

The Pathfinder Press is dedicated to informing and inspiring communities to open pathways to possibility and to conserving what is working in Dane County for people with developmental disability and those who support them. We are proud to shine a spotlight on these 'pathfinders', who are people with remarkable stories to share about living out their vision of full citizenship because they build good relationships, recruit allies and make the best of Dane County's many welcoming places. In 2018, Dane County will no longer be operating long-term care services but instead the State and private Managed Care Organizations will manage assistance for adults with disabilities. Because of this change, we invite you to join us on a learning journey as we listen, learn, share and take action together.

## Dane County Invests 38 Years in Innovation

Not all people with developmental disabilities have been able to open pathways. In far too many communities, people with disabilities struggle to experience ordinary life, a meaningful job and deeply committed relationships. But for Scott Wilcoxson and Zach Wians, our featured Pathfinders, it is the shared values between Dane County's many intentional structures of support that make these capacities possible. Dane County Human Services has provided a commitment to supported employment that has allowed both Zach and Scott to get their jobs and to stay employed.

Dane County now offers its citizens with developmental disabilities unusual opportunities for a good community life when compared with the US as a whole. Of the 1,400 people with developmental disabilities supported by Dane County Human Services in 2015...

**60% have paid employment (US= 19%; WI outside Dane County = 10%)**

**66% live with support outside their family's home (US = 44%)**

**57% use self-directed support funds to purchase the assistance they need to live in a home that they lease or own, alone or with housemates of their choice (US=10%)**

While these are impressive accomplishments compared to other places, they are far from meeting the expectations of people with disabilities, their families and their allies among service providers and County Managers. They want better jobs and more income for even more workers, opportunities for many more people to choose to move from their family homes into their own place, better opportunities for adult learning, and better support for people to contribute to civic life and enjoy Dane County's many leisure resources.

## Prioritizing Integrated Employment

Partnering with people with disabilities and employers

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| County Manager facilitated partnerships                        | <b>60% of people with DD EMPLOYED in individualized, supported employment and micro-enterprise</b> | Network of 14 collaborating providers and 12 school districts |
| Funding supports employed graduates                            |  | Diverse expertise   |
| County data tracking   |  | Person focused  |
| Transportation thru paratransit agreement with City of Madison |  |   |

## Employment Builds Capacity for Learning

By Dawn and Chris Wians, parents of recent high school graduate

We figured out what is important to our son Zach several years ago by watching what made him happy and motivated him to engage. The tricky part was turning his interests and preferences into paid employment. Falling in the middle of the Autism Spectrum, he benefits from supports to communicate, stay organized and focused. A consistent work day routine and individualized coaching in a real-life setting has helped him make a huge leap in learning to be independent.

We remember thinking at the beginning of his last year of the high school Transition Program "This is an impossible task- we cannot imagine finding one hour of paid employment and our goal is 20 hours! Plus, how will he get to his job when the school bus stops coming to the door?" For this to work we needed three things to be in place: willing employers, tailored job supports, and transportation from our home in the country to his job in the city.

By graduation we reached our goal. It was complicated. It's Zach-specific. It took time, energy and a dedicated team to make it through this transition. In addition to the typical team members - Zach, us as parents, school staff, county services coordinator, counselor from the Division of Vocational Rehabilitation (DVR) and representation from a vocational agency who will take over on-the-job coaching when school services end - we added a county liaison who connects the 12 area school districts in order to identify good matches for agencies and individual students.



Zach works part-time at The UPS Store, Dominos, Hill Electric and CPU Solutions.

Because we assume ups and downs, our team continues to focus on helping Zach keep his well-matched employment and transportation arrangements. There are still many unknowns for Zach's future as he still lives with us and we remain deeply involved in providing his care and planning for what's ahead. Eventually, in 5-8 years, we hope he will have a home of his own. As we "live into" these questions of the future... Where will he live? Who will he live with? How will he be supported? ...we will look to Zach and his team again to share ideas. We're all, parents included, on a life-long learning journey into the future.

