



BUILDING ON THE DANE COUNTY DIFFERENCE

Developmental Disabilities Coalition
Waisman Center
Dane County Human Service Department
Support Broker Coalition
Developmental Disabilities Coalition
Living Our Visions
InControl Wisconsin



Introduction


Dane County has a unique and highly effective approach for providing long term support to its citizens, particularly those with developmental disabilities. The innovative features and positive outcomes of this approach include:

- the **highest employment rate** for people with developmental disabilities of any county in the U.S.;
- a **very high proportion of people with developmental disabilities living in small homes and apartments** (including a sizable number of homeowners with disabilities);
- a **very low rate of public or private institution utilization**;
- a **highly individualized** (and often creative) **way of planning** and implementing both the transition from the children’s system and the provision of ongoing supports for people;
- **strong collaborative relationships** between county government, provider agencies, Dane County high schools, hundreds of employers, and the Department of Vocational Rehabilitation (DVR);
- an overall **system-wide commitment** to support people to have a variety of connections to community life;
- the **highest proportion of people choosing to self-direct** their services of any county in Wisconsin; and
- a **well-trained direct care workforce** with higher wages than most other parts of the state.

In addition to benefiting people with disabilities, these features and outcomes have also resulted in Dane County being highly congruent with the Olmstead provisions of the ADA, and with recent Centers for Medicare and Medicaid (CMS) rules which require that people served “live lives with the same access to community and citizenship as anyone else.” Dane County is also well-positioned for the implementation of WIOA (Workforce Innovation and Opportunity Act), which provides young adults the right to access real jobs.

There are some clearly identifiable underlying causes for Dane's success:

- Over many years Dane County has developed a very consumer-friendly approach to self-direction, which has led many consumers and families to express a strong preference for this way of engaging the service system.
- There is a pervasive commitment to helping people establish community connections, which includes county government, provider agencies, support brokers, families, and people with disabilities themselves.
- Dane County has a strong commitment to cost effectiveness, and achieves this with a variety of innovative strategies.
- The key players in the Dane County system have consistently endeavored to engage the whole person, not just his/her direct service needs, behaviors, or health issues.
- A number of agencies and systems have joined forces to successfully address the challenge of providing affordable and accessible transportation.
- Lastly, over the years, the Wisconsin Department of Health Services has provided flexible funding and other support to enable Dane county to explore new ideas, pilot innovative projects, and provide leading-edge training for human service workers, people with disabilities, and their families.



THE PURPOSE OF THIS PAPER IS TO POINT OUT THE UNIQUE FEATURES AND OUTCOMES OF THE DANE COUNTY LONG TERM SUPPORT SYSTEM, TO CLEARLY IDENTIFY AND EXPLAIN THE CAUSE-AND-EFFECT DYNAMICS WHICH UNDERLIE DANE'S SUCCESS, AND TO RAISE IMPORTANT QUESTIONS TO BE ADDRESSED BY KEY STAKEHOLDERS AND THE STATE OF WISCONSIN DURING THE PERIOD LEADING UP TO DANE'S TRANSITION TO FAMILY CARE AND IRIS IN 2018.



A Foundational Commitment to Community Connections

In 1984, a work group convened by the then Dane County Unified Services Board looked back at 10 years of services to people with developmental disabilities. Out of this reflection came a commitment to promote both the physical integration and social inclusion of all persons served into the daily life of their communities. That commitment is not dissimilar to what is found in mission statements of most long-term care organizations in Wisconsin and across the United States. What

distinguishes Dane County from most other organizations is *the extent to which that commitment serves as the foundation for all services and supports to citizens with developmental disabilities.*

Community inclusion of people who have been and still are often distanced from our communities has required two closely related strategies:

- Individualizing Supports and Services
- Deliberately Developing Community Connections

Both require a diligent practice to do the hard work towards enabling *every person* served to have the opportunities to be and be seen as a *valued citizen, neighbor and co-worker*. First, individualization creates services and supports that are unique to each person, not based upon people living in group homes or spending one's day in specialized facilities. Peoples' chances to live like anyone else in the community increase when people live and work as much as possible like anyone else in community. The different service and support elements based upon this strategy will be discussed in more detail in other sections of this paper. It is essential, however, to understand that the commitment to return all people from institutions and to focus on individualizing services for *every person* is the foundation upon which the stories of community are built. John O'Brien describes this eloquently within *Social Innovation: The Dane County Difference*:¹

Living in a home of one's own, learning things that matter in diverse and inclusive groups, contributing through a paid job and the choice of community roles: healthy communities strive to offer all citizens these opportunities. In far too many places, citizens with developmental disabilities do not experience these benefits because people mistakenly believe these opportunities are impossible or undesirable. A history of low expectations and exclusion from ordinary community life channels people with developmental disabilities into sharing their roof with a group of other labeled people they didn't choose to live with and deprives neighborhoods, schools and community employers of their contributions.

¹ http://cow.waisman.wisc.edu/Documents/Social_Innovation-The-Dane-County-Difference.pdf

The second strategy, deliberately developing community connections, cannot occur without individualization. Living in one's own home, working at the UW Kohl Center, and volunteering at Habitat for Humanity go a long way towards being perceived as a neighbor, coworker and valued citizen. But, Dane County has found that more is needed to overcome the historic perception of difference and distance that may result from impairment and disability.



The deliberate investment in developing community connections is an inherently cost-effective strategy to address that need. The system can pay direct care staff to take a person to a religious service each week, or it can focus on developing connections and find that most often members of the church, synagogue, temple or mosque will respond positively to being asked if they would be willing to assist another member to be able to attend their place of worship. While creating connections requires on-going support and coordination, this often lessens over time.

