To: P&As and Interested Others
From: Elizabeth Priaulx, NAPAS, Community Integration Specialist
Date: September 6, 2000
Re: *Olmstead* Update

This update summarizes recent *Olmstead* related activity in the courts and by, the U.S. Department of Health and Human Services. Copies of materials, pleadings or decisions mentioned in this update are available upon request from the NAPAS receptionist at eugenia@napas.org.

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THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS
***OLMSTEAD* ALERT**

September 2000

I MEDICAID WAIVER WAIT LIST CASES

A Massachusetts District Court Finds Entitlement To Medicaid Waiver Services Within 90 Days (Regardless of Funding Availability)

In July, a federal district court entered summary judgment in *Boulet v. Cellucci* and ordered Massachusetts to provide appropriate services within 90 days to all eligible individuals on waiting lists to receive Medicaid DD waiver services. Specifically, the judge ruled that "because Massachusetts has chosen to implement a waiver plan, the waiver statute provides eligible individuals in Massachusetts with an entitlement to waiver services and affords them the full protections of the Medicaid Act with regard to those services." The decision allows the state to continue its Medicaid cap, but makes it clear that the cap serves as a limit on eligibility for the waiver not as a limit on services once eligibility is established. Furthermore, the court states that "inadequate funding does not excuse failure to comply with the reasonable promptness requirement."

Boulett was filed on behalf of several named plaintiffs living in their parents' homes while waiting for services under the Medicaid DD waiver. Plaintiffs requested certification of a class composed of all individuals with DD who are not or have not received Medicaid services for which they are eligible. The court approved a somewhat narrower class composed of "all adults with DD who are eligible to receive Medicaid services under the plan's cap and who are currently on a waiting list for such services." No ADA integration mandate claim was raised in the complaint.

The *Boulet* decision is consistent with a November 1999 decision by the Hawaii District Court in *Makin v. Cayetano*, (filed by the Hawaii P&A) and a July 1999 ruling by the West Virginia District Court in *Benjamin H. v. Ohl* (filed by the West Virginia P&A) In these cases, the judges' ordered relief to address Medicaid waiver waiting lists. For a more through examination of the recent case law related to Medicaid waiver waiting lists see the fact sheet prepared for P&As by the National Health Law Program entitled "Addressing Home and Community-Based Waiver Waiting Lists through the Medicaid Program" available on the NAPAS website public page under *Olmstead v. L.C.* resources for advocates.

A copy of the *Boulet* summary judgement order is available on the members only section of the NAPAS website under program resources/Medicaid.

B. Florida Settlement Approves Far Reaching Changes to Waiver System (Requires Medicaid Waiver Services Within 90 Days, Subject to Funding Availability)

In July, a federal district court approved a settlement in *Wolf Prado-Steiman v. Bush*, requiring Florida to make procedural changes in the operation of its Home and Community-Based (HCB) waiver program in order to come into compliance with the "reasonable promptness" provision of the Medicaid Act. Specifically, the state will revise its policies concerning the receipt and disposition of applications for HCB waiver services, to begin requiring: a) access for eligible individuals to all needed services within 90 days of receipt of the completed waiver application – subject to waiver slot availability and funding; b) complete access to all services delineated in an individual support plan; and c) clear guidelines for assuring the health and welfare of waiver program participants.

The Florida P&A filed this class action in May 1998 on behalf of two named plaintiffs and an estimated class of 20,000 persons with developmental disabilities believed to be eligible for HCB waiver services statewide. The complaint alleged that the state: (a) was failing to furnish HCB waiver services with reasonable promptness to eligible individuals; (b) failing to provide services included in approved plans of care; (c) had terminated HCB waiver services to individuals improperly; and, (d) had not taken adequate steps to ensure that HCB waiver participants received services that were sufficient to assure their health and welfare. The plaintiffs' complaint contended that the state's HCB waiver policies violated the ADA integration mandate, Section 504 of the

Rehabilitation Act, the Due Process clause of the Constitution, and the Medicaid Act.

