

**TEMPLATE OF KEY ELEMENTS
WHICH MUST BE CONSIDERED WHEN DEVELOPING A COMPREHENSIVE,
EFFECTIVELY WORKING STATE PLAN FOR MOVING PEOPLE OUT OF
INSTITUTIONS AND INTO APPROPRIATE COMMUNITY SETTINGS**

**Prepared by the National Association of Protection and Advocacy Systems
October 12, 1999**

Introduction

In *Olmstead v. L.C. and E.W.*, 119 S.Ct. 2176 (1999) the Supreme Court stated loud and clear that the denial of community placements to individuals with disabilities is precisely the kind of segregation that Congress sought to eliminate in passing the Americans with Disabilities Act (ADA). The Supreme Court correctly noted that unnecessary segregation and institutionalization constitute discrimination and violate the ADA's "integration mandate" unless certain defenses are established. The decision presents new opportunities for advocating for community-based services and supports for people with disabilities.

The decision says a state may have a defense to lawsuits challenging the state's failure to serve individuals in the most integrated setting appropriate if it has a "comprehensive, effectively working plan for placing qualified persons with mental disabilities in less restrictive settings."

The Court did not define a "comprehensive" plan. It seems appropriate that a "comprehensive" plan is one that addresses the placement needs of all individuals who are unnecessarily institutionalized or at risk of institutionalization. A state may have different plans to address different populations, as long as the needs of all individuals unnecessarily institutionalized are addressed. Neither does the Court define "effective." It seems logical however that an "effective" plan must have certain important elements.

This template is designed as a tool to help advocates participating in the development of state plans to ensure that they consider certain important elements that any state plan should have. The template is intended as a baseline and not as a model plan. Advocates should add to this list as necessary taking into account the circumstances of your state. It is important to understand that any plan that is developed will need to be modified as circumstances change. The state plan should be considered to be a working document that should be reviewed at regular intervals (at least annually). The steering committee that develops the plan (including key stakeholders) should also be the group that continues to review the plan. Forums or other methods of soliciting the opinions of consumers, family members, providers, etc., should be held regularly to ensure broader stakeholder input.

The guiding principle reflected in this template is that the state must develop and enhance

community programs and services so that each individual resident can move to the most integrated setting appropriate to meet his or her needs. The community program and service shall promote choice, independence and dignity.

Element One: PARTICIPATION OF KEY STAKEHOLDERS IN THE DEVELOPMENT OF THE PLAN

Stakeholders should include representatives of those who receive, provide, administer, and monitor disability services. Advocates need to press state or local government officials to include all of these groups in the process of developing the state plan. Inclusion means more than just inviting a representative to participate, it also means ensuring that accommodations are offered that will allow full and meaningful participation for each stakeholder representative. For example, assistance might be provided with regard to reading and understanding materials, holding meetings in accessible locations, transportation to and from meetings, provision of childcare or respite services etc.

Key stakeholders may include, but are not limited to representatives from:

- *consumer self advocacy groups, for example, The Arc, independent living programs, associations for the mentally ill, mental health consumer groups or for individuals with psychiatric disabilities, groups for those with sensory impairments, physical disabilities and AIDs,
- *area agencies on aging and other senior citizen groups,
- *veterans organizations,
- *hospice programs,
- * the state legislature,
- *state agencies, for example, Department of Mental Retardation or Developmental Disabilities, Department of Medicaid, Medicare, and Social Security, Department of Special Education , Department of Transportation, Department of Housing
- *protection and advocacy agencies
- *developmental disabilities councils
- *community mental health centers,
- *providers of home based care, and respite care,
- *vendors of assistive technology,
- *nursing homes,
- *residential treatment facilities
- *state and community hospitals,
- *the medical community, nurses, social workers and case managers.
- housing providers; advocacy groups

Element Two: NEEDS ASSESSMENT PROCESS

Often states do not take the time to figure out the type and quantity of services and supports that need to be developed in the community to support persons with disabilities, nor is there a clear process for determining who needs services (e.g. the waiting list is often not well defined). This often results in a lack of community capacity which then gets used as an excuse for not providing

community supports. Also assessments must not be shaped from a consideration of the current availability or existence of a needed service or support.