This process of deliberately developing community connections needs to be learned and supported. Dane County now has more than three decades of trial and error in building these connections, and continues to learn, as described in the two examples below:

1. **Options in Community Living** has provided Supported Living for more than 35 years, tailoring support to enable people to live in their own homes. Early on, Options emphasized the need to enhance community connections, creating learning and expectations across all staff positions to emphasize developing such connections. This emphasis remains but has been augmented by adding a Community Builder position to both assist in the learning and create connections that are not always so easy to create. More recently, the value of this work has been recognized by VISTA, which has funded an additional position.
2. A similar effort has been led by **Living Our Visions (LOV)**, a grassroots organization of more than 300 families with an average of 130 families actively engaged in specific projects at any given time. One of LOV's successes has been a Bridge Builder Project in which families pooled resources to hire two community organizers to augment families' attempts to create connections themselves. Individuals supported through this project are now active in more than 40 community organizations, and increasingly playing meaningful roles in their communities.

Other intentional community building efforts exist throughout Dane County. For example, the local TimeBank has dedicated a staff to helping people with developmental disabilities in Madison and Sun Prairie access mutual exchanges with community members. Community Groundworks, an organization devoted to connecting people to nature and local food, facilitates "Gardening for Good", an integrated gardening initiative at Troy Gardens on Madison's north side. United Cerebral Palsy, the County's largest respite provider, has embedded a community builder in Stoughton, Cross Plains, and Mazomanie to more intentionally engage individuals in their local communities while simultaneously providing family care takers a much needed break.

Individualizing supports and services, and deliberately developing community connections are essential elements of Dane County’s systemic, on-going effort to enable all people to be and to be perceived as valued citizens within their communities.

Dane’s Unique Approach to Self-Direction

In 1996, with the support and encouragement of Wisconsin-DHS, Dane County applied for and received a grant from the Robert Wood Johnson Foundation to pilot self-directed services. Dane County was one of three pioneering Wisconsin counties among 100 different sites across 29 states. Upon successful completion of this pilot, Dane County embarked on the effort to reorganize its supports for adults with developmental disabilities, embracing the principles of self-determination. From 1998 through December 2004, Dane County transitioned 1,100 adults to self-directed services. Today nearly 1400 individuals with developmental disabilities direct their own support with assistance from their chosen support team. They employ 92 support brokers from six broker agencies. Self-directed services in Dane County provide individuals:

- budget authority over their individualized rate;
- authority to either hire their own support workers or contract with an agency of their choosing;
- the ability to interview and hire an *independent* support broker that is either a full-time professional, friend, or family member; and
- a County contracted safety net of “public” services available as needed in times of life transition or behavioral or physical health challenges.



Prior to the introduction of self-directed supports (SDS), County staff, parents, schools, providers, and the community shared a “whatever it takes” attitude. Since the early 1980’s, Dane County embraced integrated employment and community-based supported living, as well as a variety of supplemental supports designed to ensure everyone can live and work successfully in the community. Before and after SDS, Dane County prioritized employment first and for all. It remains a shared expectation of individuals, families, schools, County, the local office of Department of Vocational Rehabilitation (DVR), and other allies that young adults leave high school with paid employment and that working age adults use their individualized rate to purchase the assistance needed to maintain integrated employment. Individuals with additional needs purchase assistance such as community building and respite or supported living services.

Given a strong network of local providers and rich history of provider-led social change, a foundational belief in Dane County’s SDS implementation was “professionals become partners with the people who hire them. They assist people in understanding what their choices are and realizing their dreams.” That said the onset of SDS was not an excuse to preserve the status quo. SDS resulted in a number of positive changes and philosophical shifts. People with disabilities assisted by their allies:

- became purchasers of individualized supports rather than recipients of assigned services;
- had support to access needed help, regardless of their expertise in such areas as money management and budget development;
- learned to interview and hire independent support brokers of their choosing rather than accept the assignment of a case manager employed by their supported living or vocational agency;
- pooled resources to accomplish more together than they could individually; and
- invented supports that did not previously exist.

Since the onset of SDS, the support broker role has evolved significantly. Case managers who formerly directed a person’s life have become brokers of support services. For more than fifteen years, individuals have consistently encouraged their brokers, who are now free from the conflict of working for a provider agency, to help them “shop” for goods and services. Brokers now routinely advocate for jobs that pay well, are enjoyable, and match a person’s skills. When desired, brokers arrange the help necessary for individuals to start their own business. If an individual is dissatisfied with their living arrangement – too far away from work, not a good roommate, or not a good provider – the broker can help the person shop for an alternative. When a person wants to hire their own staff the broker connects the individual to a fiscal employer agent. If a broker is unresponsive, the individual replaces them.

The transition to SDS has improved person-centered practices, resulted in better individualized planning, and brought about a deeper understanding of each individual. By understanding that a person’s life, wants, needs, and desires are continually changing, brokers have become strong advocates, searching for the best supports to meet a person’s needs throughout the lifespan. When existing supports are not enough, the individual, their support broker, and allies collaborate to locate or invent new ones.

Since the introduction of self-directed services, new provider agencies and entirely new forms of support have emerged. These include:

	<p>A Micro-Enterprise and Self Employment Program designed to help entrepreneurs succeed at small business ownership</p> <p>Encore Studio for the Performing Arts, a professional theatre company consisting of actors with disabilities</p> <p>ArtWorking, a studio designed to support artists with disabilities participate in the mainstream art and business communities</p>	<p>Night Owl Support Systems, a technology monitoring system aimed at enhancing independence and ensuring safety</p> <p>Living Our Visions, a family-led, family-governed, grassroots organization building fulfilling and community-centered lives</p> <p>Increased community connecting initiatives through a local respite provider, TimeBank, and a community garden</p>
--	--	---

Two residential agencies, unresponsive to people’s needs, closed their doors in Dane County due to loss of business. New providers have formed to fill the gap.