The settlement covers 18 distinct elements related to the operation of Florida's HCB waiver program for people with DD. It includes, among other things: 1) development and implementation of a direct care staff training program designed to ensure that such staff possess "core competencies"; 2) training for waiver support coordinators and a commitment to seek additional funding to reduce support coordinator workloads; 3) development of a new "client-based" quality assurance system; and 4) the launch of citizen monitoring of community services.

A more detailed summary of this settlement is available on the members only page of the NAPAS website under program resources/Medicaid.

C. P&A Seeks Order Finding Ohio Waiver Waiting List In Violation of Integration Mandate

In July, the Ohio P&A filed a Motion for Partial Summary Judgment on a portion of the claims in *Martin v Taft*. Specifically, the P&A seeks a court order that the state is violating the ADA integration mandate because its Medicaid waiver waiting list for individuals with DD does not move at a reasonable pace, and the state does not have a plan to address the problem.

This class action was originally filed in 1989 raising Medicaid Act violations resulting from the states' Medicaid DD waiver waiting list. It was amended after the passage of the ADA to include integration mandate claims. Since the case was filed, Ohio remains heavily invested in providing congregate care. In 1989, the waiting list for community services was 6,000 people; today, the list is over 12,000 people. In 1999, admissions to institutions outnumbered discharges and the only reduction in population was due to deaths. Plaintiffs argue that, since Ohio has no comprehensive plan for reducing its reliance on congregate care, this trend is likely to continue without the court's intervention.

D) P&A Class Action Claims Tennessee Violates Medicaid Act By Limiting Access to ICF/MR and Waiver Services

In July, the Tennessee P&A filed a class action lawsuit in federal district court alleging state violations of the Medicaid Act, and seeking appropriate services for individuals with DD on waiting lists to receive Medicaid HCB services. Specifically, the suit charges that the state violates Medicaid due process requirements, and restricts access to ICF/MR and HCB waiver services, by failing provide individuals with notice of the opportunity to appeal a denial of services. In addition, the suit claims that the state violates the Medicaid "reasonable promptness" and "amount, duration and scope" provisions by capping new admissions to ICF/MRs, while at the same time failing to adequately fund Medicaid HCB waiver services.

Currently, the state estimates that 727 individuals are on Medicaid waiting lists receiving no federal or state services and dozens more are added to this list each month. An additional 116 individuals were receiving state services but no ICF/MR or waiver services. Despite the large number of eligible people waiting for Medicaid services, the state projects that in the FY 2000-2001 there will be new funding for only 164 of these individuals.

The suit seeks to enjoin the state from further violations of the Medicaid Act and a court order requiring the state to fund additional services for individuals with DD who live at home.

II HISTORIC WYATT SETTLEMENT RECEIVES FINAL COURT APPROVAL

Last month the court approved a three-year settlement period that will end the historic *Wyatt v. Sawyer* (originally filed as *Wyatt v. Stickney*) case on September 30, 2003. The settlement requires Alabama Department of Mental Health and Mental Retardation (DMH/MR) to: develop additional community-based services for people leaving state institutions; expand protection of rights for people in state hospitals; enhance agency oversight to ensure that clients in DMH/MR facilities and contracted community programs are safe and secure; and develop a community education plan to educate the public about mental illness and mental retardation, including the needs and rights of those served by DMH/MR.

The Alabama P&A will oversee compliance with the terms of the settlement. This includes working with DMH/MR on specific provisions outlined in the settlement about patient rights and safety and security in facility and community-based programs. A copy of the settlement is available from the NAPAS receptionist at eugenia@napas.org.

III INTEGRATION MANDATE CASES FILED ON BEHALF OF NURSING FACILITY RESIDENTS

A. Indiana Civil Liberties Union Files Integration Mandate Suit On Behalf of Nursing Facility Residents

In July, the Indiana Civil Liberties Union and Steve Gold, attorney for ADAPT, filed *Inch v. Humphreys,* a class action seeking to enjoin Indiana from continuing to violate the ADA integration mandate, the Rehabilitation Act, and the Freedom of Choice provision of the Medicaid Act, and seeking to require the state to immediately offer its long-term care services to class members in their homes and communities, rather than only in nursing facilities. The class is defined as: all persons with disabilities receiving Medicaid who are either unnecessarily in a Medicaid funded nursing facility or who are at imminent risk of such placement, because of the failure of the state Medicaid program to provide them with appropriate, community-based supports.