This step in the planning process should be done on an ongoing basis, but should not delay the process of moving people for whom adequate supports can be readily identified. For other people, there will need to be more planning. For example, serving people with complex medical needs in rural areas will require some creative thinking. A needs assessment would help to identify these needs and allow for adequate planning.

Individual assessment should include:

- *identification of who should conduct the assessments, what qualifications must they have, do you want a team, if you have a team of assessors, who must be included on that team, and what qualifications must they have
- *reasonably paced schedule for assessing all currently institutionalized persons
- *schedule for accessing all people in the community who may be at risk of unnecessary institutionalization
- *schedule for accessing, on an ongoing basis, new persons who develop disabilities and need community supports
- *assessments should be conducted by qualified professionals who specifically consider such factors as the array of services an individual needs, the types of services that could be provided in the community, and any reasonable accommodations that might be required to enable the individual to benefit from particular services
- *part of the assessment should include at least one face-to-face consultation with person who is being assessed for appropriateness for community placement. At the least this consultation should identify what the specific interests, goals, likes and dislikes and support needs of the individual which may factor into whether community placement is the most appropriate setting for the individual. This face-to-face consultation should be conducted using the individual with the disability's preferred method of communication
- *the individual being assessed for community placement must be given the opportunity to visit and temporarily test out a choice of community services options prior to being asked to chose where one wants to live.
- *a written individual support plan that is reviewed and revised upon the request of the individual or guardian, and at least yearly.
- *transition services to assist the individual to make a smooth change to the community.

**Element Three: DEVELOPMENT OF NEW COMMUNITY SERVICES AND
SUPPORT INFRASTRUCTURE**

A comprehensive plan should identify new and expanded community services and supports that will be made available in the community to respond to the increased demand for these services that will result from unnecessarily institutionalized persons moving to the community. Advocates should insist that as part of plan development states include improving community service infrastructure.

Infrastructure should include:

- *health care, personal assistance, therapy services, dental services, durable medical equipment and other assistive technology
- *architectural modification as a community support
- *respite care as a community support
- *recruitment of health professionals, service providers and vendors to address a wide array of needs for community supports, including, but not limited to supported living, respite care, family support, housing adaptations, vocational training, therapy services, medical and dental services, etc.
- *training for health professionals, service providers and vendors on topics that address recognition and prevention of abuse and neglect, promotion of person-center planning and community inclusion, balancing independence with health and safety concerns, education about the ADA, special education, vocational rehabilitation and civil rights for persons with disabilities
- *competency-based certification process for service providers. In addition, to general training, specific training with regard to individuals specific needs should be required.
- *support coordination or case management for persons with disabilities living in the community
- *policies and procedures for the reporting, investigation of unusual incidents, and a corrective action process to respond to abuse and neglect.
- *policy on health care decision making, including recognizing advance directives
- *appeals and grievance process for individuals living in the community and an ombuds program for individuals to access with concerns about access to services, abuse and neglect or rights violations
- *community mental health services
- *accessible affordable housing
- *accessible and affordable transportation
- *crisis services in the community, including a backup system for when scheduled service and support structures fall through, 24 hour access to medical, behavioral and psychiatric services.
- *vocational services and supported employment
- *educational programs for individuals 21 and under
- *accessible recreation and leisure
- *family support services
- *public education about community integration as a civil right
- *mandatory coordination of care for individuals moving to community placements
- *If the state contracts with a managed care entity (MCO) to provide its Medicaid services, the state contract with the MCO must make clear that the MCO is required to provide these community services and supports
- *contracts with service providers should establish clear billing procedures that delineate the specific services and supports they are expected to provide. The element is included because current experience reveals that billing procedures are complex and often providers are not informed of the services they are required or allowed to perform.
- *reimbursement rates for providers must be set at reasonable levels so as to attract sufficient numbers of qualified service providers
- *a program to re-train service providers who currently provide services in institutional settings to transition to providing services in the community

