

Information on the Home Control Manual

Theresa Varnet and Richard Spain have written a manual on home control and home ownership for persons with disabilities to provide individuals and families with information to assist them in their effort to secure control over where the family member with a disability will live and with whom they will live. The manual provides information about government benefits, trusts, estate planning, and financing strategies for obtaining and keeping a home. The information presented is necessarily general in nature; there is no one set path to be charted. Nonetheless, considerations will be explored and some solutions will be offered. While each situation is as unique as the individual involved, it is prudent to explore all options, including those which may not necessarily seem to be applicable to persons with disabilities.

While many persons with disabilities live at home with their families by choice, others do so because they are unaware of the options available to them. The manual evaluates the major barriers to independent living faced by persons with disabilities. It will also discuss how individuals and families can overcome these barriers. The two most common obstacles are a lack of finances and community based support services. Due to a financial reliance on subsistence level government benefits, such as Supplemental Security Income (SSI) or Social Security Disability Income (SSDI), people with disabilities are often unable to afford a home of their own. Even when individuals with disabilities have families who are able to assist them with the purchase of a home, they are often unable to provide the support that makes it possible for the individual to live independently.

In recent years, several factors which bolster the efforts of persons with disabilities in overcoming these barriers have made planning for home control a much more realistic option.

These events include:

- Growth in supervised apartment programs;
- Development of the Plan to Achieve Self-Support (PASS) provision by the Social Security Administration (SSA);
- Changes in U.S. Department of Housing and Urban Development (HUD) policies;
- Tremendous growth in and availability of technological devices and equipment, enabling persons who were previously unable to live alone to now do so;
- Growing knowledge of special needs trusts by attorneys;

- Changes in federal Medicaid regulations which enable parents of persons with disabilities to establish trusts;
- Changing perception and attitude towards persons with disabilities and a recognition of the ability of these individuals to grow and develop throughout their lifetime;
- Civil rights movements that recognize that persons with disabilities are entitled to an equal opportunity to enjoy life, including the right to live in the community and the ability to control their own environment;
- *Olmstead v. L.C.*, 527 U.S. 581 (1999) – Supreme Court ruling that requires states to eliminate unnecessary segregation of person with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs;
- Passage of the ABLE Act in December, 2014 providing families an opportunity to save funds for disability-related expenses above and beyond the SSI resource limit; and
- Centers for Medicare and Medicaid Services (CMS) published final rules for Home and Community Based Services, mandating that Medicaid waivers serve people in the community.

The information provided will empower persons with disabilities and their families to explore alternatives to the traditional “provider-based” service delivery system. Estate planning and the preservation of eligibility for government benefits can be extremely complicated subjects. Still, families should use information about these issues to better inform themselves of the choices available to them.

Please note that this manual is not intended as specific legal advice. When planning for the future, families should retain the services of an attorney, a financial planner and other resource persons as may be appropriate, who are knowledgeable about the needs of persons with disabilities.

In referencing the individual with a disability, the authors have used “he” and “his” in lieu of “he or she” and “his or her” for fluency and ease of reading only, not to identify disability with gender.

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