

Community Supported Living Within Family Care: Community Care of Central Wisconsin's Experience

Community Supported Living is a flexible partnership that enables a person needing support to live in *their own home* with support from an entity providing individualized assistance. It is an alliance between *a person*, and *an agency* whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own.

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Community Supported Living Within Family Care: CCCW's Experience is an updated version of one of a series of documents designed to broaden the understanding of Community Supported Living within Wisconsin. These documents are part of a process intended to result in a substantial increase in the number of Wisconsin citizens receiving long-term support who are able to receive that support in their own homes, for as long as they choose to live in those homes, in partnership with an agency that will arrange and support a variety of ongoing and needed assistance.

The primary purpose of this paper is to share the experience of one Family Care organization in exploring Community Supported Living as a cost-competitive option for people who would otherwise likely reside in nursing home, Community-Based Residential Facility or Adult Family Home. This version updates information from CCCW's original exploration of Community Supported Living, and revises the recommendations made in that November, 2011, paper based upon the rapidly emerging work on Community Supported Living throughout Wisconsin.

Family Care inherited a residential service system developed over the past fifty years and more by the State of Wisconsin and by Wisconsin's state-administered county-operated long-term care system. For most people who no longer lived with their families or who lived in their own homes before acquiring an impairment, the primary residential response in most counties was some type of institutional or community-based facility. In most of Wisconsin, Community Supported Living has not been offered until recently.

As Family Care expanded and IRIS was developed the use of facility-based residential services has been increasingly augmented by a variety of ways in which individuals are encouraged to remain in or return to their families or own homes by hiring their direct care workers directly. Until recently, however, there have been fewer resources dedicated to understanding and expanding Community Supported Living, a service provided by an agency as an alliance between a person who requires long term, publicly funded, organized assistance and an agency whose role is to arrange or provide whatever assistance is necessary for the person to live in a decent and secure home of the person's own.

Exploring Community Supported Living

In 2010, Community Care of Central Wisconsin (CCCW) began exploring whether Community Supported Living could be provided as a cost-competitive alternative to other residential services for people who desired to meet the long-term care outcome that is arguably the cornerstone of Wisconsin's long-term care system: *I choose where and with whom I live*. CCCW emerged in its pilot stages from the Portage County Human Service Department, an agency with a history and commitment to individualizing services both where people live and where people spend their day. Small residential services had been developing for many years as an alternative to institutional setting and larger CBRFs in Portage County. The county was also one of the few in Wisconsin to have encouraged and supported the agency transformation out of

community rehabilitation program facilities into more individualized and varied community employment, educational, and career building activities.

It was thus not a totally new approach for CCCW to explore the provision of Community Supported Living as another way to offer and tailor more personalized services to their members. Community Care of Portage County throughout the pilot from 2000-2008 provided opportunities for individuals to live in the community using an approach similar in some ways to Community Supported Living. The approach was to drop in Supportive Home Care hours in an individual home or 24 hour support from an agency into an individual's home or apartment.

This approach was not always sufficiently holistic to meet members' needs, and sometimes caused barriers in providing the most cost effective means of meeting an individual's outcomes. In 2010, CCCW partnered with *My Innovative Services, Inc.* (MIS), and began identifying a number of individuals who were or were likely to be living in nursing homes, CBRFs or Adult Family Homes. Those individuals were offered an alternative way to "Choose where and with whom to live." The basic features of that alternative were:

- People would have their own place, and would choose with whom to live in that place;
- People would have varied support from an agency to
 - Select where to live;
 - Obtain as much or as little support as needed, including access to support at any time of day as needed, and flexibility from day to day tailored specifically to how the individual's day is going;
 - Work together to identify needs, solve problems, and strengthen community connections;
- CCCW would expend, on average, a similar amount of funding for the individuals who chose this option as would have been expended in the residential settings they would otherwise have been placed within.

By August, 2013, 128 individuals, with a variety of support needs chose this option. They included people who were members as a result of infirmities related to aging, as well as people with developmental or physical disabilities. Many individuals were and are experiencing the need for support related to mental health, complex medical needs or behavioral challenges, and have found the personalized approach of Community Supported Living to be a positive factor in better responding to those challenges. Many of the individuals had previously lived in nursing homes, CBRFs and Adult Family Homes and wanted to return to their homes or live in a home of their own, which has most often been an apartment.

