Navigating the Systems

Systems of support for long-term care are changing. In the past, individuals’ options were limited to placements in group homes or supervised apartments. While these residential settings continue to exist for those with more intensive support needs, options have and will continue to expand. Today, housing and services are being separated or “unbundled.” Individuals with I/DD, working with individual budgets, select providers and direct the services that they choose. Increasingly, individuals with disabilities, by themselves or with supports, are controlling their own housing and services and living in more community-integrated settings. We call this independent housing.

There is a tremendous need for residential support, as well as housing that is affordable. It is likely that funding for these will come from multiple sources. We need to stop thinking of individuals with I/DD as people who need disability specific resources, and begin thinking of them as individuals who have low incomes and need resources. Given the limitations of government resources, individuals with disabilities need to access resources that are available to anyone with low income. These general resources, described in the guide, include such things as rental subsidies, food stamps, and utility assistance. Keep in mind that family income is not generally considered when determining eligibility for services for individuals who are over 18.

In most states, including Connecticut, there is no entitlement for services. States establish the number of individuals that they will serve based upon available state appropriations and available federal funding. Regulations define the means to access and maintain such benefits.

Independent housing requires that several factors be in place. There must be a readily available supply of affordable housing units. Funds, from several government sources, must be available to provide the individual with supports, based upon the person’s level of need. The individual’s personal income from social security and earnings pays for room and board, which may be supplemented by rental assistance or some form of housing subsidy.

Many housing models exist and some are described in this guide. Through person-centered planning, the individual designs where and with whom he/she wants to live. Working within the scope of an individual budget, it may be a challenge to use the available dollars to cover all of the expenses. The individuals can select multiple providers or a single entity to address all of their needs. For some, technological advances can supplement assistance previously supplied by direct support personnel.

Note: The authors did not vet the quality of service delivery in each of the models described. Most individual names and some details about their lives have been altered to protect their privacy. The authors made every effort to accurately and completely describe appropriate residential arrangements and services for individuals with a broad range of abilities and needs. We have strived to capture this range in the examples of models and description of individuals in their homes. The intensity of staff support can vary within each model.

Multiple funding sources are also described. Each funding source has its own eligibility criteria and regulations. The systems of funding are in transition and corresponding regulations are changing. To obtain the most current information, check the internet links provided.

With an understanding of these requirements and some “out of the box” thinking, you can develop an individualized plan to fit within the funding structure. We hope that individuals use this guide to find models and elements of these models that may be a match for them or their loved one. We welcome feedback to improve future editions of this guide.

Sometimes traveling to a new place can be scary as well as enjoyable. We hope that this guide will help individuals and their families as they navigate the road to independent living and find their way.

Note: This guide provides information best known at the time of publication. Much system change is in process and consequently regulations are changing. Refer to the websites for the most up-to-date information.