A guiding principle of SDS in Dane County is that “it is not acceptable to offer a “choice” of either excessive restrictions or no support at all. Self-determination means becoming more creative in helping people find ways to learn decision-making and manage their actions.”² In addition to spawning the innovation noted above, it drove Dane County to develop an array of supports considered “Public Services”, available to all when people need them. The County contracts for these services outside of people’s individualized SDS rates. This shared infrastructure is described on page 10.



Value, Cost Effectiveness, and Continuous Innovation

Attention to value and cost is an essential element of Dane County’s history of continually improving and sustaining services to people with developmental disabilities. The fiscal challenges inherent in the delivery of services to people who experience developmental disabilities has required Dane County to examine innovation and evolution

of services – not only in terms of the value they add to the lives of individuals served, but also to their affordability. Fortunately, these two requirements align with one another more often than not.

Dane County’s particular fiscal challenges result from several factors. Many are related to the higher cost of living for all Dane County citizens compared to the Wisconsin average.³

- Dane County’s overall cost of living is 8% higher than the Wisconsin average;
- its housing costs are 23% higher;
- 3% unemployment is half the state average; and
- while direct care wages are not measured specifically across Wisconsin, it is clear that the combination of the Dane County Board’s living wage requirement and the county’s low unemployment make this important cost-factor in long-term care significantly higher than in other localities.

Dane County services to people with developmental disabilities have unique fiscal challenges stemming both from its history and location, and from its success and reputation. Early leadership in school inclusion, support to people with behavior challenges, supported employment, and supported living resulted in families relocating to Dane County from other parts of Wisconsin and the United States, increasing the number of people in need of support from limited state and county funding.

The physical location of Central Wisconsin Center and Mendota Mental Health Institute, three large, former ICF-MR facilities (Allen Hall, Lakeshore Manor and Orchard Hill), and several nursing homes which had been utilized by the state in the first wave of deinstitutionalization from the State Centers contributed to Dane

² https://danecountyhumanservices.org/dd/dox/implement_choice.pdf

³ 2015 Data from the Council for Community and Economic Research, c2er.org.

County being responsible for more than 400 people living in institutions by 1984. While Dane County's leadership in enabling the return all of those individuals⁴ to have the opportunity to live valued lives in their communities has created a significant savings to Wisconsin's Medicaid program, Medicaid reimbursements for those individuals has fallen well short of the cumulative cost of their needs for support.

Over the past three decades, state funding has gotten tighter, and discretionary funding from county tax levy has been reduced. Dane County's response to these challenges has been to continually seek and create system efficiencies that both reduce cost and add value to people's lives. Both strategies are essential. These cost-efficiencies build upon and interact with one another.

The foundational innovations for Dane County can be seen within five broad categories:

- 1. The opportunity for everyone to live in community as a neighbor and citizen**
- 2. The opportunity for everyone to live in their own home**
- 3. The opportunity for everyone to work or engage in creating income**
- 4. The opportunity for all people and their families to have the responsibility and right to self-direct the use of public funds**
- 5. An understanding that these outcomes require assistance from a variety of other services and supports if they are to be achieved**



Within each of these interrelated categories, Dane County's service system has learned, adapted, and evolved in order to better support these desired outcomes, and to provide the cost efficiencies to sustain them and add to them. The five opportunities listed above are in themselves substantial innovations and are described in more detail within other sections of this paper. They have been augmented and supported by a variety of specialized services and intentional

community building strategies that are available to all individuals who receive support. These innovations are summarized below:

Investing in the learning required to replace paid services with unpaid community connections. Many individuals served within Dane County's developmental services system have friends and acquaintances who accompany them to community activities without the presence of paid staff. This outcome is intentional, teachable, and challenging, and does require an ongoing investment that pays off both in reduced cost and richer lives.

Dramatically reducing the use of licensed group living (both CBRFs and AFHs) and replacing them with home ownership; supporting families to help family members live in their own home with minimal paid support; and

⁴ Currently 35 people live at State Centers whose guardians continue to reject the offer of community service. All others returned to receive support and services in the community.

promoting Supported Living which tailors support to the unique needs of each person in the person’s own home, often with a housemate.

Dramatically reducing the use of community rehabilitation facilities for work and day activities by creating partnerships with schools to build expectations for post school employment; incentivizing employment for those individuals who leave school with a job; learning to help people develop microenterprises; investing in helping employment agencies reduce paid staff hours by learning how to “fade” paid support, how to connect with businesses (now over 900 of them), and help businesses as much as possible provide what is often referred to as unpaid natural support.

Creating one of the most comprehensive and effective Self-Directed Supports systems in the country, enabling all people and their families to self-direct the use of public funds with the assistance of a chosen Support Broker, an effective Fiscal Employment Agency, and a system of important supports (including all those described below) to all people outside of their individualized SDS allocation.

Developing a shared infrastructure described on page 10 of extra help, available to individuals as needed.

These supports *and more* flow from the commitment to, as the new CMS rule would put it, “Ensure the individual receives services in a community to the same degree of access as individuals not receiving Medicaid Home and Community-Based Services.” They are designed to implement these values affordably and sustainably, recognizing that for some people, having that “same access to community as individuals not receiving Medicaid Home and Community-Based Services” will be more costly than alternatives which segregate, congregate, and isolate.



All of these cost efficiencies are of great benefit to the individual served and to the taxpayer, but many of the cost benefits are not accrued by the Dane County Developmental Services system. The large decrease in costs achieved by Dane County’s radical reduction of institutionalization benefit the State Medicaid program, while the CIP program funding for people’s return to the community are insufficient to meet people’s needs without augmentation by county funding. Reductions in medical costs, ER visits, and police involvement have a financial benefit to other systems in addition to the primary impact on strengthening people’s health and well-being while reducing trauma. Reducing the use of mental health facilities and returning people with developmental disabilities from them saves money for the County Mental Health system, but increases costs to the Developmental Disabilities Services System.

The many partners who have worked together to develop the Dane County system stand ready to work with IRIS and Family Care to integrate the strengths of those programs in order to sustain and add to the value and cost effectiveness that Dane County has achieved.