## Featured Pathfinder: Employment Opens Pathways to Community

By John O'Brien, Pathfinder Press Editor

Scott Wilkinson has worked part time at Sequoia Library for 28 years. He is a pathfinder in Dane County's 38 year effort to support employment for people with developmental disabilities, an effort that makes the library one of nearly 900 Dane County employers who employ more than 60% of Dane County citizens with developmental disabilities. With assistance from 14 specialized service providers, these 840 workers and their employers set a world-class standard. In the US as a whole, only 19% of adults with developmental disabilities work. In Wisconsin outside Dane County only 10% of citizens with developmental disabilities work.

Most people with developmental disabilities do typical jobs with simple accommodations like specialized instruction, adjustments to supervision strategies or a technology assist. Scott is a pathfinder in Dane County's steady extension of work opportunities to people whose disabilities require more imaginative and complex accommodations. Customized employment involves discovering what a person can do that has real value to an employer and designing a job and the individualized supports that makes it possible for that person to contribute. Sequoia has the highest volume of circulation in the South Central Library System. Using a specially designed stamp, Scott smooths the library's paper flow. Gregg Drexler, Scott's manager and a Librarian at Sequoia says, "Because of the high volume of circulation, having Scott take care of that step for us is a huge time saver."



Scott contributes more than increased efficiency. Scott, at work at his Sequoia Library job of 28 years.

Scott's gifts of friendly relationship enhance the library's culture of openness and welcoming. He does not communicate with words. His outgoing personality, infectious laugh and ready smile are his vehicles for connection. He is a distinctive and positive part of many patrons' Sequoia experience.

Scott's employment is the result of many people working together in a County managed system dedicated to offering people with developmental disabilities the support they need to live good lives in their community.

Good relationships with committed support staff who appreciate who a person is, stick with them and invest in tailoring support to the person makes supported employment work. Leanna Nielsen has been Scott's Support Broker for nine years. In Dane County a person chooses a Support Broker, who does not work for any service provider, to assist them in using their Self-Directed Support Budget to what they need to live the community life they choose. Leanna recognizes her responsibility to assure that others understand what is essential to Scott, who does not use words and whose communication depends on people's willingness to pay careful attention to him. Reflecting on Scott's job at Sequoia Leanna says, "Scott is an ambassador to our communities who desperately need connection and to feel worth. We all long for such a valued role and welcomed place in others daily life. It's Scott's engaging personality that puts a smile on our faces- his gift is his ability to welcome you to this place of obvious acceptance." This understanding of Scott's gifts makes Leanna an effective ally in dealing creatively with problems as they come up.



Priority on employment means meeting life's challenges with creative problem solving. Take rides, for example. Getting to work takes extra effort for a wheelchair rider who doesn't drive. To make transportation easier, Dane County has a longstanding agreement with the City of Madison Metro Transit that provides work related paratransit rides to anyone with developmental disabilities who needs them.

Over the years, Scott has built a friendship with Stan, his regular paratransit driver, and Deb, his job assistant.

Until recently, Scott lived in Madison with three people who have been his housemates since he moved from his family home and got his job 28 years ago. Then things changed. Sustaining the household required a move to Fitchburg, beyond the reach of Madison Metro Transit. Rather than put Scott in the position of choosing between living close to his job or living with his friends, Lynnea worked with his service providers and Dane County Human Services managers to create a 'both-and' solution. With Dane County funding, Scott's household leases an accessible van that makes the whole community available to all four of them. Three times a week, Scott commutes to Sequoia. He rides the household van until inside the Madison Metro area, then transfers to paratransit for the rest of the way to work. This way of coordinating rides still has some bugs to work out, but Scott's employer values his contribution enough to be a flexible partner in keeping him at work.

What are the keys to Scott's success? Widely shared commitment to employment for people with developmental disabilities, invention of more and more ways to provide the support that people need to be successful at work, and consistent effort to build good connections with employers brings Scott's gifts to Sequoia Library's patrons and sets a standard for the rest of Wisconsin and the world.

