Role of Assessments in Determining LTSS

Jennifer Mathis
Director of Programs
Bazelon Center for Mental Health Law
1101 15th Street, NW, Suite 1212
Washington DC 20005

Underlying Service System Principles – What are the Goals?

Individuals with disabilities should have the opportunity to live like people without disabilities. They should have the opportunity to be employed, have a place to call home, and be engaged in the community with family and friends.

Individuals with disabilities should have control over where and how they live, including the opportunity to live in their own apartment or home. Living situations that require conformity to a collective schedule or that restrict personal activities limit the right to choose.

Virtually all individuals with disabilities can live in their own home with supports. Like people without disabilities, they should get to decide where they live, with whom they live, when and what they eat, and who visits and when.

To this end, individuals with disabilities should have access to housing other than group homes, other congregate arrangements, and multi-unit buildings or complexes that are primarily for people with disabilities. They should have access to "scattered site" housing, with ownership or control of a lease.

* From Key Principles of Community Integration embraced by 28 national disability orgs

How is Choice Determined?

Individuals with disabilities must have full and accurate information about their options, including what services and financial support are available in integrated settings.

They should have the opportunity to visit integrated settings and talk to individuals with similar disabilities working and living in integrated settings.

Their concerns about integrated settings should be explored and addressed.

* From Key Principles of Community Integration embraced by 28 national disability orgs

"Old Thinking" in Assessments

Focus on Deficits

 Focus on "levels of care" determined by scores and linear continuum of service settings

 Assumptions that institutionalization required if person needs help with ADLs or IADLs, "lacks insight," has co-occurring substance abuse disorders or medical needs.

"Current Thinking"

What would it take?

 Begin with presumption that individuals can live in their own homes or apartments with appropriate services

 Define the narrow circumstances in which this presumption can be overcome

"Current Thinking"

- Determinations that a person cannot live in his or her own home should be supported by specific information about what services are needed that cannot be provided in that setting.
- Specific services that are unavailable should be identified.
- Blaming the person does not help identify these gaps and does not lead to building a better system that addresses people's needs.

Assessment Provisions in Olmstead Settlements

Assessments shall begin with the presumption that NYC Adult Home Residents can live in Supported Housing. A resident will be considered appropriate for Supported Housing if desired by the resident, unless the assessment discloses that the resident:

- (a) Has significant dementia;
- (b) Would be a danger to self or others in Supported Housing even if receiving the services referenced in subparagraph d below;
- (c) Needs skilled nursing care that cannot be provided outside of a nursing home or hospital; or
- (d) Needs a type and/or frequency and duration of service on an ongoing and sustained basis in order to live in Supported Housing that is not available under the New York State Medicaid program, unless another public (e.g., Medicare) or private (e.g., Meals on Wheels) program will pay for or provide the needed service, the individual is eligible for such program, and such program is available to such individual.

United States v. New York, O'Toole v. Cuomo Settlement

Meaningful Choice

- Ongoing efforts to educate residents of institutions about their options for living in integrated settings, including the services and financial support available if they choose to live in their own homes or apartments. These efforts are often called "in-reach."
- Providing opportunities for residents of institutions to visit integrated settings, such as "scattered site" supportive housing, and to speak with peers who live in those settings.
- Developing and using assessment tools that begin with the presumption that
 people with disabilities can live in their own homes and, for the rare circumstance
 in which that is not the case, identify what services a person needs that could not
 be provided in his or her own home.
- Developing sufficient housing and service capacity in the community so that residents of institutions have a meaningful opportunity to live in the most integrated setting appropriate.
- Ensuring that assessments of residents' needs are done when housing and services are actually or will soon be available.

^{*} From Senate HELP Committee Olmstead Report

Community Integration for People with Disabilities: Key Principles

General Principles

- Individuals with disabilities should have the opportunity to live like people without disabilities. They should have the opportunity to be employed, have a place to call home, and be engaged in the community with family and friends.
- Individuals with disabilities should have control over their own day, including which job or educational or leisure activities they pursue.
- Individuals with disabilities should have control over where and how they live, including the opportunity to live in their own apartment or home. Living situations that require conformity to a collective schedule or that restrict personal activities limit the right to choose.

Employment

➤ Individuals with disabilities should have the opportunity to be employed in nonsegregated, regular workplaces. Virtually all individuals with disabilities can be employed and earn the same wages as people without disabilities. When needed for such employment, they should have access to supported or customized employment. They should be afforded options other than sheltered work, day treatment, clubhouses, and other segregated programs.

Housing

- ➤ Virtually all individuals with disabilities can live in their own home with supports. Like people without disabilities, they should get to decide where they live, with whom they live, when and what they eat, who visits and when, etc.
- To this end, individuals with disabilities should have access to housing other than group homes, other congregate arrangements, and multi-unit buildings or complexes that are primarily for people with disabilities. They should have access to "scattered site" housing, with ownership or control of a lease. Housing should not be conditioned on compliance with treatment or with a service plan.

Choice

Individuals with disabilities should have the opportunity to make informed choices. They must have full and accurate information about their options, including what services and financial support are available in integrated settings. They should have the opportunity to visit integrated settings and talk to individuals with similar disabilities working and living in integrated settings. Their concerns about integrated settings should be explored and addressed.

Public Funding

➤ Government funding for services should support implementation of these principles. Currently, public funding has a bias toward institutionalization, forcing individuals to overcome myriad barriers if they wish to age in place and remain in their communities.

These community integration principles are embraced by:

ADAPT

American Association of People with Disabilities

American Diabetes Association

Association of University Centers on Disabilities

The Arc of the United States

Autistic Self-Advocacy Network

Bazelon Center for Mental Health Law

Depression and Bipolar Support Alliance

Disability Rights Education and Defense Fund

Easter Seals

International Association of Peer Supporters

Little People of America

Mental Health America

National Alliance on Mental Illness

National Association of Councils on Developmental Disabilities

National Association of Rights Protection and Advocacy

National Association of State Directors of Developmental Disabilities Services

National Association of State Mental Health Program Directors

National Coalition for Mental Health Recovery

National Council for Community Behavioral Healthcare

National Council on Independent Living

National Disability Rights Network

National Federation of the Blind

National Mental Health Consumers' Self-Help Clearinghouse

National Organization on Disability

Paralyzed Veterans of America

TASH

United Spinal Association