A Shared Infrastructure of Public Services

Sometimes people need extra help to successfully live and work in the community. Dane County contracts with organizations for a number of specialized services and community building activities that exist outside of a person's individualized budget and are available as needed to all who receive support.

Organizations and programs that comprise Dane County's safety net include:

Progressive Community Services

- **Transition Coordinator** Assigned to work with young adults in their last year of school who are not enrolled in children's long-term support services. Work with individual, their family, school staff and DVR to coordinate a smooth transition to adult services.
- **Supported Self-Employment** Planning and technical assistance to develop small businesses and micro-enterprises. A funding partnership with DVR.
- **Partners with Business (PWB)** technical assistance to empower businesses to provide a highly cost effective alternative to traditional supported employment.

United Cerebral Palsy Intensive, time limited assessment and planning for individuals entering adult services in a time of crisis or from an institutional setting or rehabilitation facility.

Waisman Center

- **Community TIES** Short-term and on-going behavioral consultation and support.
- **DD Informed Psychiatry** Specialized psychiatry for people requiring unique accommodations, reducing costly use of mental health facilities.
- **Crisis Response** Intense, coordinated, rapid response to individuals at risk of hospitalization, institutionalization or inappropriate arrest.
- **Training & Consultation** Centralized, affordable, values-based, skills training for individuals, families, and paid staff; can be customized to meet individual team needs.
- **Rhythms** Shared learning, training, consultation, and mentorship designed to better support people with complex sensory differences.
- **Living Our Visions** Assistance to organize individuals and their families to take collective action that ensures fulfilling community-centered lives.
- **WIN Nursing** Individualized, community based nursing consultation.
- **Communication Development Program** Assistance developing augmentative and alternative communication systems.

Responsive Solutions Inc. (RSI) An independent non-profit that works closely with Waisman Center and Night Owl Support Systems to coordinate crisis interventions and ensure people have highly trained staff

and safe environments during times of physical and behavioral health challenges.

- **Crisis Staffing Pool** Highly trained staff available on short notice to support people at imminent risk of hospitalization or institutionalization in their own home or a specialized, safe environment.
- **Safe House** Highly modified home designed to safely support individuals during periods of acute dysregulation and crisis, diverting them from costly, traumatic psychiatric hospitalizations or jail. Night Owl Support Systems central monitoring site is co-located within the Safe House.
- **Adaptations & Modifications** Consultation and coordination around home modifications and adaptive aids for people needing physical and behavioral accommodations.

Create-Ability Intensive hands-on support, training, and oversight to certified adult Family Home Providers.

Madison Metro City/County funding partnership that provides 192,000 paratransit rides per year at a service level that exceeds the requirements of the Americans with Disabilities Act such as door-to-door service.

Night Owl Support Systems, LLC Enhanced independence through the use of technology and remote monitoring, coupled with a staff responder as back-up. Central monitoring site located within RSI's Safe House.

Movin' Out Individualized housing counseling to help low-income people with disabilities and their families purchase their own homes by providing individualized housing plans and lining up down payment assistance. Development of integrated, accessible, affordable rental units marketed to low-income individuals with disabilities.

Mobility Training and Independent Living

Skills Time limited training to learn public transportation routes or skills needed to move to or remain in one's own home without on-going supported living services. Madison Metro provides free life-time bus pass to people successfully able to learn main-line bus routes and fade use of para-transit.

Dane County TimeBank Assistance to people with disabilities which enables them to fully participate in the local TimeBank, exchanging services and skills with neighbors and community members.

Elements of the Dane County System: Housing & Supported Living



Performance

In 2016, 988 of the 1424 (69%) Dane County adult waiver participants with developmental disabilities live outside their parental home. 808 of these individuals (87%) use self-directed funds to purchase Supported Living services which are fully compliant with the Center for Medicaid Services (CMS) home and community based settings rule. 65 individuals have purchased their own home with assistance from Movin' Out.

Approach

Supported Living is a relational, value based process of providing assistance to people in their own home. People either directly hire their staff or more commonly purchase assistance from one of 18 supported living agencies. Assistance may range from a few hours per week up to multiple staff 24 hours per day. This flexibility is designed to meet the needs of all individuals: those with minimal support needs, and those who need skilled support up to 24 hours per day.

Support arrangements include:

- Come in support where staff “drop by” a person’s home for short periods of time based on what is needed on a particular day, as well as what is needed on a regularly scheduled basis.
- Live-in support where an employee of a Supported Living agency lives in a person’s home and is ready to work, but typically unpaid, during overnight hours. In this type of support arrangement people may or may not be able to be left alone.
- Frequently, technology and remote monitoring are used to maintain safety and alert agency “on call staff” of the need to respond.
- Supported Living assumes that provider organizations have robust 24/7 on call responders to provide the assistance when it’s needed, regardless if it is within “typically scheduled hours” or not.
- Paid asleep or awake staff 24/7 due to intensive needs all throughout the day and night. Typically, these individuals would not be able to be left without support due to the complexity of support needs and safety issues.

Underlying Assumptions

Supported Living services assume:

- Assistance is based on an individualized, person-centered plan.
- Individuals sign their own lease and/or own their own home.
- Each person chooses who they live with and how they share their support.
- With appropriate support, everyone can succeed in their own home regardless of the severity of their disability. Each person receives what they need when they need it, adapting over the lifespan, from

age eighteen through the end of life. This includes fading support when people gain skills and become more autonomous as well as increasing the level of assistance people need to age in place.

- People have control over who comes into their home to provide support, and they have the opportunity to meet potential team members in advance of support being provided.
- Agencies will stick with people through thick and thin, in times of crisis and uncertainty.
- If a person chooses a new supported living agency, the provider will change, but the person will remain in their home.
- Individuals receive assistance to live a full life, safely, as a part of their community, contributing and sharing their gifts with others.

