Consumer Action Series

WORKING PAPER

Community Integration: The Role of Individual Assessment

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Introduction

This Working Paper is the fourth in a series exploring the central policy issues that arise from the United States Supreme Court’s decision in Olmstead v. L.C., which addressed the “community integration” provisions of the Americans with Disabilities Act (ADA). In Olmstead, the Supreme Court determined that the medically unnecessary institutionalization of persons able to benefit from and desiring community placements constitutes discrimination under the ADA in situations in which a state can achieve community integration through reasonable modifications of its programs and services and without a fundamental alteration. The decision also set a “reasonable pace” standard for achieving community integration.

A key element of the Olmstead decision concerns the role of state professionals in the individual assessment process of determining “eligibility for habilitation in a community based program.” The Court referred to a link between community integration and assessments by state treatment professionals without further elaboration, leaving unclear the exact scope and application of the process, as well as how the process should take place.

This Working Paper was developed to consider possible approaches to interpreting the concept of individual assessments. While the process of carrying out an assessment raises basic issues that are integral to a public determination of whether an individual qualifies for a good, benefit, or status, in reality there appear to be two types of assessments that states need to consider. This paper attempts to identify the two classes of assessments and identify issues for consideration in both cases.

The first type — which we term a “liberty” assessment — is a rare, threshold assessment that arises in a small percentage of cases involving an individual who resides in an institution over which a state has power and control (e.g., a state mental hospital), but who is seeking community integration. The assessment process that arises in this type of case essentially determines an individual’s liberty, (i.e., freedom from unlawful restraint). As with the plaintiffs in Olmstead, this type of assessment considers the manner and setting of care appropriate for an individual—whether the placement in the state facility is appropriate or whether the individual would benefit from living in the community. This process does not seek to determine whether an individual qualifies for assistance under the terms of a waiver or other government program, but rather where and how the treatment is to take place.

2 42 U.S.C. §§12101 et seq.
5 Olmstead, 527 U.S. at 602.
The second type of assessment arises routinely and occurs when an individual makes a claim for the benefits or resources necessary to support a decision to live in the community. This “coverage” assessment assumes that the individual filing the claim is not objecting to the manner and setting of care or that the state’s treatment professionals have determined that community placement is appropriate (and thus the individual’s liberty is not threatened). This type of coverage decision, akin to a coverage decision made by any insurer, typically arises in a Medicaid context and triggers not only ADA and potentially constitutional considerations, but the procedural requirements of the Medicaid program itself.

When one examines closely the elements inherent in individual assessments, it becomes evident that many of the factual issues about the individual that must be explored in a liberty determination (i.e., the decision as to the manner and setting of care) parallel the issues that must be examined in a coverage determination regarding eligibility for assistance. It is possible that individuals whose liberty decisions are theirs to make (because they are not subject to state control) nonetheless may not qualify for benefits under the state’s coverage criteria for community-based resources; however, according to some advocates, the typical basis for a denial is not that the individual does not medically qualify for assistance, but that no resources are available.

At the same time, it is essential for planning purposes that states recognize and distinguish in the administration of their programs between the two types of assessments in order to avoid undue administrative burden and to confine their liberty determinations to those instances in which a decision by a state official regarding community appropriateness is integral to community residence. Without this separation of assessment activities, a state also may risk adding an unnecessary layer—namely, a state’s determination as to the appropriate manner and setting of care—to the process of assessing for resource appropriateness, which alone could be viewed as raising administration fairness issues under the ADA.

This Working Paper begins with a brief recap of the Court’s Olmstead ruling related to assessments by state professionals. It then considers the two types of assessments: those related to liberty and those related to coverage, both of which arise in the context of community integration. In considering the resource assessment process, we examine both basic considerations about the minimum procedural fairness matters that arise in coverage and resource assessments, as well as the special rules that apply in the case of Medicaid.

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Background and Overview

The issue of assessment by state professionals arose in *Olmstead* in the context of a special set of circumstances. In *Olmstead*, the individuals were residents of a state mental institution and their discharge hinged on a decision by state officials in charge of medical decision-making for the state regarding the appropriateness of community care. Indeed, the two plaintiffs in the case had been determined by the state’s own treatment professionals to be qualified to live in the community, but nonetheless languished in an institution because the state failed to make the resources available to allow this to occur. In other words, the state’s decision that community placement was appropriate was made without any regard to the resources necessary to achieve liberty, itself a violation of the ADA. This failing on the state’s part lay at the heart of the case.

