

**The *Short* Guide to Supported Living in Wisconsin
What It Is ... What It Is Not ... What It Might Become**



Supported Living is 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.*

September, 2011

Introduction

The *Short Guide to Supported Living in Wisconsin* is the 1st in a series of documents designed to broaden the understanding of Supported Living within our state. 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. The purpose of this *Short Guide* is simply to define Supported Living, distinguish it from other ways in which people receive support where they live, and describe its value to people in need of support and to the systems that support them.

Wisconsin's Family Care, IRIS and County Long-Term Care programs currently offer an empty promise for many people who are not offered the needed support to have a place that looks like, feels like, and *is* their own home. Supported Living is one way of providing that support for people who no longer live with a family member, or who are unable to independently hire and direct their own support staff.

Wisconsin's Department of Health Services (DHS) has offered direction and guidance to the managers and staff of Wisconsin's long-term care programs regarding the importance of people being able to decide where and with whom to live:¹

When people participate in human service systems, they often feel a loss of control over their lives as professionals or others in authority get involved. In our long-term care system we strive to empower program participants (members/consumers) to have choices—to have a "voice" or say about things that affect their quality of life and to make decisions as they are able ... The following statements reflect some of the ways in which the system can help support people to maintain control over their lives:

I decide where and with whom I live.

One of the most important and personally meaningful choices I can make is deciding where and with whom to live. This decision must acknowledge and support my individual needs and preferred lifestyle. My home environment has a significant effect on how I feel about myself and my sense of comfort and security.

Supported Living is an option that would enable many Family Care members and IRIS participants to obtain the needed support to live where and with whom they choose.

Beginning with a Supported Living Summit on October, 2010, *in Control Wisconsin* has been facilitating the development of a plan for the expansion of supported living (see Appendix). That plan was created by a diverse group of Wisconsin citizens representing individuals with disability; families; service providers; advocates; DHS; Family Care; Dane County; and IRIS. The full report from the October, 2011, Supported living Summit, is available at the inControl Wisconsin web site, www.incontrolwisconsin.org by searching within *Supported Living* under *What We Do*.

The *Short Guide to Supported Living in Wisconsin* incorporates several element of this plan, particularly in describing what it is, what it is not, and what it might become in Wisconsin. The word *Short*

¹ From *Member Outcomes in Family Care and Partnership*. Wisconsin DHS. March 18, 2010

emphasizes that this guide is an overview. It is the first of several documents that will describe the opportunities of and challenges to providing supported living in greater detail.

What It Is ...

Supported Living has a long history in Wisconsin, long at least within the context of what is really only a half century of bureaucratically organized and funded community services for people with long-term care needs. *Options in Community Living* in Madison is sometimes referred to as the *Grandmother* of Supported Living in the United States. Yet, despite this 30 year history within Wisconsin, you will find no definition or description of Supported Living within the service taxonomies of what can be funded through Wisconsin's County, Family Care, or IRIS programs.

What, then, is Supported Living? John O'Brien described it well in 1993², and taking slight liberties with that description, we propose a common definition of Supported Living to be used in Wisconsin and elsewhere:

Supported Living is 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.

This simple yet elegant definition highlights three essential features of Supported Living that distinguish it from the many other ways people who receive long term care in Wisconsin call home:

- The phrase *home of the person's own* emphasizes that people who receive Supported Living own or lease their home. The home "belongs" to the person, not to a service provider. The importance of that characteristic cannot be overstated;
- The role of the agency is "... *to arrange or provide whatever assistance is necessary.*" This emphasis differentiates Supported Living from other important ways people have organized assistance within their own homes. Thousands of people in Wisconsin currently hire support staff directly; with the assistance of a co-employment agency; or, through an employee leasing agency. These three important ways of helping people live in their own homes limit the role of an agency, if an agency is used at all, to finding; hiring; paying; and, in some situations training direct support staff. In contrast, ***Supported Living*** provides an additional variety of organized assistance to support people with the assistance they may need, some of which is routine and occasional, some of which is complex, ongoing and creative in addressing needs that may be present on a continual basis;
- Highlighting that people in need of support are in *an alliance* with an agency stresses the relational aspect of Supported Living, a relationship that requires co-operation rather than control on the part of either party.