Individuals pay for their housing and living expenses so are likely to need help finding a compatible housemate to share expenses, accessing affordable housing subsidies, and housing counseling services such as Movin' Out, Inc. as well as other low-income assistance such as FoodShare, food pantries, senior meals, health care, and free community events.

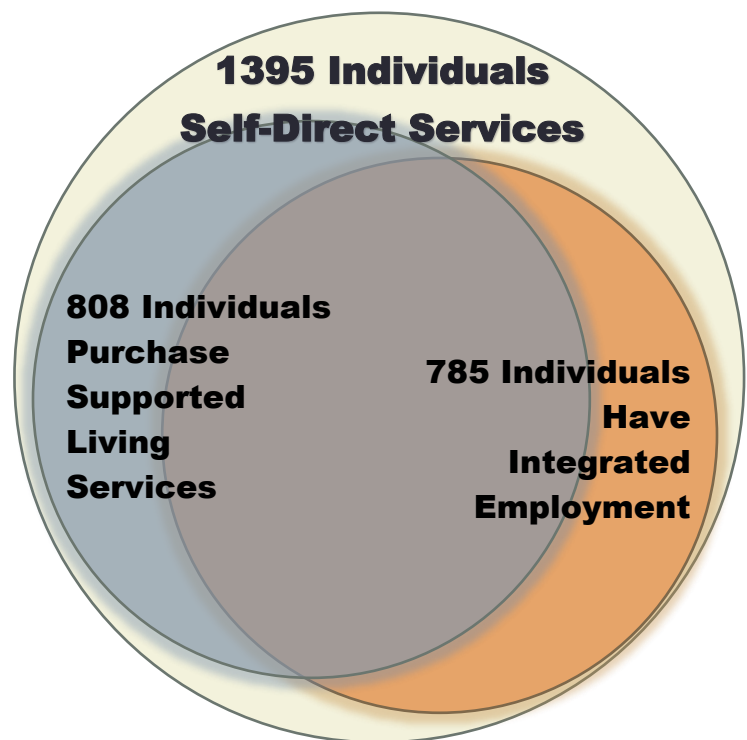
Some people may need support beyond what their supported living agency can provide. In times of changing needs or crisis they can access additional supports that are part of Dane County's shared infrastructure described on page 10.

Supported Living is *not*:

- an agency owned or leased home
- a family home
- a licensed home
- filling beds or slots
- a list of tasks and transactions

People can often purchase more support if they pool resources and share staff. Sharing home supports with housemates or others living in close proximity are hallmarks of the efficiency of Supported Living in Dane County. Support arrangements vary based on a person's needs as does the assistance provided to each individual.

1424 Recipients of Adult DD Services in Dane County



Supported Living Agency responsibilities include, but are not limited to:

Advocacy & Support	<ul style="list-style-type: none"> Commit to thoughtful, individual support planning that keeps the hopes, dreams and interests of the person at the center Stick with people as their lives change Keep looking for another way to offer and provide support in difficult times Support people in all stages of life, including end of life Support autonomy and choice in daily life and decision making about bigger life choices including medical care, service needs, etc.
Community & Relationships	<ul style="list-style-type: none"> Provide respectful, trained staff to deliver all needed assistance Assist people to build and maintain relationships with family, friends, neighbors and co-workers Assist people to engage in meaningful activities in their home and in the community Assist people to join and participate in spiritual communities Maintain thorough personal histories for each person, including medical information appointment and screening histories, medication histories, etc. Develop ways to assist people to share their story with people who are new to them Support active community involvement in non-segregated activities
Daily Living	<ul style="list-style-type: none"> Assist with meal planning, food shopping, meal preparation and clean up, and with eating assistance, as needed Problem-solving assistance Assist people to manage their personal budget, and budget funds for all needed and wanted purchases Assist people to have personal spending money, and to shop for needed purchases Assist people to care for themselves, to complete daily routines and to be ready for work, etc. Maintain a complete record of all contact information for each individual Assist people to create and maintain their personal calendar of important events in their lives
Health Care	<ul style="list-style-type: none"> Provide all assistance necessary to access acute and primary health care Communicate actively with health care providers Arrange and assist with medication management Assist with all necessary personal cares Provide safety and emergency training to people supported
Housing	<ul style="list-style-type: none"> Locate and modify housing for each individual Assist to maintain the cleanliness and safety of individual's homes Arrange for opportunities to consider sharing home and support Assist with planning for, and making moves to new housing
Transportation	<ul style="list-style-type: none"> Provide assistance with transportation, either directly via staff vehicles, or by arranging mobility training or paratransit services

Elements of the Dane County System: Integrated Employment

Approach

Within Dane County's model of self-direction, integrated employment is prioritized as the most effective means of achieving community inclusion for individuals with DD. Having an integrated job with pay at or above minimum wage creates the valued social status of being a contributing, productive, tax paying citizen of the County. Community jobs offer the opportunity to demonstrate competence, belonging, and autonomy and provide the means for individuals to contribute earnings to sustain their household, whether they live with or apart from their families.



For over 30 years, Dane County has made *employment the first and primary service* funded as individuals enter long term support from their local high school at age 21. This approach enlists schools, families, WI Division of Vocational Rehabilitation, and long term support agencies around the common goal of seamless transition and sustainable employment for all and embodies the public policy priorities of the *Workforce Innovation and Opportunity Act (WIOA)* and recent *Centers for Medicare and Medicaid Services (CMS) rules for Home and Community-Based Services* that require settings be integrated in and provide full access to the community.