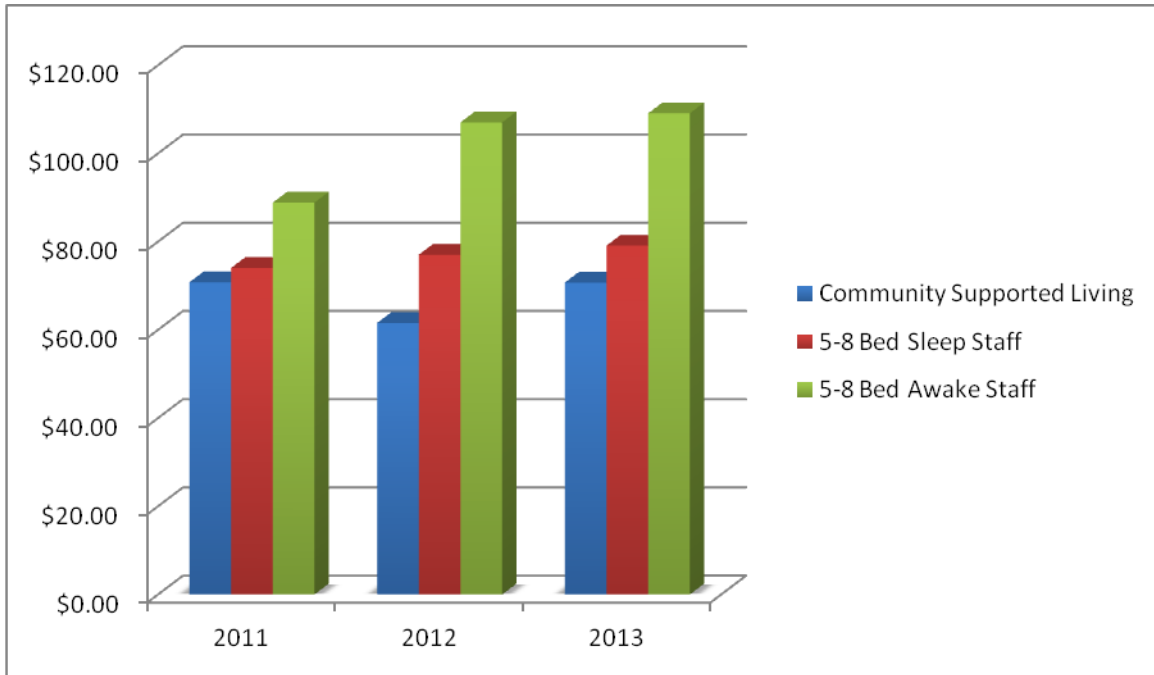
Summary of Outcomes

Overall, the outcomes described by the 128 individuals who chose this option, their families, and CCCW staff were positive, and often surprising. Individuals who had struggled in a variety of ways in residential facilities are thriving in apartments of their own, with more personalized, flexible and creative support. People have expressed their pride in being in or back in their own home; have relished the freedom and security that the right amount of support at the right times has provided; and have enjoyed the flexibility that allows them to live typical lives in their homes and communities.

For CCCW, the delight in helping people lead more fulfilling lives has been coupled with a hoped-for but not necessarily anticipated overall reduction of costs compared to the alternatives in which this cohort of members would otherwise have lived. Costs increased for some individuals, although in many of those situations costs have been reduced over time. For most people, residential costs went down. As a whole, CCCW spent less (see chart below) in helping this group of individuals achieve better and more fulfilling outcomes in where and how they live. Real lives, real homes, competitive costs.

The chart below shows that as of August, 2013, 128 members currently living in a home that is their own with services from a Community Supportive Living agency cost on average \$70.71/day. The same individuals living in a residential setting of 5-8 beds, with sleep staff at night would cost on average \$79.03/day. CCCW would have spent 11.8% more (\$391,500 annually) on the same individuals in this setting type instead of Community Supportive Living. The same individuals living in a residential setting of 5-8 beds, with awake staff at night would cost on average \$109.09/day. CCCW would have spent 54% more (\$1.79 million annually) on the same individuals in this setting type instead of Community Supportive Living.

Community Supported Living Daily Costs vs. Other Typically Used Residential Models



	Community Supported Living	5-8 Bed Sleep Staff	5-8 Bed Awake Staff
2011	\$70.77	\$74.03	\$88.84
2012	\$61.54	\$77.03	\$107.03
2013	\$70.71	\$79.09	\$109.09

What It Looks Like – The System Perspective

This exploration began in partnership with *My Innovative Services, Inc.*, a provider based in Green Bay¹ that provides a variety of residential and vocational services. MIS proposed to CCCW that they would offer up to 24 hour support to people in ways that would enable people to be in their own homes, and be and feel in charge of their own lives. Discussions between the two agencies focused on how to meet those desired personal outcomes while being cost-competitive with other residential services. The