**Element Four: TRANSITION SERVICES TO PREPARE INDIVIDUALS FOR A
CHANGE IN PLACEMENT**

Elements to consider in a Transition plan:

- *allow individual to request a temporary six-month hold on the institutional bed at the time of initial community placement.
- *allow preplacement home visits and overnights
- *pre-service training for community support staff - prior to actual placement - on individual service needs.
- *choice of alternative placements if the initial placement is discovered not to be appropriate in first 6 months and any time thereafter based on assertion of inadequate services or harm
- *if a school age individual is transitioning an IEP should be in place prior to the move
- *each individual shall have a “transition profile” which can be shared with community support staff prior to the move, Including: name, age, sex, communication method, ability and language, diagnosis, intellectual level, mobility level, hearing, vision and dental status, mealtime patterns, nutritional needs, level of supervision required, environmental adaptations and modifications needed, allergies, general health condition, emergency health care needs, preferred number and characteristics of house mates, preferred geographic location, anticipated adjustment issues, vision for the future, safety concerns, description of personality, skills and interests, spiritual and religious preferences, and vocational interests.

**Element Five: DATA COLLECTION WHICH IS INDIVIDUALIZED AND TIED TO
INDIVIDUAL PROGRAM PLAN**

The state should implement a tracking system to monitor the progress of each individuals program plan. This tracking system will help the state document progress towards implementation and identify where progress is lagging. This will also allow the state to identify barriers and problem solving activities at the individual and state-wide level.

A state’s data tracking system could be designed to collect general state-wide data and also data which may only be meaningful to a few individual program plans. Overall data should be kept simple and meaningful.

In order to ensure that data is routinely reviewed, barriers are identified, and problems solved the state may wish to create a data review team to meet monthly at the regional level. The purpose of the meeting would be to review the data, identify trends and issues, and implement actions to prevent issues, solve problems, and improve trends.

Collecting data is the first step in the process, but the most important thing is for this data to be aggregated and reports to be developed and run on a regular basis to help inform decision-making by program administrators. Part of the development of a quality assurance system should be to define what data is to be collected, who is going to collect it, which reports will be developed and how such reports will be utilized (e.g. some data could be tied to outcome measures and used to evaluate providers' performance).

Specific data to collect could include:

- *number of individuals moved to the community, type of placement and location of placement and services and supports
- *numbers of individuals returning to institutions in the first six month, one year, or five years after placement in the community.
- *incidents of abuse or neglect, name of service provider, location of abuse, type of abuse, resolution taken, follow-up planned.
- *data on consumer satisfaction with services and supports, quarterly, yearly, etc.
- *numbers of trained or training service providers and location of providers - reviewed for possibility of shortage
- *number of community placements available and location of community services
- *track comments about inadequacy of services by particular providers
- *track grievances, including the issue grieved, the service provider who is the subject of the grievance, if applicable, and the resolution of the grievance
- *track the length of time it took to get assessed for community placement
- *track the length of time between when the person was assessed as appropriate for community services and when the individual received the needed community service

Element Six: OUTCOMES MEASUREMENT AND TARGET DATES

State should provide specific measurable goals and these goals must be tied to resource allocation. Time frames and outcome measurements must also include consequences if the time frames are not met or if the goal is not reached. One obvious consequence is that if the state plan is not “effectively working” the state will no longer have a defense to an ADA lawsuit for unnecessarily institutionalizing persons with disabilities.

State plans should not be sequential by institutional type or type of disability or age. In other words, the plan must apply the same time frames for the community integration of people in nursing homes and state hospitals as for those in public and private intermediate care facilities. Advocates should be wary of a state plan that omits individuals in any of these institution or that is sequential in nature, thereby giving one group preference over another based upon type of disability or institutional setting in which they reside.

