

BLUEPRINT:

COMMUNITY SUPPORTED LIVING WITHIN WISCONSIN'S LONG-TERM CARE SYSTEM



WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

BLUEPRINT

IS PUBLISHED BY



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WITH DEVELOPMENTAL DISABILITIES

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WHAT IS COMMUNITY SUPPORTED LIVING?

One of the exciting changes that has accompanied Family Care and IRIS has been the recent growth of Community Supported Living across Wisconsin.

Community Supported Living is a flexible partnership that enables a person needing support to live in their own home with support from an entity that provides individualized assistance.

Components of Community Supported Living include that the individual, with assistance as needed:

- Lives in a non-regulated setting and exercises choice in regard to location and appearance
- Has their name on the lease or mortgage of a home that is not owned or controlled by a service provider
- Chooses who to share a home with
- Chooses who is engaged in providing their supports
- Directs when, where, how, and what type of supports are provided
- Directs and has access to individualized and integrated community participation
- Is provided respectful supports that honor privacy and choices

Community Supported Living organizations:

- Assist in finding a home that meets the individual's needs
- Assist in managing living in one's own home
- Help develop community involvement and relationships that promote full citizenship
- Coordinate education and assistance related to finances, healthcare, and other needs
- Assist with day-to-day planning and problem solving
- Train and support people who assist the individual
- Provide 24-hour flexibility in responding to the needs of an individual, including emergency situations

Community Supported Living:

- Recognizes interdependence and community participation as a part of everyone's life
- Respects and honors informed decision making of people, and supports people to build and sustain relationships
- Supports informed decision making and risk taking while always endeavoring to ensure safety and security, recognizing that all people have the right to make mistakes
- Can customize support to people at any level of need for assistance



HOW COMMUNITY SUPPORTED LIVING HELPS PEOPLE FIND AN

There are three distinct ways in which people receive support or services within th

1. A COMMUNITY SUPPORTED LIVING ORGANIZATION PROVIDES NEEDED ASSISTANCE AND STAFFING

Person or family holds lease or mortgage and control who lives there. Person typically determines who provides support, in conjunction with a Community Supported Living Agency.

A Community Supported Living organization provides ongoing staffing support and assistance to the person beyond simply providing direct support workers. Support can be occasional, and up to 24/7. Typical features include:

- Assistance in finding and, when desired, changing affordable housing
- Assistance in helping set up and manage living in one's own home
- Attention to issues of safety, security, and stability
- Training and supporting people who assist individual
- Coordinating needed assistance related to household tasks and finances, health care, community activities, and membership
- Assistance with day-to-day planning and problem solving
- Being responsible and responsive in the event of a crisis
- Whatever else is necessary

When people live in their own home with support through Community Supported Living, the home belongs to the person, not to an agency. There are no admission or discharge criteria. If an agency no longer wishes to serve a person, the agency leaves, not the person. The agency does not set rules governing personal possessions, decorations, hours, meals and meal times, who may visit and when, privacy, and more. By obtaining support through a Community Supported Living organization, individuals or families who are unable to assume day-to-day responsibility for hiring, supervising, and coordinating needed assistance have another option to find an affordable home and obtain the necessary flexible and sustainable support that will enable them to live in their own homes.

To be clear, this paper does not make an argument that obtaining support through Community Supported Living organizations ought to be the preferred way to obtain and organize assistance where a person lives. Community Supported Living organizations do, however, on one hand offer a cost-competitive alternative to facility-based services, and on the other hand provide a viable option for individuals who are no longer able to organize assistance by themselves or through support of a family member, as described below.

2. A PERSON OR FAMILY HIRES STAFF

- Hire staff directly, pay payroll taxes, and perform other employer duties
- Controls who works there by hiring staff directly or in concert with a co-employment or employment leasing agency

There are currently several thousand individuals or families in Wisconsin who have chosen to be responsible for hiring and managing staff that come in to their home. This has long been an option desired and experienced by individuals with physical disabilities. More recently, it has been an option exercised by family care givers to support older family members who have impairments related to aging, or younger family members with developmental disabilities.

This manner of obtaining support requires active and ongoing engagement of the individual or family in finding, training, supporting, scheduling, and administering the employment of direct support staff. It maximizes control over who provides paid support and scheduling when that support is provided.

D LIVE IN THEIR OWN HOMES

their own homes.

3. AN AGENCY PROVIDES SUPPORTIVE HOME CARE, PERSONAL CARE, OR HOME HEALTH CARE

- A person owning their home or living with their family can hire a Supportive Home Care, Personal Care, or Home Health Care Agency. The agency hires, trains, schedules, and sends staff into a person's home.
- Person or family holds lease or mortgage and controls who lives there; agency controls and schedules staff sent in to work there.

Individuals typically have an option of selecting which agency provides needed support, but have little or no involvement in selecting staff who are hired to provide support, and do not control the hours that staff are available. Ideally, the agency will work with the individual or family to assure that agency staff are acceptable and competent, and in scheduling support in a flexible manner. The agencies limit the assistance they send in to the home to the specific service they provide at the agreed upon time.



THE PLACE OF COMMUNITY SUPPORTED LIVING IN OUR SYSTEM

Community Supported Living offers an alternative to facility based residential services by enabling people to live in a home that is their own, as typical citizens do. On average, Community Supported Living can be provided at no more cost, and for many people at less cost than facility-based residential services. The focus on individualizing services enables organizations to provide what each person needs, and to utilize the strengths and resources of the individual, the family when involved, and the community.

For individuals or families who choose to hire their own staff directly, or to obtain a specific service through a Home Health Care, Personal Care, or a Supportive Home Care Agency, there is no need for the additional support offered by Community Supported Living. Community Supported Living does offer a sustainable option for individuals who are not able to or no longer wish to organize assistance by themselves or through the support of family members.