## Keys to Dane County's Success

Dane County's accomplishments, and its capacity to seek ways to meet ever higher expectations, are the result of local and state investment in developing a managed system of supports and a collaborative management culture. Going forward, conserving this success so that it is not lost will require a shared commitment to inventing better and better ways to enable people with developmental disabilities to exercise their human and civil rights.

The current Dane County system is founded and managed on the recognition that success depends entirely on interdependence. The people who make up the whole system recognize the necessity of respectful relationships aimed toward high expectations at every level from the provision of day-to-day assistance to maintaining the network of 12 school systems, 14 employment support providers and almost 900 employers that creates employment for 840 people.

**Shared Leadership** More than 40 years of purposeful leadership and focused investment of money and talent, shared among elected officials, County Human Service managers, organized people with disabilities, their family members, and service providers, has developed capacities that work together to produce the benefits that citizens experience today.

**Self-direction** People and guardians, with the assistance of a Support Broker who is independent of any service provider, self-direct an individual budget according to an individual support plan. They have the option of self-managing all or part of their budget. This gives people and their families the power to use scarce funds in ways that let them purchase what is important to them.

**Priority on Employment** has resulted in a managed system of supported employment providers. This network has developed distinctive and necessary specialties in areas like self-employment and small business. It has also underwritten a transition policy for special education graduates that results in more than 92% graduation with paid community jobs, which the adult service system continues to support with no waiting.

**Supported Living** Supporting people to lease or own their own homes allows people flexibility in where and with whom they live and how they choose to be supported at home. County investment in Movin' Out, a parent founded housing agency and developer focused on people with disabilities, has increased the stock of integrated, accessible and affordable housing and helped more than 65 Dane County citizens with developmental disabilities buy their own home and hundreds of others to secure affordable, safe rentals.

**Specialized Supports** A number of specialized supports have developed to assist people at critical moments in their lives. At the individual level TIES provides a variety of supports to people who present families and service providers with behavioral and psychiatric challenges. WIN nurses provide health advocacy. An experienced advocate supports victims of crime. For the system as a whole, an agreement with the City of Madison Metro Transit supports cost effective paratransit for those who need it.

**Multiple Investments in Innovation** have enabled family groups to organize and develop new ways to assist people to set up their own households, find better jobs, and build relationships.

**Alone these capacities would be far less effective than they are when they work together.** Preserving and continuing to build on the benefits that Dane County citizens get from the present system of County managed support for people with developmental disabilities sets the challenge for the coming implementation of Family Care.

## State Mandated Family Care and IRIS

The Governor and State Legislature have decided that by April 2018 the Dane County Human Services Department will no longer manage long-term care services and supports for adults with disabilities and frail elders. Public funds for many services will be managed under Family Care by Managed Care Organizations (MCO) or by the state managed IRIS program, which offers an alternative self-directed individual budget.

Thoughtful Dane County citizens have concerns and questions about how this change will keep strengthening the **Keys to Success**. Active, organized citizen advocacy offers the best chance of conserving and improving the benefits that have resulted from our locally accountable County managed system. You have much to contribute.

The good news is we have time to plan, but not a lot of time. Look for changes to begin in 2017, as the state Department of Health Service (DHS) begins the process of moving from a county operated system to a State and privately operated Family Care and IRIS system.

## Resources to learn more:

**Be a Full Partner** is published by the Department of Human Services to explain the process and details of Family Care.  
<https://www.dhs.wisconsin.gov/publications/p2/p23189.pdf>

**Benefit Package Comparison** is an easy to read chart illustrating similarities and differences of IRIS and Family Care, including Home and Community Based Waiver Services and Medicaid Card Services for Long Term Care.  
<https://www.dhs.wisconsin.gov/publications/p0/p00570.pdf>

**Family Care and IRIS Ombudsman Program** is available for Family Care, Partnership and IRIS enrollees age 18-59 and people who are eligible for these programs but haven't enrolled yet.  
<http://www.disabilityrightswi.org/programs/fcop>

## Preparing for Family Care and IRIS

### Stay Informed

If you are reading this, you or your loved one likely qualifies for long-term care and you want to understand what the changes will mean for you and your family. The following steps offered here will guide you as you gather and review documents, prepare with your team, and begin to take action together with others to preserve self-determination and make Family Care and IRIS the best it can be for Dane County citizens. Many local disability groups are mobilizing to learn more about the upcoming changes. For easy access to these website links, view the Pathfinder Press online at [www.ddnetworkinc.org](http://www.ddnetworkinc.org) and click on 'Pathfinders'.