People with disabilities in Indiana have been frustrated for years by waiting lists for Medicaid home-based waiver services. Ironically, the individuals on the waiting list are the lucky ones, since the Medicaid waiver has been "closed" to new applicants for two years. The complaint argues that rights violations arise from the state's failure in two years to evaluate persons to determine if they are appropriate candidates for home and community-based services, or to offer such services to persons who could reside in the community with appropriate services and supports, or to expand the waiver to the extent necessary to avoid unjustified institutionalization

A copy of the complaint is available on the members' only page of the NAPAS website under program resources/community integration. Similar district court cases filed by P&As, raising ADA integration mandate claims on behalf of nursing facility residents, include: *Rolland v. Cellucci* in Massachusetts; *Barthelemy v. Louisiana*; *Olesky v. Michigan*; and *Davis v. California.* These cases are also available from the NAPAS receptionist at Eugenia@napas.org.

B. California Nursing Facility Residents Sue for Right to Live in Community

The California P&A, along with several disability advocates, filed *Davis v. California*, a federal class action seeking access to community-based long-term care services in order for people with disabilities to avoid unnecessary institutionalization in nursing facilities. The lawsuit alleges that the City and County of San Francisco, as well as several state agencies, are discriminating against people with disabilities by failing to utilize existing Medicaid funding and other funding sources for home and community-based services, and instead are committing the vast majority of available funding to institutional care.

The named plaintiffs reside at Laguna Honda Hospital in San Francisco, or are at risk of institutionalization there, and represent a class of people in the same situation. Laguna Honda is a 1200-bed nursing institution, the largest of its kind in the United States. Plaintiffs have been given no option but to remain institutionalized in violation of the Medicaid Act and the ADA integration mandate.

The Independent Living Resource Center (ILRC) joined the lawsuit as an organizational plaintiff. Plaintiffs are represented by the California P&A, the Bazelon Center, and a coalition of disability rights organizations.

IV OLMSTEAD INTERPRETATIONS

A. Third Circuit Rejects Argument That Opposition To Community Placement Creates A Right To Remain In An Institution

On July 25, 2000, the United States Court of Appeals for the Third Circuit issued a decision that involved whether and to what extent the *Olmstead* decision can be used by institutionalized persons and/or their families who assert a right to remain institutionalized. The case, *Richard C. v. Houstoun*, has been ongoing since 1989.

Pursuant to a Settlement Agreement in the case reached a few years ago, Pennsylvania decided to close Western Center (located just south of Pittsburgh) and move its remaining residents to community settings. In late 1998, a handful of family members who had long opposed the Settlement Agreement and the closure sought to intervene in the case. The family members asserted the *Olmstead* decision as a basis for their intervention. They argued that *Olmstead* recognized the right of persons to receive services in an institution and that persons could not be forced to leave such institutions absent the consent of the resident or a family member/guardian. They based this argument on the language in *Olmstead* that said that an ADA claim can be established if 1) professionals recommend community placement; 2) the individual involved does not object; and 3) creating the program is not an undue burden. The families argued that point 2 of the test was not met. In September 1999, the United States District Court for the Western District of Pennsylvania denied the family members' motion to intervene and specifically rejected their *Olmstead* claim. See *Richard C. v. Houstoun*, Civil Action No. 89-2038 slip op. (W.D. Pa. Sept. 29, 1999) .

Although Western Center closed in April, 2000, the family members continued their appeal to the Third Circuit. In its July 25 decision, the Court emphatically rejected the family members' arguments. Specifically, the Court wrote, "The *Olmstead* Court did not, as Proposed Interveners contend, decide that efforts to place persons with disabilities who reside in state-run institutions into more integrated community-based settings where treatment professionals believe such placements are appropriate can be a form of discrimination under the ADA."

Unfortunately, the Court decided to make this an unreported decision and "Not Precedential" -- which means that it is not binding. It -- as well as the opinion of the District Court -- can be cited, however (if you do so, note that it is an unpublished, non-precedential decision).