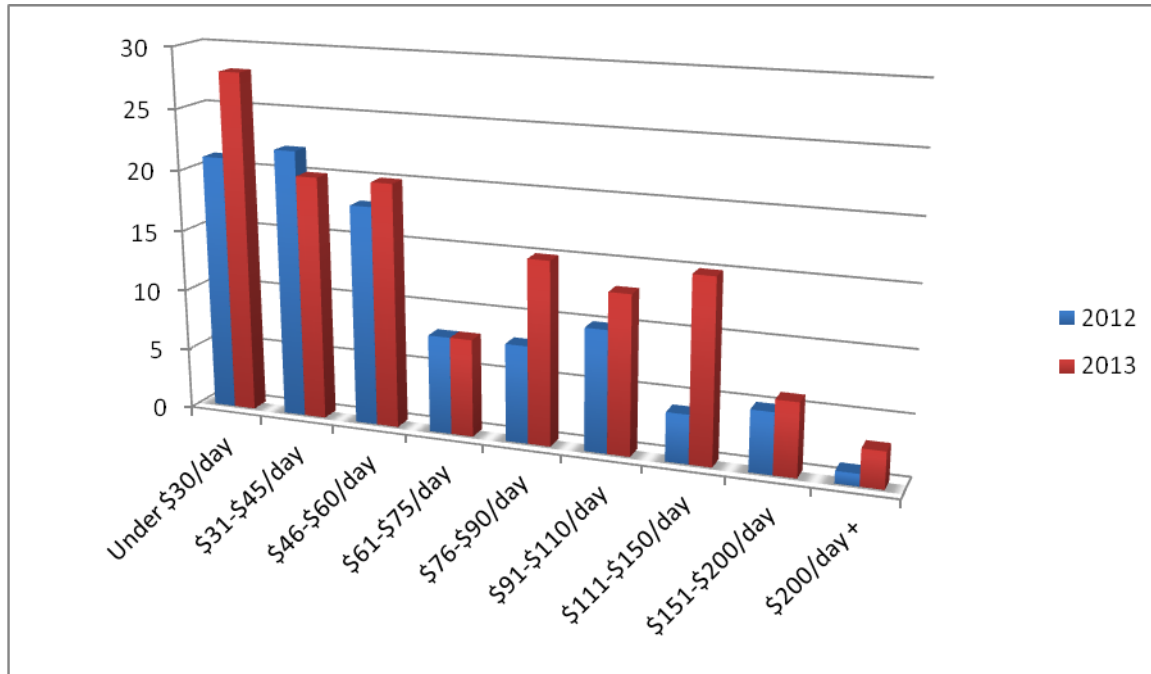
¹ See <http://www.myinnovativeservices.com/home>

structural principles and practices that have led to the success to date of this approach include:

- Individuals control or lease their own homes, with their own financial resources. MIS has worked successful with landlords in the Central Wisconsin Area to assure that the rent is within the means of the individuals choosing this option. There are times that a member's past legal concerns create a barrier for renting an apartment. During these times, creative options are explored from a trial with a landlord, to another person renting on behalf of a member (example: family member), with a last case model of MIS renting the apartment.
- Each person, along with their chosen allies, and support from their CCCW care management team and MIS staff identifies where and how they wish to live;
- MIS assists in helping people find places to live. For some individuals, this includes identifying apartment complexes in which MIS also rents a unit for staff, and for use by individuals on a short-term or crisis basis;
- The group of individuals offered the choice of Community Supported Living as part of this pilot live in relative geographical proximity to one another. While CCCW now covers five counties in central Wisconsin,² the initial group of 54 individuals live primarily in and around either Wisconsin Rapids, Stevens Point, or Wausau. The current group of 128 individuals live in Wisconsin Rapids, Stevens Point, Wausau, Marshfield, and Antigo. The overall physical proximity lends itself to the flexible manner in which staff can provide both routine, spontaneous, and crisis-related support; to being able to know and support local community connections; and as a result of both of those factors to provide support economically;
- The group of individuals offered the choice of Community Supported Living have diverse needs for support, ranging from relatively little to extensive and complex. This mix was important in order to learn what was possible in terms of costs and in learning if there are any limitations on who might be offered this option in the future; Daily rates range from \$3/day to over \$200/day as demonstrated in chart below:

² Portage, Wood, Marathon, Lincoln and Langlade

**Number of Members in Rate Bands
(2012 data based on 98 members
2013 data based on 128 members)**



- There is an extensive use of technology, which is typical of Community Supported Living as it has developed within Dane County and across Wisconsin. MIS partners with *Simply Home*³, a national provider of assistive technology and remote monitoring to monitor needs and assist individuals at the time assistance is needed. This approach addresses safety, health and security (other important outcomes in people’s lives), and does so in a way that respects and supports people to live without staff constantly present in their lives;
- CCCW and MIS have developed a trusting relationship that includes a flexible manner of paying for services. CCCW uses an acuity model in determining rates for members in residential settings. This model is used as a guide in determining the rate for the Community Supported Living model. MIS meets the individual and the team and talks about their desired long-term care outcomes. MIS then determines on average how many hours of support it will take to meet the individual’s outcomes. Based on that assessment a *daily rate* is determined, again using the acuity model for residential as a guide. The rates are flexible and

³ See <http://www.simply-home.com>

offer the ability to increase and decrease needed support at any time the individual's outcomes or needs change. There is also a mutual expectation that MIS will continually be working on reducing costs and improving quality whenever possible. While a cynical view would suggest that it is not in an agency's best financial interest to reduce their costs and thus their income, the working partnership and trust that comes from the member, the funder, and the provider working together in creating great outcomes at lower costs has been part of the formula for the success that has been achieved to date.

What it Feels Like – the Personal Perspective

The principles and practices we design are best understood and evaluated by looking at the lives of the people we support. In looking at the lives of the people who are part of this exploration of Community Supported Living, it is striking to see the number of people who go beyond being feeling “satisfied with services” to feeling in charge of their lives ... experiencing privacy, freedom, pride in being in or returning to one's own home. Individuals who by their own and by others' judgments were perceived to be struggling and unhappy in nursing homes, CBRFs and Adult Family Homes are by their own and others' judgments having fewer problems and are much happier in their own homes, with a different manner of support provided to meet their needs. As the Dalai Lama, among others, has suggested, happiness is a universally valued outcome. It is no small achievement in our service system to meet people's needs in a way that increases their chances to be happy.

Kelly⁴ was living in an Adult Family Home because of her intellectual disability and mental health needs. She showed her unhappiness where she used to live in a variety of ways, one of which was her refusal to take medications important to help maintain her mental health. Non-compliance is the term we typically use for such behavior, and it is not unusual for us to respond with behavioral plans to deal with that non-compliance within residential facilities. Listening to Kelly, however, led CCCW and MIS to take a counter-intuitive approach. Rather than increasing restrictions on Kelly within a residential setting that was not her own, Kelly was supported to have her own place, with support staff who live nearby, not with her. Kelly is no longer “non-compliant”, takes her medication, and has shown she needs less support from residential services and from the RN on her Care Management team.

Brad's teachers and family did not believe he could live in his own place after graduation, but would need an Adult Family Home or CBRF because of his need for medication to control seizures; his intellectual disability; and, his lack of “independent living skills.” They had not heard of the concept of Community Supported Living. Brad now receives support in his own apartment for an average of about 15 minutes a day. Staff are available nearby where Brad lives. His family and teachers have learned more

⁴ The individuals described in these stories have given permission for the stories to be shared and have asked that their privacy also be respected by using other names. Some of these personal perspective are a combination of similar situations.

about what Brad can do, and how Brad can live with the right support, in the right amount, provided in a flexible manner.

Albert is 93 years old and was living in a nursing home following surgery. He has a number of medical problems, and his wife (also in her 90s) and family were afraid he would not be able to return home because of the extensive personal care assistance he needs at this point in his life. Some of that care is relatively predictable in terms of scheduling, while other care needs are not so predictable (using the toilet, for example). When Albert is incontinent at night, a sensor informs staff to immediately come to the home and change his bedding and night clothes. The ability of an agency to combine routine and as needed support, both personal and through the use of technology, enables Albert and his wife to remain together in their own home, and to do so without the intrusiveness of staff living with them.

Ralph is in his fifties and has had several different physical or mental health diagnoses. He was unhappy living in a CBRF, feeling cut off from his family and not connected to the others who lived there in terms of shared interests. Despite being surrounded by other people, Ralph felt isolated and unhappy, while his guardian felt the CBRF was the best setting to attend to his physical and mental health needs.

CCCW and MIS discussed the option of Community Supported Living with Ralph and his guardian. They described how Ralph's special needs for assistance could be met in a manner in which his basic human needs for a home, relationships, autonomy, health, safety and security could all be met. Ralph now lives in his own apartment, closer to and more involved with his family, and receives support from MIS in managing his health care, shopping, taking care of his home, and staying connected with family, friends, and others in his community.