In setting the standard for state conduct in cases involving medically unnecessary institutionalization under public programs, the Court stated as follows:

> [Community integration] is in order when the state's treatment professionals have determined that the community placement is appropriate, the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and the placement can be reasonably accommodated, taking into account the resources available to the state and the needs of others with mental disabilities.\(^7\)

This holding contains a number of ambiguities, including which types of cases tie the issue of liberty to a state determination. In his concurring opinion, Justice Kennedy used somewhat different terminology to describe the issue of medical decision making, effectively broadening the classes of medical professionals who make the threshold liberty decision: “[t]he opinion of a responsible treating physician in determining the appropriate conditions for treatment ought to be given the greatest of deference.”\(^8\) The Kennedy concurrence thus appears to follow the Court’s holding in *Youngberg v. Romeo*,\(^9\) which recognized the weight to be given to treatment professionals in determining the appropriateness of care without regard to whether such professionals were state employees or private practitioners. Justice Kennedy’s concurrence also emphasized that in cases in which institutionalization is linked to disability or health status, the integration determination is a medical one that implicates a critical role for the treating professional, whoever that treating professional may be. In a few instances the power to make this decision lies with a state professional because of the nature of the confinement. In most cases, however, the decision will be made by the individual patient in consultation with his or her personal treatment professional.

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\(^7\) *Olmstead*, 527 U.S. at 587.

\(^8\) *Olmstead*, 527 U.S. at 610 (Kennedy J., concurring) [emphasis added].

Liberty and Resource Assessments

Table 1 presents a classification for approaching the issue of individual assessments as part of the *Olmstead* planning process. As the table indicates, there are two types of assessments that the state will need to address: those that arise because of the nature of the confinement (i.e., a confinement that is subject to state professional decision making); and those that arise because an individual requests a benefit or service, typically Medicaid.

Table 1. An Individual Assessment Taxonomy

<table>
<thead>
<tr>
<th>Issue</th>
<th>Key Elements</th>
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</thead>
<tbody>
<tr>
<td><strong>Threshold Liberty Decisions</strong></td>
<td>• Cases in which the individual is under the control of a state treatment professional (e.g., confinement on state order or in a state institution).</td>
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<td></td>
<td>• A threshold liberty assessment is not triggered when the individual's confinement was the result of a private decision (e.g., where a personal treatment professional makes a decision that while institutional care was at one time medically necessary, community residence is now medically appropriate).</td>
</tr>
<tr>
<td><strong>What types of cases trigger a liberty decision by state treatment professionals?</strong></td>
<td>• Made by a state treating professional where the place of institutionalization is a state institution or an institutional placement otherwise ordered by the state.</td>
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<td></td>
<td>• Made by the individual in consultation with his or her personal treating professional in cases in which the confinement itself is not connected to a state decision.</td>
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<tr>
<td><strong>Elements of a liberty decision.</strong></td>
<td>• Assessment of the specific facts of an individual case, including ability to live in the community in light of existing resources and consideration of whether community integration can be achieved through a reasonable modification of existing resources.</td>
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<td>• Assessment by a professional who is qualified by specialty and training to make the assessment.</td>
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<td>• Assessment using objective evidence, clinical observation, and assessment tools that are reliable and valid.</td>
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<td>• Appeals rights because the assessment involves “state action.”</td>
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<tr>
<td>Issue</td>
<td>Key Elements</td>
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<tr>
<td>Resource Allocation/Coverage Decisions</td>
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<tr>
<td>When do resource assessments arise?</td>
<td>• Individual seeks benefits and services to enable community residence.</td>
</tr>
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<td>Who makes the resource assessment?</td>
<td>• State agency officials administering the program in question.</td>
</tr>
<tr>
<td>Elements of a resource assessment.</td>
<td>• Assessment of the specific facts of an individual's case in light of the program eligibility criteria, including an assessment of whether, with a reasonable modification in benefits and service rules, community integration could be achieved.</td>
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<td></td>
<td>• Criteria that are rationally related to the program's objectives.</td>
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<td></td>
<td>• The ability on the part of the individual to submit information regarding the need for services and the appropriateness of the services.</td>
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<td></td>
<td>• Consideration by a professional who is qualified and trained to make the type of assessment in question.</td>
</tr>
<tr>
<td></td>
<td>• Assessment using objective evidence, clinical observation, and assessment tools that are reliable and valid.</td>
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<td>• Appeals rights because the assessment involves “state action.”</td>
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<td>• In the case of Medicaid resource assessments, proper application of Medicaid requirements.</td>
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**Threshold Liberty Assessments**

Where a state’s decisions implicate an individual’s basic liberty and regardless of whether the decision was made in a civil or criminal context, basic due process considerations arise. In those cases in which the person seeking community integration under the ADA is in (or at risk of) the type of confinement in which the state plays a formal role (e.g., a civil commitment), the state must fashion a threshold assessment process that satisfies not only the substantive considerations of the ADA in terms of measuring the appropriateness of community integration, but one that also is procedurally fair. Taken together, key constitutional due process cases involving liberty interests of confined persons\(^{10}\) identify certain elements of a fair process:

- A process that is accessible to the individual and that the individual can seek out (i.e., not wholly at the discretion of the state).