Performance

Dane County's "integrated employment first and for all" approach has produced the following:

- 60% rate of integrated employment (compared with 20% statewide; 8% in Family Care and 5% in IRIS)⁵
- total earnings averaging between \$3.6 and \$3.9 million per year⁶
- 92% of Dane County students with DD leave high school with paid jobs⁷ (compared with 26% nationally)⁸
- over 900 Dane County businesses employ individuals with DD with the support of 14 vocational provider agencies
- more cost-effective outcomes through supported employment than would otherwise be created through work centers with regard to cost-per hour worked (\$10.45 vs \$15.91) and cost-per dollar-earned (\$1.75 vs \$6.72)⁹

⁵ WI DHS, Program Participation System (PPS) Employment Outcomes Report, October 2015 and Institute for Community Inclusion (2012).

⁶ WI DHS, Program Participation System (PPS) Employment Outcomes Report (10/2015) & DCHS SE Report (4/2015)

⁷ Dane County Department of Human Services, 2011-2016 Transition Outcome Summary, September 2016

⁸ 26% of students with DD and multiple disabilities are employed 2 years after high school as reported in The Implications of the Workforce Innovation and Opportunity Act for Seamless Transition of Youth with Significant Disabilities: A Policy brief prepared for the Collaboration to Promote Self-Determination, Richard G. Luecking, Ed.D. (5/1/2016)

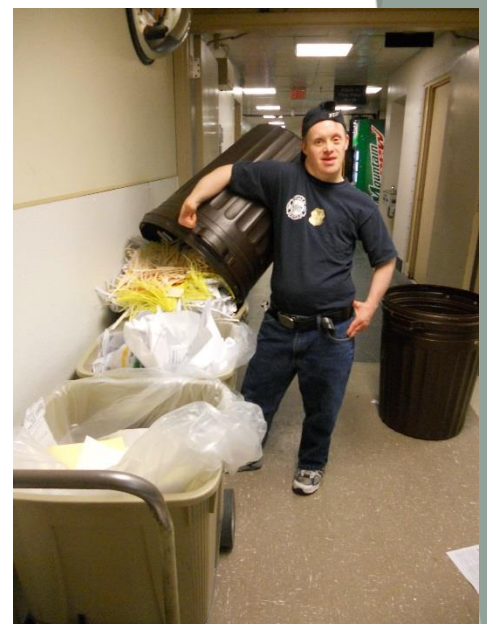
⁹ An Evaluation of the Long-Term Service Costs and Vocational Outcomes of Supported and Center-Based Employees in Wisconsin, Robert Cimera, Ph.D., August 2010.

Community employment and community based day support enable parents of individuals with DD to work and continue in their care-giving role until their adult children move to more independent settings in the community. This decreases the need for costly residential supports (avg. \$50,000/year per person) in the interim.

Underlying factors

Critical to the achievement of these integrated employment outcomes are the following:

- cross-agency and cross-system *commitment to “employment first and for all”*
- access to *reliable, affordable, and responsive transportation services* that enable employees with DD to get to and from their jobs safely and on time
- investment in *training and support of local vocational provider agencies* that collaborate with long term support funders, schools, employers, and *one another* to implement best practice supported employment services
- *timely payment and streamlined reporting requirements* to keep provider administrative costs as low as possible
- *fair rates* for quality supported employment services to better sustain adequate capacity to meet the demand for integrated employment supports
- *access to a shared infrastructure including Waisman Center behavioral and physical health expertise* that enables job success, even for the most significantly challenged individuals with DD
- *single-minded focus on cost-effective sustainable customized jobs* through creative approaches such as Discovery, Partners with Business (PWB), Project SEARCH, supported self-employment and robust transition planning and transition technical assistance
- *strong collaborative relationships* with area high schools, supported employment providers, and the WI Division of Vocational Rehabilitation (DVR)
- *a shared commitment to braid Long Term Support and DVR funding* and resources to achieve *seamless transition* from high school to long-term support
- *commitment to fulfill the requirements* of the Workforce Innovation and Opportunity Act (WIOA) and the CMS non-residential settings rules for Home and Community-Based Services (HCBS)



Elements of the Dane County System: Family Networks

Approach

Families often provide daily supports including personal care, supervision, service coordination, and medical and financial management. Nationally, families provide more than \$475 billion per year in unpaid direct care for their family members, which would otherwise have to be paid for by Medicaid.

Families can also play a key role in creating opportunities that lead to greater community integration and less service utilization. The preferred options for families are often supported living, community employment, and community integration that lead to better quality of life outcomes at lower cost. Additionally, when families transition caregiving to another family member or have ensured that their loved one can live and work in the community with supports, the system continues to benefit.

Nationally, families identify being connected to other families as one essential strategy to allow them to provide support to their family members across their life span. Family Networks are a cost-effective way to facilitate and connect families to do together what a single family cannot do alone.

Family Networks in Dane County:

- Solve real-world challenges that affect the quality of life and outcomes for people with disabilities—community living, community integration, and obtaining and maintaining community employment
- Seek out cost effective community-based solutions and resources, personal resources, and unpaid supports, in lieu of more costly Medicaid funded services.
- Develop innovative, cost-effective, and replicable approaches to service delivery.
- Plan and prepare for a time when family caregivers may no longer be able to provide the same level of care and succession of caregiving.

Dane County funds an infrastructure of two full time family organizers to build and sustain robust family networks. The organizers provide coordination, training, and technical assistance to Living Our Visions (LOV), a network of more than 300 families. LOV connects families with one another, identifies shared issues and supports development of cost effective solutions. LOV provides educational events for families by families, which support the values of community inclusion, integrated employment, and blending unpaid and paid supports to create full lives. In addition, LOV families develop replicable training processes and models for blending paid and unpaid supports that increase cost-effective employment, community connections, and supported living outcomes.

LOV also supports projects focused on transition planning for aging caregivers and technical assistance to community organizations interested in better supporting individuals with disabilities.



Cost Savings through Community Supported Living

Family Networks encourage families to share resources with one another, blend paid and unpaid supports, contribute personal resources, and creatively work with service providers to best meet their needs. When these strategies are used intentionally, there is significant reduction in supported living costs. In order to systematically increase the use of these strategies, LOV families designed a replicable “Moving On” planning process to assist families in achieving high quality and cost-effective supported living outcomes.

