be served in a more integrated setting, when individuals will move, the supports that will be provided, and what it will cost. We hope that MHD will take this opportunity to re-draft its report so that it can take advantage of this opportunity to move individuals to the most integrated setting appropriate in compliance with federal law

Below is another example of input from four consumer representatives on the Maryland *Olmstead* task force expressing dissatisfaction with the “final” Maryland plan:

This document does not meet the goal [of a comprehensive plan]. There are no

time lines for bringing the State into compliance with federal law, no proposals for reallocation of resources to reverse the State's history of institutional bias, nor even a commitment to actually spend the resources allocated by the Governor and the legislature for the current fiscal year. There are simply "strategies." This is not enough.

B. Review the State Assessment Process. Encourage a Uniform Assessment Tool that will Specifically Consider *Olmstead* Compliance. This Tool should Supplement, not Replace, other Assessment Mechanisms

HHS recommends that:

The plan ensures that individuals with disabilities benefit from assessments to determine how community living might be possible (without limiting consideration to what is currently available in the community). In this process, individuals are provided the opportunity for informed choice.

The plan evaluates the adequacy with which the State is conducting thorough, objective and periodic reviews of all individuals with disabilities in institutional settings (such as State institutions, ICFs/MR, nursing facilities, psychiatric hospitals, and residential service facilities for children) to determine the extent to which they can and should receive services in a more integrated setting.

The plan establishes similar procedures to avoid unjustifiable institutionalization in the first place.

HHS recognizes that states will need to conduct assessments of all individuals with disabilities to determine what services are necessary to support the individual in an appropriate community setting. Ensuring effective assessment practices must be a key element of *Olmstead* plans.

Disability advocates need to encourage states to follow some basic parameters for assessments consistent with the *Olmstead* decision. NAPAS and the California P&A have identified basic assessment parameters, which can be downloaded at www.protectionandadvocacy.com under "disability rights information/Community integration/*Olmstead v. L.C.* information." At the very least, assessments should follow these basic rules:

- Planning should start with, and seek to implement, the premise that the person can live in the community. The services and supports needed to ensure the individual's safety, well being, and growth should be identified through the assessment process. Determinations of support needs must be made absent any consideration of whether the move to the community would be a fundamental alteration.

- Planning should be "person-centered" and "individualized" meaning the person's hopes, desires, likes, and strengths are considered as well as their needs, concerns and medical or behavioral challenges.
- Guidelines used by states for placement into the community or particular community programs should not be factors in determining whether an individual can be served in the community with appropriate supports. Such guidelines are typically developed without consideration for the affirmative requirement of the ADA as interpreted in *Olmstead*. Instead, they reflect a "priority" system which arbitrarily limits community services to a very limited number out of many individuals who could safely live in the community, or reflect the lack of community supports.

These principles are just a start for what is required in an adequate assessment process. To further delineate what is required, we recommend that advocates push for states to work with people with disabilities, children's advocates, advocates for the elderly, community integration experts, and community based providers. Advocates who believe a state's evaluation process is inadequate should file complaints with OCR.

C. Consider Litigation (But Carefully)

In some states, policy advocacy has little chance of yielding results. In other states, agency officials may be using the *Olmstead* planning process merely to deflect efforts to actually implement the ADA integration mandate. In these states, litigation may be the best means by which to bring about *Olmstead* compliance.

Even in these states, however, advocates should carefully weigh the pros and cons of bringing litigation. As the law is still developing in this area, advocates should file only the strongest cases, which have the best chance of success. For example, early *Olmstead* cases should probably be brought only where the state's professionals have declared that the plaintiffs could be appropriately serviced in a community setting; where the plaintiffs do not object to being placed in the community; where there are no administrative mechanisms, such as an effective plan, that will ensure that plaintiffs will be placed in the community in a reasonable amount of time; and where there are good responses to the state's fundamental alteration defense.

VIII CONCLUSION

None of the reports available, as of September 2001, fully meet the principles for *Olmstead* plan development recommended by the U.S. Department of Health and Human Services. Although this question was not asked directly in the survey, it is apparent from responses to other questions in the survey that none of the plans currently in development fully meet the five principles for plan development recommended by HHS. HHS would not consider most plans to be comprehensive because they do not include time lines or budgets. Furthermore, plans are so short on details related to existing or anticipated community-integrated services that although advocates 38 states said their state has or is developing a plan, only advocates from 11 of those states could obtain enough detail from their state plan to provide a rating of how well their plan addresses housing, transportation, health care access, provider access, employment, discharge planning, informed choice, consumer control of services and supports or quality assurance.

Clearly, advocates in those 38 states and the District of Columbia - where planning has begun or is nearly completed - must not settle for the plans as they are. In addition to urging states to augment plans and make them comprehensive, advocates must make a long-term commitment to ensure that the recommendations in plans are actually implemented. Furthermore, advocates must continue to remind states that development of an *Olmstead* plan should not preclude immediate efforts to move individuals into appropriate community settings.

Advocates should assess whether a voluntary compliance strategy has worked in their state and whether additional steps should be undertaken to ensure that their state complies with *Olmstead*'s mandates. For further information regarding state efforts and what advocates can do, please contact the National Association of Protection and Advocacy Systems at 202-408-9514 or see our website (www.protectionandadvocacy.com).

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