Below are some examples of specific measurable goals and target dates:

- *specific numbers of people to be moved out of institutions, specific institutions to be targeted, specific dates upon which states will have move specific numbers of individuals.
- *outcomes and goals should be establish for each area of the plan. For example:
 - training program for service providers will be developed by a certain date and a certain number of service providers will have received the training by a certain date etc.;
 - individuals who are recently in need of community supports shall be assessed within a specific number of days and services shall be provided to these individuals with in a certain number of days;
 - certain number of monitors will be trained within a specific number of days and a certain number of facilities will be monitored by a specific date;

- certain number of individuals who have moved from institutions to the community will be placed in supported employment by a specific date and a certain number of individuals will receive appropriate vocational training by a certain date etc;
- people living in institutions will be reassessed for community placement appropriateness at least every 3 months;
- state will be able to provide a certain number of days of respite services to individuals with non-specialized needs, within a certain number of days after the request is made, and to individuals with specialized service needs within a certain number of days from the time the request is made.

Element Seven: MONITORING/QUALITY ASSURANCE

The state must establish a method of evaluating programs at the individual and state-level to ensure that they are effective at the individual level and that they met certain state standards and requirements. Quality assurance also involves improving the capacity of providers to implement continuous quality improvement activities, including problem solving, promotion of self-determination, and ability to problem solve.

It should be recognized that there often are at least a couple of agencies/entities that have some responsibility for monitoring. This can include: service providers, personal assistants, home health agencies, vocational providers, the Medicaid agency, licensing staff, case managers/support coordinators etc. In order for quality assurance to be effective, all of these should be coordinated. This can be done through a comprehensive quality assurance plan. Such a plan also could pull in the data collection, aggregation and reporting piece, including who is going to collect which data, etc.

Key elements of Monitoring/Quality Assurance include:

- *regular review of individual service plans
- *monitoring teams, which include persons with disabilities, family and community members, service providers, an individual familiar with the range of community services available to persons with disabilities, and a representative of the state agency that has oversight authority for the community program
- *training for monitors
- *monitors should be given the authority to review records access community placements and services
- *specific schedules for monitoring and selection of sites to be monitored
- *a meaningful self assessment process
- *confidentiality of personal information
- *specific and detailed reporting requirements for monitors that are reviewed by the state
- *service provider and vendor training and education to ensure quality services are offered
- *people with disabilities must have access to a community ombuds program to assist individuals work with service providers and case managers and resolve disputes or other concerns.
- *self-advocacy training and education to consumers so they understand they have certain rights to quality services and the opportunity to obtain ombuds assistance if these rights are violated.

- *service provider standards, rights and expectations
- *appeals and grievance procedure that individuals with disabilities and providers may access if rights are violated, (For example, the Medicaid Act provides specific due process rights for services provided under Medicaid)
- *training both consumers and providers how to recognize abuse and neglect
- *regulations for reporting and investigating abuse and neglect allegations
- *regulatory penalties for abuse and neglect including a registry of service providers who have been convicted of abuse and neglect.
- *state reporting on its progress moving unnecessarily institutionalized persons into the community that the state is required to distribute to consumers, families, and providers.
- *responsibility for quality assurance should be vested in a person who has authority to tell program directors his findings and this person should not be answerable to any person in control of the programs being evaluated.
- *monitoring should involve more than just a paper review. Monitoring should also include a face-to-face discussion with the child about whether they feel safe, how their lives can be improved and if they are unhappy with any person or situation in their life. Monitoring should also include a discussion with the individuals service providers and if a child is involved, the child's family and teacher

Element Eight: RESOURCE DEVELOPMENT

The state should consider the following mechanisms for increasing resources available for community supports and services for people with disabilities:

- *new waivers development
- *restructuring Medicaid funding rules to promote community integration
- *using tobacco settlement money to enhance community supports
- *passing a state-level Mi-CASSA (Medicaid Community Attendant Services and Supports Act) bill. Such a bill would make it possible for a state to allow an individual eligible for nursing facility services or intermediate care facility services to choose to use these Medicaid dollars for community attendant services and supports.
- *shifting funds from institutions to community programs by closing down wings of large facilities.

Element Nine: The state plan shall be reviewed, revised and updated every two years or sooner if appropriate.