These short vignettes are an illustration of the relationship between the principles and practices of Community Supported Living, and the manner in which people typically respond when we pay at least as much attention to our universal needs for love, autonomy, a home that is our own, and relationships as we do to the particular needs that we address related to an impairment or combination of impairments. By no means are all 98 of the individuals who chose to learn with CCCW in this manner now leading idyllic lives with no particular problems. One of the challenges that Community Supported Living embraces is how hard it can be for any of us to deal with the complexities and difficulties that life presents. Those challenges are often amplified by having one or more significant physical, developmental or mental health impairments. Personalizing services through more deeply understanding and addressing basic human needs as well as disability related needs can help meet those challenges.

Continuing the Learning Within Community Care of Central Wisconsin

Community Care of Central Wisconsin has learned that Community Supported Living is a preferred, viable and cost-competitive option for its members. Overall, it has been less costly than other residential options that individuals would have utilized, and there is a strong consensus among CCCW staff and management that it has contributed towards

helping most members who have selected it to achieve a more fulfilling life, particularly in their homes and communities. It has also met an important test of attending to outcomes related to safety, security, stability and health.

What's next? CCCW is working towards creating a "Community Supported Living First" philosophy that will need to address a number of questions and learning opportunities identified to date, including:

1. Community Supported Living remains a relatively new concept in most parts of Wisconsin, not only to individuals, and families, but to Family Care and IRIS administrators and staff as well. Members and their families can't ask for and Care Managers or IRIS Consultants are unlikely to suggest supports and services of which they are unfamiliar. If people need paid support that they cannot or do not wish to purchase directly in their own home, or for a family member in their home, a common response is to suggest the person "needs" a nursing home, CBRF, or Adult Family Home.

When CCCW asked staff to list the biggest barriers to the choice of Community Supported Living, the most frequent response was the belief that the person needed too much support to live in their own home. Sometimes that belief came from a family member or guardian, sometimes from professionals - teachers, vocational service staff, care managers or RNs. Now being able to *show* individuals, families, administrators and professional staff how Community Supported Living can lead to more fulfilling lives at, on average, no more cost than more restrictive settings has been an important next step.

2. How do we enhance the efficiency and flexibility that helps Community Supported Living work with effective and creative policies and procedures related to what we pay for and how we pay for it?
3. CCCW is still learning how to best respond as members learn about and request support to live in their own homes in the manner that we are describing in this paper. It appears that for many people with complex needs and high cost support plans Community Supported Living leads to better outcomes at no more, and often less cost. It is likely and we would like to test to see if it is also a cost-effective option for those individuals whose support costs are among the highest within CCCW.
4. As members and their teams request the flexible agency support that we are describing in this paper in order to meet their desired outcomes of where and how to live, can CCCW respond to those requests wherever the member lives? The cost-competitiveness of Community Supported Living within CCCW has in part resulted from the relative proximity of members to one another. Will that continue to be a "pre-requisite" for who can be supported? Are there other ways in which CCCW might continue to explore the development of Community Supported Living that would support people across the five counties wherever people choose to live?

5. As members with low incomes choose to live in their own homes, housing costs can be a barrier. What are the possibilities to better assist people as that issue arises? Can Family Care offer flexible assistance in this area of “room and board” in a manner similar to how it has addressed this barrier for CBRFs and Adult Family Homes?
6. How might the current practice of Community Supported Living through *My Innovative Services*, or through future agencies that may provide this service for CCCW become even more responsive, flexible and personalized? What can be learned from other Community Supported Living agencies in Wisconsin and elsewhere? What can be learned by further listening to the individuals being served, their families, their care management teams about how best to provide the support people need and want to live in their own homes with needed support?
7. The appropriate use of technology is in its infancy. CCCW *will* continue to expand its exploration of technology options that expand the safety, security, and freedom of members while enhancing cost-effectiveness.

Continuing the Learning Within Wisconsin

Many, if not all of the issues that CCCW has identified as needing further attention were shared through a 2012 ad hoc Community Supported Living work group brought together through the leadership of the Board for People with Developmental Disabilities and the Wisconsin Department of Health Services. While DHS is reviewing how best to address the recommendations of that work group, Community Supported Living is increasingly being provided by other agencies and within other MCOs.

Community Care of Central Wisconsin has challenged itself and challenged other Wisconsin funders to explore whether it is possible to create affordable alternatives that will enhance their members’ personal fulfillment and enable their members to choose where and with whom to live. At a time when other primary “solutions” to concerns regarding residential services costs have been limited to increasing the size of facilities in which people are allowed to live, moving people to other settings, or reducing provider rates, rigorous learning about the costs and personal outcomes of various ways of providing residential services is timely. Community Supported Living is an option that is increasingly being understood as an integral part of that learning.

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