

The Report of the Subcommittee on Rights and Engagement

March 2003

Introduction

No topic is more fundamental to people with psychiatric disabilities than their human rights. This Subcommittee Report is predicated on the belief, supported by data, that advancing and protecting human rights promotes recovery and facilitates engagement in mental health treatment. People are more likely to recover from a mental disorder when they are treated with fairness and respect. Conversely, when human rights are ignored or neglected, the preconditions for recovery are undermined.

The Subcommittee sets forth policy options that aim to engage individuals in treatment and preserve their rights by emphasizing accessible community-based services and providers' voluntary legal compliance. The major approaches to achieving these goals are through national leadership, inter-agency collaboration, and broad dissemination of information and technical assistance to all stakeholders in the mental health system. The Subcommittee emphasizes engaging the individual in acceptable voluntary treatment as the front line approach to advancing the legal rights of adults with serious mental illness (SMI) and children and youth with serious emotional disturbance (SED). While successful engagement may be accomplished in many ways, consumers must first have readily available to them an array of acceptable community-based services from which they can voluntarily choose.

The Subcommittee recommends informational remedies, such as promoting broad awareness of regulations and their legal implications and providing technical assistance, as the first means of ensuring the legal compliance necessary to protect the rights of adults with SMI and children and youth with SED. Should these methods prove ineffective in resolving the problems, the Subcommittee strongly supports the use of mediation and alternative dispute resolution to address a possible abuse of legal rights.

In those instances where mediation and alternative dispute resolution do not lead to voluntary legal compliance, the only remaining remedy may be litigation. Using litigation as a remedy is sometimes associated with unintended costs and consequences, and so must be carefully considered, and only after all other possible remedies have been exhausted. At times, however, litigation may represent the remedy of last resort to protect individuals' legal rights in the mental health system.

Promote Engagement in Community Treatment

Policy Option 1. Expand Community Treatment Alternatives

Individuals with the greatest mental health treatment needs can be most effectively engaged in voluntary treatment when a broad array of community-based treatment options are made readily accessible. Lacking choice of acceptable treatment options, adults with SMI and children and youth with SED and their families are unlikely to engage in treatment or participate in appropriate and timely interventions. Thus, consumer access to a range of effective community-based treatment options is critical to achieving full community participation for persons with psychiatric disabilities. To ensure this access, the array of community-based treatment options must be expanded.

Evidence supports the effectiveness of a full range of community-based alternatives to hospitalization and emergency room treatment. Creating alternatives to in-patient treatment improves engagement in community-based treatment and reduces unnecessary institutionalization. In particular, community-based treatment options for children and youth with SED must be expanded. These young people are too often placed in out-of-state treatment facilities, hours away from their families and communities. This unacceptable situation serves to further segregate children from their families and communities and impedes effective treatment.

Too often, the services absent from a community's mental health care continuum are precisely those services that would most likely engage the consumer in voluntary treatment. Consumer-oriented approaches such as employing consumers as providers and establishing consumer-operated services might increase the likelihood of engaging hard-to-reach consumers. There should be a high priority on incorporating these alternatives as a part of every local mental health system.

The Department of Health and Human Services (DHHS) should clarify funding guidelines and provide technical assistance regarding a full range of community-based services (e.g., consumer-run services, mobile crisis units, hot lines, personal care attendants, other non-hospital crisis services, and within-community placement of children and youth with SED) to expand community treatment alternatives and reduce hospitalization and emergency room visits. Private and public funding mechanisms should be made sufficiently flexible to allow access to the full range of effective community-based alternatives.

Policy Option 2. Eliminate Discrimination in the Workplace Based on Receipt of Mental Health Treatment or Current Diagnosis

The paradox faced by people with psychiatric disabilities is that they are encouraged to seek treatment and yet a record of seeking treatment often has far more adverse employment consequences than does forgoing treatment. The Federal government should serve as a role model for the states and the private sector in eliminating discriminatory employment policies based on outmoded stereotypes of people with mental illness. All levels of Federal government should delete any blanket exclusion or discrimination on the basis of past mental health treatment or current diagnosis, and should review their employment policies relating to the same.