See *Richard S. v. DDS* (summarized in the May NAPAS Olmstead Update) A similar ruling was made by a California district court this Spring, in *Richard S. v. DDS* .

In this lawsuit the P&A, as intervenors, challenged an internal policy of a state developmental center which allowed conservators or family members to prevent people from moving out of a Developmental center by giving them the power to veto treatment team recommendations for community placement. The judge ruled in favor of the P&A and agreed that the developmental center's policy giving family members or conservators the right to prevent community placements even when the rest of the treating professionals agreed that the person could live successfully in the community violates the ADA integration mandate.

B. HHS Releases The Second And Third in a Series of State Medicaid Director Letters Regarding Olmstead

On July 25, 2000, the U.S. Department of Health and Human Services' (HHS) Heath Care Financing Administration (HCFA) and Office of Civil Rights (OCR) sent two letters to all State Medicaid Directors addressing questions related to state compliance with the *Olmstead* decision. The letters are intended to build upon an earlier HHS letter sent to all State Medicaid Directors in January which conveyed HHS's initial approach to compliance with *Olmstead.*

The first of the two letters issued on July 25, 2000, entitled "*Olmstead* Update 2: Questions and Answers," answers many of the questions HHS has received concerning *Olmstead* compliance. The second letter, entitled "*Olmstead* Update 3," provides specific changes or clarifications to federal Medicaid policy related to the provision of Medicaid home and community services (HCBS) for people with disabilities. The changes and clarifications are intended to assist states to support the transition from institutional settings to the community.

Both these letters, with attachments, are available on the NAPAS website on the public page under "*Olmstead* Resources for Advocates." Individuals with questions concerning these letters are instructed by HHS to contact Mary Jean Duckett (410-786-3294) or Mary Clarkson (410-786-5918) at HCFA. (Both of these HCFA officials have spoken at NAPAS conferences and are familiar with the P&A Systems.)

1. Highlights From The July 25th Letter Entitled "*Olmstead* Update 2"

Q6. Why should a State engage in planning activity undertaken in response to an OCR complaint? Will it protect the State from other investigations or litigation?

A. . . . Where States or other "respondents" (entities against which OCR has received complaints) engage in planning processes in good faith and at a reasonable pace, OCR may determine it is possible to allow plan development to proceed in lieu of investigation. Where a State or other respondent evinces no intent to undertake planning, or where delays in doing so evidence a lack of good faith, or where States or other respondents utterly fail to involve stakeholders in plan development, OCR may determine it necessary to commence full-blown investigation. Following investigation, if a violation is found and no resolution is reached, cases may be referred to DOJ for litigation.

The second part of the question concerns the effect of such planning efforts upon legal claims brought by private litigants, or by non-OCR government actors, such as the DOJ. An agreement between a State and OCR would not have any direct impact on pending and future Title II litigation brought by a private party or DOJ unless the private parties or DOJ enter into explicit agreements with the State that incorporate OCR's agreement, either in whole or in part.

Q8. In its letter to State Medicaid Directors dated January 14, 2000, DHHS recommends that States "actively involve people with disabilities in the planning process." Does this mean the Department believes that groups should be involved in medical treatment decisions?

A. . . . All stakeholders, including advocacy organizations, should participate in the plan development process to ensure that any plan is comprehensive, works effectively and is designed to meet the needs and concerns of all people with disabilities. Consumer directed organizations, such as independent living centers, often have specific expertise in helping people with disabilities transition from nursing homes and institutions into the community which States may wish to utilize. Decisions regarding the treatment and specific placement of an individual with a disability must be made by that individual in conjunction with the individual's treating professionals.

Q15. What, if any, relationship does *Olmstead v. L.C.* have to Section 504 of the Rehabilitation Act of 1973 (Section 504)?

A. Section 504, which was enacted some seventeen years before the ADA, prohibits discrimination on the basis of disability by entities which receive Federal funding. Section 504 and the ADA use the same definition of disability. Title II of the ADA extends Section 504's prohibition of discrimination in Federally assisted programs to all activities of State governments, including those that do not receive Federal financial assistance. Although the *Olmstead* decision interpreted the ADA, unjustified segregation by a Federally funded program would also constitute disability discrimination under Section 504. A State program receiving Federal funds must comply with both Section 504 and title II of the ADA.