Cost saving examples include:

- One individual returning to parent’s home every Saturday reduces long-term care support by 1248 hours per year.
- A small group individuals living in close proximity (same neighborhood or spread throughout a typical apartment complex) share paid staff and their families collectively hire, coordinate and train these supporters as well as provide back up support as needed resulting in significantly lower overhead costs.
- Families hiring short-term staff to focus exclusively on independent skill building such as cooking and grocery shopping in order to reduce the need for long-term support in these areas.

Cost Savings through Community Employment and Community Connections

Intentionally blending system and family resources also results in increased community connections and integrated employment. LOV families co-designed a family-led employment tool which focuses on high quality job matching and using the personal networks of families for job placement. Using this process, 85% of project members gained an average of 15 hours per week of employment and most individuals needed only periodic spot checks from job coaches rather than 1:1 job coaching.

In another project, twenty-six individuals pool \$3500 per year of existing service budgets and their work earnings. These families hire a staff person to build independence and connection to community activities. By capitalizing on natural supports in work places, faith communities, clubs, and adult education courses, individuals are active in their communities for more than 4,000 hours per year without paid staff.

Specific Causes and Underlying Factors

Robust Family Networks require infrastructure investment and Dane county invests in two full-time family organizers to build and sustain networks. Families report that they are already stretched and stressed from providing daily supports to their loved ones with disabilities, so small amounts of paid staff are essential to identify interested families, facilitate groups, identify resources, and provide crucial technical assistance.

In addition, Dane’s Family Networks rely on the creativity and financial flexibility of the service system to make innovative ideas work. When families pilot new, cost effective projects, they often need short-term or start-up funds to determine the efficacy of a strategy. They also need assistance determining how non-traditional, cost effective supports can be included and funded in their service plan. A robust self-direction system that allows individuals and their families to choose their own providers and includes mechanisms for hiring outside of traditional agencies is also essential. Finally, families are able to innovate, provide more supports themselves, and rely on less costly community alternatives because there is a commitment from Dane county to provide a safety net of additional supports quickly in the event that a person or families abilities or needs change.

Elements of the Dane County System: Behavioral & Physical Health



Individuals with developmental disabilities frequently have co-occurring mental health conditions and/or present complex health care needs. When unaddressed, these needs are often expressed through challenging behaviors.

When these challenges are deemed to be too complex or occur more often and with sufficient intensity, it has not been uncommon to move individuals to more restrictive settings. These settings might

enhance safety, but often limit community membership and choice. Doing so often only increases the number of stress triggers resulting in challenging behaviors - which may have been occurring because previous support efforts did not allow for enough choice and meaningful community engagement in the first place. Unfortunately, this is a common life dilemma for people with developmental disabilities.

To address these challenges, Dane County Human Services has partnered with the University of Wisconsin Waisman Center since 1986 to create an auxiliary infrastructure of person centered, positive behavior, and health care supports focusing on health, wellness, and safety. Waisman Center outreach services strive¹⁰ to promote full community membership, control and choice about needed supports services, and stress the fundamental importance of meaningful activities and meaningful long-term relationships¹¹ and include:

Community TIES Outreach Behavior Consultants

- Develop long-standing relationships with the person and his/her support team through visits at home, at work, and in the community.
- Offer individualized situational counseling and/or facilitate access to other available therapeutic resources (psychotherapy, psychiatry) in the community.
- Write Behavior Support Plans that are focused on holistic and proactive approaches.
- Offer individualized trainings to individuals, families and/or paid support staff.
- Consult around specialized supports (which might include home modifications, restrictive measures, or proactive outreach to law enforcement) to prevent unnecessary out of home placements or hospitalizations.

¹⁰ <http://cow.waisman.wisc.edu/>

¹¹ There is wide-spread consensus in the field of IDD and Positive Behavior Support that effective supports to people who experience disabilities and challenging behavior need to be embedded in a person centered, relationship-based approach:

-Pitonyak, D. (2014). The Importance of Belonging; <http://www.dimagine.com/Belonging.pdf>

-Guidelines for Positive Supports in DHS-Licensed Settings. A Resource Manual for Minnesota's DHS-Licensed Providers for Developing Positive Support Strategies, responding to Interfering Behavior and Developing Positive Support Transition Plans. Version 1.0 April 2016; <https://edocs.dhs.state.mn.us/lfserver/Public/DHS-6810C-ENG>

Community TIES Clinic

Offers DD informed psychiatric care and consultation to Dane County residents with developmental disabilities who are unable to obtain psychiatric care from other providers due to behavioral issues, medical complexity or their financial situation.

Waisman WIN (Wellness Inclusion Nursing) Community Nurses¹²

- Assess nursing support needs of individuals with complex medical needs.
- Provide consultation, training and education to individuals with disabilities, their families and community support teams.
- Provide education and advocacy to medical staff in medical settings.
- Coordinate hospital stays and discharges to facilitate a smooth and positive process.
- Advocate and assist in planning plan for end of life care.

Crisis Response

- Assist in crisis service coordination - especially if a situation involves law enforcement or emergency mental health practitioners.
- Facilitate a DD informed emergency psychiatric consultation through the TIES clinic or through Journey Mental Health.
- Collaborate closely with Responsive Solutions, Inc. (RSI) to provide additional, highly trained support staff in an individual's home or work place.
- Coordinate a temporary respite stay at the RSI Safe House - as an alternative to an involuntary hospitalization or arrest.

Performance

Investment in person centered positive supports and creating a supportive infrastructure and safety net has resulted in individuals with complex support needs to successfully live, work, and participate in the community, while minimizing costly institutional stays.

Only a few people's needs at times tax local providers and crisis resources to the point that short term placements in IMDs or DD institutions are necessary.