Policy Option 3. Eliminate Discrimination Based on Psychiatric Disability in Substance Abuse Programs and Discrimination Based on Substance Use in Mental Health Programs

Although co-occurring mental health and substance abuse disorders are common, substance abuse programs often refuse to accept people with a psychiatric disorder into their programs and residential facilities for people diagnosed with a psychiatric disorder are often unwilling to accept people with substance use problems. Thus, the neediest citizens are turned away when they seek assistance. Exclusion of people from substance abuse programs solely on the basis of psychiatric disability violates the Americans with Disabilities Act (ADA), as does the exclusion of people with substance use disorders from mental health treatment programs.

DHHS should strictly enforce the ADA to prevent denial of access or rejection of applicants to Federally funded substance abuse treatment facilities solely on the basis of psychiatric disorder. Likewise, DHHS should prevent the exclusion of persons with substance use disorders from Federally funded mental health treatment programs. CMS has launched initiatives to clarify existing Medicaid policies related to the treatment of adults, children, and youth with co-occurring disorders, and to provide technical assistance to assist States in more effectively utilizing Medicaid programs for persons with co-occurring disorders. The Subcommittee applauds these efforts.

Promote the Right to Remain Engaged in Treatment and Freedom from Unnecessary Institutional Treatment

Policy Option 4. Eliminate Trading Custody for Care

Loving and responsible parents, who have exhausted their savings and insurance to provide services for a child with a serious emotional disturbance, are often confronted with a tragic choice: Forgo the mental health services that their child desperately needs, or relinquish custody of their child to the state so that Medicaid services can be accessed. A more family-friendly policy must be found. Ensuring equitable coverage of mental health care in commercial insurance plans, as the President has urged, would be a good step toward eliminating custody relinquishment. Issues of custody must be separated from issues of care. DHHS should generate a range of options to pursue in remedying this untenable situation.

Policy Option 5. Educate Mental Health Consumers about Advance Directives

One way to establish a person's preferences regarding treatment is for the individual to communicate those preferences in advance, i.e., to complete an advance directive. The Patient Self-Determination Act of 1991 requires facilities receiving Medicare or Medicaid to inform patients of their right to create an advance directive under applicable state law. In accordance with this Act, hospitals and community facilities should educate mental health consumers about advance directives, and consumers should be encouraged to complete them. Federal hospitals should serve as role models for the States in implementing the Patient Self-Determination Act's requirements, as well as determining and disseminating the best practices in this area.

Policy Option 6. Conduct Mediation Training for Mental Health Care Consumers and Staff

Clients and staff's use of mediation to resolve their conflicts about treatment issues has shown promise. The Americans with Disabilities Act itself explicitly indicates a preference for mediation over litigation of disputes. DHHS's Office for Civil rights and the Department of Justice (DOJ), in their collaboration on an alternative dispute resolution (ADR) pilot program, should use DOJ's highly regarded mediators to conduct regional mediation training for consumers and staff on consumers' legal rights in the mental health system. Once trained, these consumers and staff could, in turn, serve as mediators themselves and train others to be mediators.

Policy Option 7. Support Research on Outpatient Commitment Outcomes Where it Already Exists

Few issues are more controversial than “outpatient commitment” – a legal order to adhere to prescribed treatment in the community. Because of the inconclusive evidence on the effectiveness of outpatient commitment, the Federal government should take no position on the expansion or contraction of current outpatient commitment laws at this time. Rather, the Federal government should support state-of-the-art research on the outcomes of outpatient commitment where it already exists and disseminate the findings of that research.

Policy Option 8. Fully Implement *Olmstead*

In the 1999 *Olmstead* decision, the Supreme Court held that unnecessary institutionalization is discrimination under the Americans with Disabilities Act (ADA). The Court found “confinement in an institution severely diminishes the every-day life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.” The President urged swift implementation of *Olmstead* in his 2001 Executive Order, mobilizing Federal resources in support of *Olmstead*.

Strong national leadership is imperative to urge and assist State and local governments towards voluntary *Olmstead* compliance. The Subcommittee calls upon DHHS, especially its Office for Civil Rights (OCR), to provide this leadership. DHHS is also urged to emphasize that *Olmstead* applies with special force to children and adolescents, whose entire lives can be damaged by unnecessary institutionalization. The Subcommittee supports the following specific policy options:

- DHHS and OCR should follow through on their current voluntary compliance initiatives to expeditiously implement *Olmstead*, including widespread dissemination of information about voluntary *Olmstead* compliance and the promotion of community care, technical assistance for States, and clarification of Medicaid policies affecting individuals with psychiatric disabilities.
- OCR and DOJ should continue their collaboration on an alternative dispute resolution (ADR) pilot program to resolve *Olmstead* non-compliance complaints.
- To ensure community needs of unjustly institutionalized persons are adequately met upon their discharge, financial incentives should be linked to discharge standards and best practices, and DOJ should continue to enforce CRIPA provisions for monitoring discharge plans.
- DHHS should ensure the Federal government, itself a provider of hospital care to persons with psychiatric disabilities, serves as a model to the States and localities in fully implementing *Olmstead* in its own facilities.
- To measure progress in implementing *Olmstead*, States should consider maintaining waiting lists of unnecessarily institutionalized persons

Policy Option 9. Eliminate Unjustified Institutionalization by Guardians

Public and non-relative guardians for incompetent or indigent persons with serious mental illness can potentially fulfill a valuable advocacy role on behalf of their institutionalized wards, advocating for the least restrictive placement. Unfortunately, these guardians typically have enormous caseloads and cannot properly monitor their institutionalized wards. Guardians may “voluntarily” institutionalize their wards, and many states make no provision for review of the necessity of these commitments.

To eliminate unjustified institutionalization by guardians, OCR is urged to formulate policy on guardians' "voluntary" institutionalization of their wards and disseminate this policy to all stakeholders. To evaluate the extent

of such unjustified institutionalization, DOJ should review the scope and appropriateness of guardianship regarding unnecessary institutionalization, in accordance with CRIPA.

Protect Human Rights of Consumers Engaged in Institutional Treatment

Policy Option 10. Provide Treatment when Treatment is Mandated

The Subcommittee believes that mandating people to participate in nonexistent or inadequate treatment is unacceptable. If hospitalization or outpatient commitment is legally mandated, then treatment must be provided. To insure that individuals confined involuntarily to institutions are provided adequate and sufficient treatment to permit a reasonable opportunity for rehabilitation, cure, or reintegration into the community, DHHS and its Office for Civil Rights (OCR) should develop policy and guidelines for mandated treatment standards. In order to evaluate the extent of individuals mandated to treatment who do not receive adequate treatment, the Civil Rights Division of the Department of Justice, which has responsibility for monitoring and protecting individuals involuntarily confined to institutions, should continue to endorse CRIPA.

Policy Option 11. Support Initiatives to Minimize Seclusion and Restraint

It is now the professional consensus that the best way to reduce restraint deaths and injuries is to minimize restraint use to the greatest extent possible. High restraint rates are seen as evidence of treatment failure. Many facilities and state agencies have had substantial success in restraint reduction, while also reducing staff and patient injuries.

DHHS should immediately issue regulations to implement protections under the Children's Health Act of 2000 in order to reduce injuries and deaths from seclusion and restraint. DHHS should follow these regulations with technical assistance and guidelines for States and Federal facilities on how to comply with the new seclusion and restraint standards. To measure progress in this area, Federal facilities should maintain a seclusion and restraint database, using the format developed by the National Association for State Mental Health Program Directors.

Policy Option 12. Strengthen P&As' Capacity to Safeguard Rights of People with Psychiatric Disabilities

The Protection and Advocacy Agency (P&A) is mandated to advocate on behalf of individuals with disabilities. P&As provide legal advocacy services under a number of programs, including Protection and Advocacy for Individuals with Mental Illness (PAIMI). P&As are responsible for investigating incidents of abuse or neglect on behalf of people with psychiatric disabilities in public or private facilities. Thus, P&As play a critical role in protecting the rights of these individuals with psychiatric disabilities while institutionalized.

To strengthen P&As' capacity to safeguard the rights of individuals with psychiatric disabilities in both the community and in institutions, P&As should meet with their regional constituents to clarify investigative priorities. P&A protections should be expanded to include Federal institutions and hospitals, as well as advocacy on behalf of children and youth with SED to help them remain in their communities. DOJ, in its enforcement of CRIPA, should review the effectiveness of P&A Agencies and involve P&As in their investigations and litigation enforcement as appropriate to ensure rights protection in institutions

Policy Options 13. Promote the Application of Procedural Justice

It is easier to engage clients in treatment when they believe they have been treated fairly by the legal system than when they feel they have been ignored and treated unjustly. DOJ and DHHS should provide technical assistance to promote the application of procedural justice (e.g., to lawyers, hearing officers, and practitioners) to promote recovery through engagement. The Federal government should adopt the National Center for State Courts' standards for representation of people with psychiatric disabilities in its own commitment proceedings, and should encourage the States to do so as well.