• Assessment by qualified professionals who have the requisite training and skills to conduct an assessment.

• Consideration of the specific evidence of an individual's case, including the status of the individual and the resources that will be needed to achieve community integration.

• Consideration of whether the resources that are available can appropriately support community residence with reasonable modification (e.g., authorizing additional hours of community in-home care).

• Assessment process that, if it includes standardized tools and instruments for assessing the potential to benefit from community residence, makes use of tools that are evidence-based and have been shown to be valid and reliable in the literature (i.e., reliably predictive of the successful achievement of community residence within available resources as reasonably modified).

• Ability on the individual's part to submit evidence from consulting or other relevant professionals regarding the appropriateness of community residence, at least on appeal.

Resource and Benefit Decisions

The far more common type of assessment is one that is designed to determine an individual's eligibility for resources, benefits, and services. This assessment is comparable to the types of assessments that insurers make as part of a coverage determination process.

Simply because an individual desires to live in a community and can demonstrate with medical evidence the appropriateness of community residence with proper services and supports, it does not necessarily stand to reason that the individual qualifies for the services that he or she may need. However, Olmstead stands for the proposition that in administering public resources, state agencies must make reasonable modifications to promote community integration. Thus, the resource and benefit assessment process is really an individualized fact-finding process regarding what resources an individual needs to live in the community, and whether the state provides the requisite resources or could do so with reasonable modification to how it administers certain programs and services. Thus, for example, if the individual can live in a community if certain types of housing services are available, the state's task would be to examine its housing resources to

determine if the service exists or could be developed through reasonable modifications in the housing programs it does offer.\footnote{Stewart, et al., op.cit}

In addition, where the resources at issue are Medicaid benefits, states must comply with program requirements, including the application, promptness of services, amount, duration, and scope requirements, as well as to the fair hearing requirements where a request is denied. An extensive body of case law interpreting these requirements in the context of persons with disabilities\footnote{See Wilder v. Virginia Hosp. Ass’n, 496 U.S. 498 (1990); Perry v. Crawford, 990 F. Supp. 1250 (D. Nev. 1998); Catanzano v. Dowling, 847 F. Supp. 1070 (W.D.N.Y. 1994); Doe v. Bush, 261 F.3d 1037 (11th Cir. 2001); Cramer v. Chiles, 33 F. Supp. 2d 1342 (S.D. Fla. 1999); and Easley v. Snider, 36 F.3d 297 (3d Cir. 1994).} and desiring community services has held that in light of Medicaid requirements and their intersection with the ADA’s reasonable modification test, the state’s resource assessment process not only has to involve qualified personnel making decisions using reasonable measurement tools and individualized evidence but also:

- Individual recipients must be afforded an opportunity to apply for assistance and have their eligibility for benefits determined in accordance with standards of reasonable promptness.

- Individuals are entitled to an individualized determination regarding the medical appropriateness of the benefits, and they must be permitted to submit evidence of the appropriateness of care in a community with proper supports (e.g., the opinion of their treating health professionals).

- Where the state plan offers both benefits through a waiver program as well as standard community benefits, a determination would need to be made regarding the availability of waiver services. Where no waiver slots are available, the state would need to further consider whether basic state plan services could support community integration with reasonable modification.

- Under the Medicaid fair hearing regulations, the individual would have the right to appeal a denial of assistance whether on medical grounds or on the grounds that the resources do not exist. In keeping with the ADA’s reasonable modification requirement, the fair hearing should be structured to allow the presentation and consideration of evidence regarding whether, with reasonable modification, the benefits and services available under the state plan can be adapted to the individual’s needs in order to achieve community integration.
Key Cases Addressing Assessments

In the context of assessments (whether liberty- or resource-based), a number of cases are of particular relevance.

The Role of Medical Evidence

Youngberg v. Romeo is one of the leading cases on the issue of medical evidence, holding that individuals in involuntary civil confinement situations have a constitutional right to have treatment designed by health professionals and that the role of professional opinion is so great that courts must defer to professional judgment.