2. Highlights from The July 25, 2000 Letter Entitled "*Olmstead* Update 3[1]"

- Date of Eligibility for HCB Waiver Participants (Attachment 3-a)

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[1]As reported In The National Association of State Directors of Developmental Disabilities Services, Inc. Newsletter (waiver wire 00-10).

This attachment principally concerns the date upon which certain individuals become eligible for HCB waiver services. In the case of some individuals, their eligibility for Medicaid hinges on the receipt of HCB waiver services. Absent "admission" to the HCB waiver program, these persons would not otherwise be eligible for Medicaid. These individuals are known as the "special home and community-based waiver group under 42 CFR 435.217" (individuals who would be eligible for Medicaid if they were in an institution).

In the case of these individuals, the attachment points out that the earliest date upon which they are eligible for HCB waiver services (and, thereby, the soonest a state may begin to claim federal financial participation (FFP) for services provided to such individuals) hinges on when five basic requirements have been met: (a) the person is determined to meet institutional financial eligibility requirements; (b) the person is determined to meet level of care requirements; (c) the individual has been found to meet the target group criteria specified in the HCB waiver program; (d) the person has chosen to receive HCB waiver services and been "admitted" to the program; and, (e) a plan of care (POC) has been finalized on behalf of the person that contains at least one service offered under the program (to satisfy the requirement that the individual "will receive" HCB waiver services).

In some cases, a gap can arise between the time when the first four requirements are met until a complete POC can be developed and finalized. Services furnished to the person during this "gap period" are not eligible for FFP since POC has not been finalized. Billing/claiming for HCB waiver services may only commence once the POC is final and, thereby, the person's date of eligibility has been established. This attachment sanctions the practice of preparing a "provisional" POC until a fuller plan of care is prepared and finalized. The period covered by this interim POC cannot exceed 60-days. A provisional POC may enable a state to collect FFP for HCB waiver case management and other services during the period during which a more complete plan is being prepared.

- Habilitation/Extended Habilitation Services (Attachment 3-d)

This attachment makes it clear that habilitation and extended habilitation (prevocational, supported employment and educational) services may be furnished to any HCB waiver participant, irrespective of the nature of his/her disability. Historically, the provision of habilitation has been closely identified with HCB waiver programs for persons with mental retardation and other developmental disabilities. However, as the attachment points out, neither federal law nor regulations limit the provision of these services to persons who have mental retardation or a related condition or whose disability arose before the age of 22. It is worth pointing out that, as a result of this policy clarification, states that operate HCB waiver programs for persons with physical disabilities now have clear sanction to add the coverage of employment-related services.

- Nurse-Delegated Services (Attachment 3f)

This attachment clarifies that nurse-delegated services may be billed/claimed in the category of service through which they are actually furnished rather than classified/claimed as a "nursing service." This clarification applies both under the HCB waiver program and the state Medicaid plan (e.g., the provision of nurse-delegated services under personal care). The attachment may assist states in simplifying their coverages. State laws and regulations dictate whether nurse-delegated services are permissible.

- States May Not Limit Home Health to "Homebound" Individuals (Attachment 3-g)

Under the Medicare program, the provision of home health services is limited to "homebound" individuals. In some cases, states have imposed this same restriction on Medicaid state-plan home health services. Medicaid law (§1902(a)(10)(D) of the Social Security Act) requires that a state provide "for the inclusion of home health services for any individual who, under the State plan, is entitled to nursing facility services." In this attachment, HCFA concludes that limiting the availability of home health services to homebound individuals: (a) violates statutory

requirements concerning the comparability of services (by making home health services available to some recipients but not others) and (b) is an impermissible limit on the "amount, duration and scope of services."

- Services for HCB Waiver Participants Out-of-State (Attachment 3-e)

This attachment discusses how states may accommodate HCB waiver participants who receive their services and supports out-of-state. The attachment contains HCFA's observations regarding how such topics as provider qualifications and quality assurance (including the use of state-to-state compacts) can be addressed when a person is served out-of-state.