Within Wisconsin there are a growing number of agencies that provide only Supported Living. A number of other service agencies offer Supported Living as an option within the array of services they provide, and a growing number of funders and agencies are now engaged in learning how to provide Supported Living, as part of the initiative that began with last October's Supported Living Summit. A

² John O'Brien. *Supported Living: What's the Difference?* Responsive Systems Associates, Inc. 1993.

resource list of those agencies is being compiled and will be published and updated on the inControl Wisconsin web site.

Throughout the world, Supported Living has emerged as a way of providing support and services that are cost-competitive compared to facility-based models of what are typically referred to as residential services. Within the United States and Canada supported living agencies are proliferating. Beyond North America, the interest and learning around Supported Living is growing as well. TASH, an international advocacy organization, is currently focusing on the development of Supported Living as an essential service element if government systems are to support people to have fulfilling lives as members of their communities. International conferences have been created³ that focus on Supported Living. There are families and individuals, particularly in Australia, who have worked together to create small Supported Living services, often in co-operation with a “hosting” service agency. That work will be a focus of a subsequent paper within this Supported Living series. All of these initiatives will inform our continuing work in Wisconsin.

What It Is Not ...

There are a large number of places in which people live while receiving public funding to meet long-term care needs. They range from places that are distinctly unhome-like, to those that are indistinguishable from the houses, apartments and condominiums that Wisconsin citizens typically call home. The following two tables list and briefly describe those places:

Table 1: Places Owned or Leased by State, County, or Agency

Places Owned or Leased by State, County, or Agency: License or Certification Required	# of People Who Receive Services	Control of Place, Who Lives in Place, Who Works in Place
State Center for People with DD	No size limit	Facility
Other ICF-MR (DD)	No size limit	Facility
Nursing Home (Elderly, PD,DD)	No size limit	Facility
Residential Care Apartment Complex	No size limit	Facility
Community-Based Residential Facility	5-8 people	Facility
Community-Based Residential Facility	9 or more people	Facility
Licensed Corporate Adult Family Home	3-4 People	Facility

³ A May, 2007, international week-long event in Ashville, North Carolina was sponsored by the North Carolina DD Council and was created around the learning of 8 agencies that had transformed to provide only individualized supports; an international event on individualizing services with a particular focus on Supported Living was conducted in September, 2011, in San Francisco with enthusiastic representation from seven countries.

Certified Corporate Adult Family Home	1-2 People	Facility
Certified Owner-Occupied Adult Family Home	1-2 People	Facility

The places in Table 1 are licensed or certified. They are owned by and belong to an agency. *They do not belong to the person⁴ receiving support or services.* The facility decides whether or not to admit or discharge the person; decides where in the facility the person sleeps and keeps personal possessions; and hires staff. The facility owner or manager, typically in response to policies and rules related to funding, licensing or certification, sets and administers rules governing the setting. These are not places in which Supported Living is provided.

Table 2: Places Owned or Leased by a Person Receiving Support

Places Owned or Leased by a Person Receiving Support: No License or Certification Required	# of People Who Receive Services	Control of Place, Who Lives in Place, Who Works in Place
Own home or living with Family: no paid support		Person or family
Own home or living with Family: Hire staff directly, pay payroll taxes and perform other employer duties	Typically 1-2 people	Person or family control place, who lives there, who works there
Employee Leasing: Agency provides staff but not additional ongoing support and assistance to people living in own home or home of family	Typically 1-2 people	Person or family control place and who lives there: Agency typically controls who works there, with input from person
Co-Employment: Own home or living with Family: Hire staff through an Agency	Typically 1-2 people	Person or family control place, who lives there, and who works there

This second table is a list of places in which the person (or others authorized to make legal decisions for a person) owns or leases the home. Supported Living, as noted below, is similar in many ways to the places in Table 2, but is also significantly different:

Supported Living:	Typically 1-3	Person or family hold lease
-------------------	---------------	-----------------------------

⁴ All references to a “person” throughout this document recognize that some people have individuals who are authorized to assist in decision-making through such mechanisms as power of attorney or guardianship.

