

Special Housing for Special People

Parent Participation Project

Introduction

Preparing for the future can be daunting for parents of children with developmental disabilities. Many parents have experienced frustration in getting the services their children need, because the system of public services has limited funding, is not always user friendly, and operates differently depending where a person lives. Many parents want to be more proactive in finding residential services for their children and also have resources to contribute to a home and supports. However, many parents have found, amid the countless details involved, that there is no single source of information or assistance.

The Parent Participation Project was a dream of NCCH, who partnered with Welcome House to create this manual. It was funded by several foundations in Northeast Ohio, and the following county boards of mental retardation: Cuyahoga, Geauga, Lake, Medina and Stark. Its purpose is to provide a complete source of information for parents interested in family-directed housing, also called a consortium. The goal is to provide parents and other family members with information and support to empower them to meet their child's residential needs. This manual is the first step toward that goal.

Information in this manual is from several sources: interviews with families who financed a home, county boards of MR/DD, and service providers. It attempts to answer the questions that parents have about housing and services. It will also raise issues that need to be considered when developing a home and supports for a person with a disability. For many years the mr/dd system in Ohio has encouraged parents to join together in groups of three to four families to form a "consortium" which would share in jointly funding the purchase of a house for their own children with disabilities. Success in developing a consortium home will depend on the ability of the local county board of MR/DD to provide funding for supports in the home. Most funding of supports is provided through the Medicaid Waiver program. The number of Waivers available in each county in the state varies over time. While a Waiver slot may not exist today in a particular county, it could be available in the future. Parents need to work closely with staff at their local MR/DD board.

Developing the best possible home and supports can be time-consuming, difficult and frustrating. Who better, though, to meet the challenge than parents? People with disabilities and their families have always been the driving force behind service development. Before there were county boards and adult training centers, activities and classes were held in churches and community centers, often staffed and funded by the participants' parents. Parents and family are best suited to meet the challenges of ensuring that a child with disabilities has a safe and nurturing place to live.

Al Etmanski says it eloquently in his book *A Good Life*: "We are the conductors of the symphony of caring, comfort, and support for our relatives. No one else has the breadth of vision and the passion."

A few things readers should know:

1. Most of the manual addresses the MR/DD (Mental Retardation and Developmental Disabilities) system, but much of the information can be useful to people who receive services from other systems.
2. The system of supports operates differently in each state. The level of residential support is different in each county of Ohio. This manual addresses the system in Ohio.
3. This manual is written for any person who is helping a friend or family member plan for the future. Because the majority of people using the manual will be parents, the reader is often referred to as "parent." Likewise, the use of "child" refers to this relationship and not to an individual's age.
4. Every attempt has been made to avoid professional jargon or abbreviations. The glossary in Appendix D defines many terms.
5. Nothing in this manual should be considered legal advice. Families are encouraged to consult their attorney, financial planner, or other professionals before making important decisions.