- Community Reintegration (Attachment 3-f)

This attachment contains clarifications and changes in Medicaid policy that are intended to assist states in overcoming barriers to the community reintegration of institutionalized persons with disabilities. The attachment addresses four distinct topics: (a) the provision of case management services to institutionalized persons; (b) obtaining federal financial participation (FFP) for the costs of "accessibility assessments"; and (c) obtaining FFP for environmental modifications completed in advance of a person's return to the community. In the discussion that follows, the term "institutionalized person" means a person who is a resident of an ICF/MR (regardless of size or ownership (public or private), a person who is served in a nursing facility, or a person served in a hospital setting.

(1) Case Management

The placement of institutionalized persons in the community typically involves the collaboration of institutional and community case managers over an extended period of time. However, present Medicaid policy poses various obstacles to this collaboration. When a state underwrites the costs of community case management as a transitional case management service, HCFA policies heretofore have limited states to claiming only the costs of transitional case management services furnished to institutionalized persons during the 30-day period immediately preceding the person's discharge. In this attachment, HCFA:

(a) Increases from 30 to up to 180 days the period of time for which the costs of case management activities on behalf of institutionalized persons may be claimed under the TCM option provided that the TCM services were related to achieving the individual's community reintegration and the person actually leaves the institution. The 180-day limit is defined as the "last 180 consecutive days of a Medicaid eligible person's institutional stay." In this case, the claim may be made regardless of whether the person's community reintegration takes place through the HCB waiver program or by other means. These costs may not be claimed if the person moves from one institutional setting to another;

(b) Provides that the same costs instead may be claimed post-placement as case management under a state's HCB waiver program by the state's establishing a special billing unit to account for the costs of pre-placement case management services provided in advance of community placement. HCFA further provides that the date of service of these pre-placement case management services is the day the person actually is discharged from the facility; and,

(c) Clarifies that a state may claim the costs of case management services furnished to institutionalized persons as an administrative activity. Administrative case management activities would be claimed at the applicable matching rate for administrative costs. Such services may include case management services specifically intended to assist institutionalized persons to return to the community but also presumably could include other case management services conducted on behalf of institutionalized persons. The administrative claiming option may prove useful to states in underwriting various activities associated with the comprehensive plans that many states have been developing in the wake of the *Olmstead* decision.

(2) Assessments for Accessibility

Next, the attachment outlines three options for states to claim for the costs of conducting assessments to determine if the person's home or vehicle should be modified. These options are not limited to persons who are reentering the community from the institution but may be furnished on behalf of any HCB waiver participant at any time.

(3) *Environmental Modifications in Advance of Placement*

The next two sections of the attachment concern: (a) claiming via the HCB waiver program the costs of environmental modifications made in advance of the individual's placement from an institutional setting to the community and (b) allowing a state to recover the costs of environmental modifications made in advance of placement as an administrative expense if the person dies prior to placement.

- Personal Care/Personal Assistant Retainer Payments (Attachment 3-c)

Present HCFA HCB waiver policy precludes a state from making payments for days of service when the HCB waiver participant is hospitalized or away from his/her living arrangement for other reasons. In the case of community residences funded through the HCB waiver program, a state may not make an "absent-day" payment (the equivalent of an institutional "bed hold" payments).

In this attachment, HCFA creates an exception to its policy of not allowing absent day payments by providing that a state may make "personal care retainer payments" when individuals receive personal care/personal assistance services through an HCB waiver program (as opposed to the Medicaid state plan). HCFA provides that "the personal assistance retainer time limit may not exceed the lesser of 30 consecutive days or the number of days for which the State authorizes a payment for 'bed-hold' in nursing facilities." HCFA appears to restrict the use of "personal care retainer payments" to situations where the individual is not served in a provider-controlled living arrangement (e.g., a group home). As a consequence, "personal care retainer payments" would be limited to situations where the person lives in a home of his/her own (e.g., a supported living arrangement). As a consequence, this attachment does not appear to fundamentally alter HCFA's present prohibition against making absent-day payments when persons are served in group homes or similar residences.