2014: only 12 Dane County adults with developmental disabilities service recipients (0.8%) were admitted to one of Wisconsin's State Mental Health Institutes. The average length of stay for these individuals was 24 days. These 12 individuals—arguably the most challenging and complex individuals to support—with the added assistance of services were able to successfully live in the community at a rate of \$491.73 per day. Without comprehensive behavioral health supports and the investment made by Dane County, these 12 individuals would likely be institutionalized at a rate of \$1275 to \$1630 per day.

¹² The role of the WIN program and its impact on individuals with developmental disabilities is described in this study:

- Roll, A., Bowers, B. (2016). Promoting Healthy Aging of Individuals with Developmental Disabilities: A Qualitative Case Study. Western Journal of Nursing Research, 1-18. <http://wjn.sagepub.com/content/early/2016/09/09/0193945916668329.full>

2015: 4 adults with developmental disabilities (0.3%) were admitted to one of Wisconsin’s State Mental Health Institutes. Average length of stay was 11.5 days.

The people who challenge the system in this way have been the focus of intensive efforts to creatively develop and further redesign supports to make supported life in the community a reality for all Dane County residents with developmental disabilities.¹³

Elements of the Dane County System: Transportation

Approach

Transportation is key to meaningful participation in the community and to employment. In Dane County, individuals with DD have access to reliable and affordable transportation to travel to ordinary places such as stores, restaurants, and places of worship, as well as their jobs. Dane County has prioritized transportation services to ensure that individuals with DD can contribute to their communities in meaningful ways.

Performance

Dane County promotes transportation options that encourage independence, are accessible and used by the general public, are efficient and cost effective, and draw upon a mix of resources.



For example, Dane County Human Services has an agreement with the City of Madison to braid funding and resources to better serve individuals with DD. Specifically, the agreement identifies rides to/from integrated community settings as the responsibility of the City, while the County takes responsibility for rides to/from its Day Service and Pre-Vocational programs as well as specialized rides for passengers with unique support needs. To that end:

- The City of Madison provides \$2.6 million in local match to draw down \$3.9 million in federal Medicaid Waiver funding to provide 192,000 Metro para-transit rides per year to 565 individuals with DD (an average of 28 rides per month). Most of these para-transit trips are *employment related*. Metro’s service options include “door to door” and “leave attended” enhancements that exceed ADA requirements. People who require this extra help can request physical assistance from the para-transit vehicle to the door of their destination. Drivers remain with individuals until they have ensured the person has adequate assistance. ***These enhancements are essential and ensure that those with the most significant impairments can travel safely and independently to community destinations.***

¹³ Flexible and, when necessary, intensive support assists families through childhood and adolescence - achieving permanency for every child has been an objective for more than 25 years. A Treatment Foster Care option has been developed for a few young people who are better assisted in a supported living arrangement than in a family or foster family setting.

- Dane County provides \$1.63 million (combination of local and Federal Medicaid Waiver funding) to provide 95,000 specialized rides to 415 individuals with DD (an average of 19 rides per month). Again, most of these trips are *employment related*.

To stretch limited transportation resources, Dane County asks all families, particularly those in rural areas, to assist with transporting their adult children to and from their jobs as their schedules allow. Dane County pays for those *employment related rides* that families cannot provide, often by reimbursing vocational support agencies for travel related staff time and mileage.

Dane County also provides funding for *mobility training* to ensure that individuals who can use the mainline bus to go to/from their jobs are equipped to do so. In turn, the City of Madison provides *free bus passes* to those who successfully reduce their reliance on para-transit.

Underlying Factors

1. *Dane County prioritizes transportation as a critical prerequisite to high levels of integrated employment.* Without a reliable and affordable way to travel to/from work, it would be impossible to achieve and sustain a 60% rate of integrated employment for individuals with DD in Dane County.
2. *We recognize that transportation also is key to community integrated living.* Affordable housing is widely dispersed in our community. Access to public transport options like Metro para-transit enables individuals with DD to live where they choose and with whom they choose in typical residential neighborhoods.
3. *Family led and community building initiatives are also highly reliant upon access to reliable transportation.* Currently, adults with DD have the means to independently participate in community life where natural support replaces more costly paid staff at places like health clubs, churches, and community organizations (like Knights of Columbus and LOV).
4. *Practical and sustainable transportation is a catalyst to meaningful self-direction.* Individuals cannot make meaningful choices regarding how they spend their days, evenings, and weekends without access to rides that provide the freedom of movement enjoyed by community members without disabilities.
5. *Focused attention on transportation enables the Dane County Long Term Support system to more readily meet the compliance requirements of current Federal legislation* such as the Workforce Innovation and Opportunity Act (WIOA) and the Centers for Medicare and Medicaid Services (CMS) residential and non-residential settings rules for Home and Community-Based Services (HCBS).



Conclusion

The Dane County long-term support system for people with developmental disabilities is unique in Wisconsin, and is highly regarded nationally. With the support of state government, it has served as a leader and a proving ground for new ways to better support people and create inclusive communities. It has also been a place where a strong partnership has developed over many years between the county-based long term care system, provider agencies, support brokers, employers, schools, families, people with disabilities, and the public transit system.

There are many reasons to take the steps necessary to ensure that these good things continue to happen for people with developmental disabilities in Dane County. In this paper, the essential elements of the Dane County system and its unique partnerships have been described. For some of the things that are happening in Dane County now, it is hard to find analogs in the current Family Care and IRIS counties. But we believe these things are possible in a Family Care/IRIS environment, and that many of the positive outcomes in Dane County are in fact the desired outcomes of the designers of Family Care and IRIS. Keeping all these good things happening in the future in Dane County will require a concerted effort and an earnest dialogue among Dane County staff, the Wisconsin Dept. of Health Services, MCOs, ICAs, people with disabilities, families, and a variety of other Dane County stakeholders.