Agency provides ongoing support and assistance to person beyond providing direct support workers. Support can be occasional, and up to “24/7”	people	or mortgage and control who lives there. Agency, person, family typically determine who works there
---	--------	---

The person chooses where to live, not an agency. There are no admission or discharge criteria. There are no agency rules governing personal possessions, decorations, privacy, and more. Supported Living is distinguished from the other four types of places within Table 2 by the *additional flexible, creative and needed assistance* Supported Living agencies provide *beyond* the hiring and sometimes training of supported home care or personal care staff.

An Illustration ...

The following story⁵ illustrates how Supported Living differs from the facilities listed within Table 1, and the other important ways listed in Table 2 in which people are supported to live in their own homes:

In 1998 I volunteered for a recreation program in which I was paired with a man named John. John lived in a group home. He had Down Syndrome and hip dysplasia. John was a very interesting and very troubled man. The other three people who lived in this group home seemed comfortable there. John, on the other hand, alternated between being compliant and rebellious. He began a period of self-induced vomiting and was hospitalized to deal with the behavior. After his release from the hospital the group home said it could no longer support him and he was placed at a county nursing home.

Several months later two people from Neighborhood Connections, an agency that provides Supported Living for people with disabilities, met with John several times and began a process of helping him move out of the county nursing home and into a place of his own. A man was hired to live with John and provide support. Together this staff person and John, with support from the agency, found an apartment in which to live.

However, everything did not get suddenly better for John. The hired roommate had another job and was gone most days. John had a vocational services provider but refused the job opportunities offered him. He was alone a lot of the time. He felt abandoned by his mother who had moved from the area, by his group home who refused to take him back, and now by his roommate who was overwhelmed by John’s anger and could not effectively break through. The paid roommate began to stay in his bedroom while John raged alone. John covered the walls of the apartment with thrown food and continued to vomit. His hip problems worsened. His teeth deteriorated because of the vomiting. He and those around him shared a sense of despair.

⁵ The direct support person who wrote this story chose to respect the long-time friendship he describes by using a different name for the person he supports.

As someone who knew John socially I was hired by Neighborhood Connections to provide respite for the paid roommate, working one evening a week and every other weekend. My orientation towards the work was conventionally liberal and paternalistic, I was the able one helping the disabled one. Our pattern from our association in the recreational program was for me to suggest activities and for John to choose among them. We continued this pattern, I would usually call before my time with him to propose activities. He would choose. We would then do the activity he chose when we were together.

The turning point in our relationship and perhaps in our lives was when John began calling me. The narrow purpose of his calls was to check on when I would be there and what we could do when I arrived. But those first calls signaled John reaching out, looking forward, beginning to assert some control over his life. And it seemed I was the one he chose to reach out to.

It is twenty years later and John and I are still together. Even after years of being with John much of everyday, he still calls me daily. These calls are almost as important as our actual time together. They still serve the planning function, but they also allow him to vent if something is not right, to sing, to talk about “Days of Our Lives” and generally to stay connected.

Looking back, I think John’s group home imposed too many institutional restrictions over money, food and schedule. John was and is too fiercely independent for that. On the other hand, his early time with Neighborhood Connections suffered from inadequate support ... too much time alone, too little structure. *Perhaps* that was a necessary period for us to get to know him better, to clear the way for a new way of living, to evolve in that new way where John started to acknowledge a need for support, and John began to shape that support in a way that was helpful to him without being restrictive.

At the same time we caregivers rebuilt our patterns and our ideas of supporting John. John wanted to shop. We shopped the second hand stores every day with as much money as he could afford. He wanted to go to McDonalds every day. We went to McDonalds every day. He wanted to go to the park for a picnic every day. We had a picnic every day. The question for us caregivers, if there should have been one at all, was why not? If his choices seemed unwise (too much junk food), wasteful (buying the same kinds of things over and over), or inappropriate (dumpster diving), I let him know my opinions. In spite of my efforts to steer him however, John had the ultimate say. Once his intentions were clear, my goal was to help them be realized.

It has been twenty years since the pivotal changes in John’s life. I wish I could say that our time together is easy and harmonious. Some days are like that. Some are impossible and I wait for them to end. But each day is one more in a long string of days with consistent and reliable support from me and from Neighborhood Connections. And each day, John expects and deserves just that.