At the same time, the initial assessment (whether for liberty or resource needs) may be initiated through a preliminary process that rapidly assesses an individual against standard instruments to determine the appropriateness of community services. In Doe v. Bush, the court found permissible a state assessment process in which the first stage of the assessment regarding appropriateness of inpatient care in a facility for developmentally disabled persons was a paper screening tool based on patient files, rather than a face-to-face individualized assessment. This holding suggests that assuming that the preliminary screening device is a valid and reliable instrument and is properly applied to a relevant group of individuals (i.e., is not applied to make decisions about persons for whom the tool was not developed in the first place), such a preliminary screen would be acceptable. (Again, the state would have to allow a review of any denial, whether liberty or resource/coverage-related, that is based on the individual’s failure to meet the threshold requirement).

Cost Effectiveness of the Site of Care

Whether liberty- or resource-related, it appears that an assessment can take into account the overall cost of the care, so long as a reasonable modification standard is used to ensure that modifications with modest cost implications are not overlooked and as long as a review of the decision is possible. In Catanzano v. Dowling, the State of New York required that in deciding the appropriateness of home health care, a certified home health agency compare the cost-effectiveness of home care versus residential healthcare. In the case, the court determined that cost comparison could be made, but that such a determination amounted to a decision by the state (through its private contractor) regarding home health care eligibility and that Medicaid procedural requirements thus applied as if the decision had been made by a state official.

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14 Doe, 261 F.3d at 1057.
What Evidence Must be Considered? The Role of State Judgment

Because the assessment process we described here is individualized and factually complex, the role of evidence and the process for considering it (whether in a liberty or coverage resource context) is of central importance. The scope of evidence to be considered in a community integration case is broad and includes evidence related to the individual’s medical, housing, and employment needs; the individual’s preferences; the level of information available to the individual; the level of risk the individual would bear in the community setting; any history of success or failure in a community setting; the quality of life the individual would have in the community and facility settings; and the availability of services in the community. In addition, the requirements of the ADA would necessitate that consideration be given to whether the level of modification necessary to adapt community resources to individual needs is reasonable or whether fundamental alteration in existing programs and services would be required to support community residence.

Under circumstances comparable to the type of individual assessment tasks contemplated by Olmstead, states have engaged in similar findings. For example, in Easley v. Snider, the state rejected a request for additional individual personal support services designed to help persons with disabilities complete tasks that individuals receiving home and community services would have to complete on their own in order to qualify for the waiver. The state’s rationale for this coverage limitation was that the ability to complete certain tasks independent of assistance by a personal aide was a basic eligibility prerequisite for its program. Thus, although the plaintiffs are indeed at liberty to live in a community setting, the practical reality was that the state’s resource availability for coverage purposes was conditioned upon the ability to perform certain tasks. In this case, the court did not require any modification of criteria, essentially determining that the redesign of the state’s waiver program to cover persons who could not provide essential tasks on their own was in essence a fundamental alteration of the program.

However, Parry v. Crawford held that not actually being mentally retarded was not a good reason to be denied services that were intended for mentally retarded individuals. The court ruled that the individual’s condition, insofar as it was related to mental retardation, qualified the individual for the services. The court essentially found the state’s method for measuring coverage eligibility too restrictive and not sufficiently flexible to reach conditions related to retardation that would benefit from the same mix of services.

A state may consider the level of risk assumed by the individual in extending coverage. Thus, Doe v. Bush held that an important consideration in determining which type of service is appropriate is making sure that the individual’s health will not regress in the

16 36 F.3d 297 (3d Cir. 1994).
18 Id at 1255.
considered setting. In other words, even where an individual is at personal liberty to reside in a community, a state can, in setting the coverage criteria it plans to use for resource allocation purposes, take personal safety into account. Again, of course, the Olmstead decision would require that the state consider whether with reasonable modification in the configuration of the resources, personal safety concerns can be overcome.

19 Doe, 261 F.3d at 1058.
Conclusion

This review suggests that individualized assessments occur in both the small subset of cases involving formal state determinations of liberty, as well as the more common state decisions involving whether an individual who desires to live in a community qualifies for the coverage and resources the state provides. In the former situation, basic elements of due process compel certain safeguards both in the initial assessment and on appeal. The resource assessment cases are far more common, since most persons in or at risk for institutional placements are not in confinements in which the state plays a committing role. The placement is the result of a medical decision that institutional care is necessary, and the individual may pursue community placement in consultation with his or her treating physician or health professional.

But even where the liberty question is not at issue, the state has the basic resource and coverage decision to make. This means a decision regarding the needs of the individual, the medical evidence supporting community placement, the use of measurement tools that are valid, reliable, and relevant to the case at hand, consideration of available resources and program benefits, and a determination as to whether community residence can be achieved with reasonable modification in programs and services that are offered. Where Medicaid is involved, the resource rules are governed by that program’s subsequent standards, and the procedural requirements of prompt decisions and access to a fair hearing level appeal also come into play.