WHERE TO GO IF YOU ARE INTERESTED IN LEARNING MORE

Community Supported Living is a relatively new idea in many parts of our state. As a result, some County Programs, Managed Care Organizations, IRIS Consultants, and ADRCs know more about it than others at this time.

If you have questions about Community Supported Living after contacting Family Care or IRIS, feel free to send an email to A Simpler Way at dwharks@gmail.com.

Dennis Harkins

A Simpler Way

June 2013

WISCONSIN'S HISTORY

Over the past 50 years, Wisconsin has developed a complex and varied response to supporting people where they live. For people with developmental disabilities, that began with the creation of group homes and owner-occupied adult foster homes. Housing complexes were created for older people and for people with physical disabilities. The Independent Living movement led to various ways in which people with physical disabilities could receive paid support in their own homes. Aging advocates created an emphasis on “aging in place” with a focus on a variety of ways that paid support could enable people to remain in their own homes rather than go into nursing homes. Community Supported Living was originally developed for people with developmental disabilities as an alternative to group homes and institutions.

After 50 years of growth and learning in Wisconsin, there are several distinct ways in which Wisconsin citizens live and obtain support while receiving public funding to meet long-term care needs:

Institutional Care, Adult Family Homes and CBRFs:

Most funding dedicated to supporting where people live remains in the institutions, and in the types of community based residential facilities (CBRFs) that were developed primarily in the 1970s. When people use the term “residential services” they are typically thinking about those types of facilities.

These types of residential services are owned by and belong to a service provider. They do not belong to the person receiving support or services. The facility decides whether or not to admit, discharge or move the person to another setting; decides where in the facility the person sleeps and keeps personal possessions; what hours “residents” keep; who may visit and when; and what decorations and personal possessions are allowed. The facility management develops and administers rules governing the setting in response to state policies and rules related to funding, licensing, or certification.

Community Supported Living enables people to live in their own home, not a place that belongs to an agency. The importance of that point cannot be overstated.

Individual's Own Home:

Most people who receive long-term support in Wisconsin live in their own home. Many adults receiving services are living with their family, sometimes because they and the family believe that is ideal, and sometimes because they may not be aware of or have support to access ways in which a person could live outside of the family home. Other adults are living in a home of their own by themselves, with a spouse, or with a person with whom they share living expenses.

COMMUNITY SUPPORTED LIVING

Community Supported Living enables people to live in their own home, not a place that belongs to an agency. The importance of that point cannot be overstated. Home is at the center of our lives. It is home base for our relationships with friends and family. We choose who we live with, who we invite into our home, and how we spend our time. We choose what we do within our home, how we create our place with our own particular mix of decorations, colors, pictures, and cherished items.

Community Supported Living enables people to live with as much support from a family as they and their family wish, but without a family member being responsible for all aspects of finding and supporting a person. Family members can help in finding a home, but also get help in doing so. Families can help in planning, problem solving, wondering about the future, but can do so as mom, dad, sister, brother and not as staff recruiter, care manager in charge of completing various forms, or back-up staff if someone doesn't show up in the morning.

Community Supported Living is one way to enable individuals or their families to lease or own a home that looks like, feels like, and is their own. It is a growing and viable alternative to institutions and facility based residential services.

TWO EXAMPLES OF COMMUNITY SUPPORTED LIVING

The stories below illustrate how Community Supported Living can be an option, both for people who are now living in regulated residential facilities, as well as for individuals currently living at home.

BOB'S STORY

Bob attended a self-advocacy group meeting to learn how to better understand self-determination and self-directed supports. Part of that learning included asking people to share what they would like to change in their life. With quiet eloquence, Bob shared his desire to move from a group home into his own home. He talked about the frustrations of living with other people who he did not choose to live with, rules that were not his, and staff that were well-meaning but not supportive of how he wanted to live his life.

After the meeting, Bob shared with a care manager his desire to have his own home. Together, they worked out a plan for a Community Supported Living agency to help Bob find a home that he leases and belongs to him. While he now gets assistance from a community living agency, there are no agency rules to follow, only his own. The assistance Bob and the agency identified together as important for him comes from family, friends, and neighbors of Bob, and from staff who understand the particular needs Bob may have, and embrace his desire to have a place that is truly his.

Bob is proud of the fact that the dream he first expressed at a self-advocacy group meeting is now a reality.



Community Supported Living agencies can help people have a home, maintain connections, and provide a variety of creative and flexible assistance.

JANET'S STORY

Janet continued to live at home with her mother and younger brother after graduating from high school. Janet's mother, Helen, used the funding available for Janet's support to find, organize, coordinate, and supervise a variety of paid assistance that Janet needed. Because Janet's impairments require extensive support for communication, mobility, and continued learning, Helen sometimes felt she was more of a care manager, human resource recruiter, and agency supervisor than a mom. She felt that her life, and Janet's, were becoming increasingly focused on Janet's need for support, and less on helping Janet create her own life as people tend to do at her age.

Helen learned about Community Supported Living agencies that could work in partnership with families and individuals to help people have a home that is their own, maintain connections with family and friends, and provide a variety of creative and flexible assistance.

Over a six-month period, Helen and Janet worked with the Community Supported Living agency to develop a plan for Janet to have a place of her own. Janet, Helen, and the agency looked at a number of places and found an apartment that Janet loves. The agency recruits, hires, and supports staff, including staff that Helen and Janet had previously hired. They help Janet manage her home, and help with the many aspects of life that originate from her home.

Helen says she is now "Just a mom" again. Janet values her involvement, as does the agency, but Helen now feels that Janet can and will do just fine when Helen heads south for the winter to spend time with her parents. "I love it when Janet proudly points at the map of Florida and lets me know I can leave any time!"

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