John had lived in two kinds of the places listed in Table 1, places that were not his own. As the story described, John is fiercely independent, like most American citizens. And, like most American citizens, John wants to live in his own home, not in someone else's.

John also needs support, more support than he can muster through his own resources. John did not have a family member available and willing to take the lead in obtaining the type of support described in Table 2 that would have allowed him to live in his own home and direct the support needed to do so. Connecting John to a Supported Living agency has allowed him to have a home that is his own, a life that is his own.

This very brief story also suggests what all agencies that thoughtfully provide Supported Living have learned. Helping people to live in their own homes takes skill, integrity, flexibility, creativity, and a need to continually listen to and learn from and with those we support. It includes enabling people to hold the lease, or increasingly the mortgage, and it is so much more. That "so much more" will be the focus of subsequent papers in this series on Supported Living, and is also well-described in the paper by John O'Brien cited earlier (see footnote number 2).

What Supported Living Might Become ...

Supported Living has the potential to be the primary, cost-competitive option within IRIS, Family Care and our current County programs for people who share the typical American desire to live in a home of their own rather than in a facility or someone else's home (the Places in Table 1). It also has the potential to be a permanent and sustainable alternative for individuals whose family members are now actively involved in the hiring or leasing of staff to come into their own home (the Places in Table 2 other than Supported Living).

Subsequent documents in this series will highlight the way in which Supported Living has been a cost-competitive manner of helping people live in their own homes within Family Care; describe how Supported Living agencies have been created and sustained by families; share stories of Supported Living throughout Wisconsin; and describe in more detail how Supported Living "works" to provide flexible and needed support, creativity, security and stability in people's lives.

Supported Living is a valuable, underutilized, cost-effective option that is little understood by most funders, service agencies, schools, and individuals and families in need of long-term support. As those who rely upon services, inform others about services, provide services, and fund services better understand the nature of Supported Living, *it might become* a familiar and powerful way that individuals and families who wish to decide where to live, and with whom to live partner with agencies to obtain the support they need to do so.

Thanks to Sue Helgeson, who is living in her own home, in a partnership with a Supported Living agency, and whose picture on the cover page more than replaces 1000 additional words I could have written describing Supported Living.

Appendix

Self-Directed Supports and Supported Living in Wisconsin

inControl Wisconsin is facilitating the plan for the development and expansion of supported living that was developed in late 2010 by a diverse group of Wisconsin citizens representing individuals with disability; families; service providers; advocates; DHS, several Family Care agencies; Dane County; and IRIS. This plan is designed to enable Wisconsin citizens who need long-term support to have the option of having their own place to live, with needed support.

The *minimum* elements of this plan include:

- A “common language” describing Supported Living ... what it is ... what it is not;
- A written plan to increase the understanding and utilization of Supported Living as a cost-competitive alternative within IRIS and Family Care;
- A description of how supported living has been used to reduce costs and enhance personal outcomes within Family Care;
- Specific stories that illustrate the personal and systems benefits of and cost-competitiveness of Supported Living compared to facility-based residential services;
- Since Supported Living does not rely on buildings and does not have DHS funding and reporting codes, development of multiple strategies to increase its visibility;
- Strategies and learning opportunities for current agencies to transform facility-based residential services to supported living opportunities;
- A training template on Supported Living development and implementation strategies that include:
 - Starting with community rather than services
 - Importance of family and friends
 - Practical ideas on how natural supports can work
 - Specific training for MCO care managers and for IRIS staff
 - Adding more tools to the Supported Living tool box, such as:
 - Bartering
 - Time banks
 - On call support
 - Sound response
 - Sensors for falls, incontinence
 - Other technologies
- A template for program evaluation and learning about Supported Living;
- An “unofficial registry” and description of current Supported Living agencies in Wisconsin;

- A description of how Supported Living effectively works towards safety, stability and security in people's lives through:
 - Clear attention to risk
 - Back-up systems
 - Technology responses (e.g., sound response)
 - Education on the “dignity of risk” and clarity that the concept does not include “abandonment”

- A description of how individuals receiving support and families have developed their own “agencies” to provide supported living.