#### WI Department of Human Services (DHS)

<https://www.dhs.wisconsin.gov/familycare/index.htm>

#### Aging and Disability Resource Center (ADRC)

<http://www.daneadrc.org>

#### Living Our Vision (LOV) Dane

<http://lovdane.org/calendar>

#### The ARC - Dane County

<http://arcdanecounty.org>

#### Dane County Developmental Disabilities (DD) Coalition

<http://www.whatdoesfamilycaremeanfordanecounty.com>



### Gather and Review Documents

To begin your transition from Dane County to privately managed long-term care, you will be formally asked to meet with the ADRC for Options Counseling. Eventually you will decide between IRIS and Family Care and choose a Managed Care Organization (MCO) or IRIS Consulting Agency (ICA). The next step is to negotiate a person-centered support plan. In these meetings it's important to know what services you have now, what they cost and why, and how they are interconnected. Here's a list of some documents to review with the people who know you best as you prepare. You may not have or need every document listed. These are examples of important documents to help you tell your life story.

- COP/CIP Narrative** This profile is written by you and your Support Broker and includes information about you, and the financial, medical, educational, vocational, home supports, communication, social/emotional and other services you currently access. In addition, it may address concerns, safety, emergencies and who's responsible to help you.
- Individualized Service Plan** This is a state DHS form that details all of your public Medicaid and/or Medicare benefits, type of service and provider, the medical professions you see, your income, etc.
- Annual Support Budget** Includes your Self-Directed Support Rate, DVR funds, and/or other funds and summarizes person-centered services such as support broker, home supports, work supports, and other supports.
- Long Term Care Functional Screen** The LTC-FS looks at a person's ability to complete both Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs). ADLs include bathing, dressing, eating, mobility in home, toileting and transferring. IADLs include meal preparation, medication administration and medication management, money management, use of a telephone and transportation.
- Other documents** may include: Public benefits and wage records, Personal Care Plan, Risk Assessment, Behavior Support Plan, Police Plan, and professional assessments, recommendations, and implementation strategies.

### Prepare with Your Team

Sit down with the people in your life who help you plan for your day-to-day needs. This includes family, close friends, your Support Broker, and paid staff that help you manage and support your life. Start by asking some of these questions:

- What matters to you?
- What do you choose to do each day and where?
- How do you get there?
- Who helps you and how do you prefer to be helped?
- What do you need to live your life that you can not do for yourself?
- What is your core concern/need?
- How does this issue relate to your daily wants and needs?
- Does the issue affect your health or safety?
- Does the issue affect your ability to care for yourself?
- What services do you currently receive?
- Is it at the level you desire?
- How is your primary care being provided currently?
- Are your behavioral health needs being met?
- What services does your medical insurance provide?
- Do you get and need food assistance?
- Do you need supplemental Social Security income?
- Do you need assistance with paying utilities, etc.?
- Can you self-direct parts of your plan of care?
- Does your caregiver need planned time off? (respite)
- What is essential for you to maintain your health, safety, wellbeing, occupation, living arrangement and connections?



### Begin to Take Action

Once you review and think about what is important to you, and how all of the pieces interconnect to make your life meaningful as a citizen, you can begin to take action. Having this knowledge will help you and your team strengthen the person-centeredness of your plan.

Watch for coalitions to form to preserve what works for Dane County citizens. Together, citizens will work to advocate for the supports and services that make Dane County a good place for people with disabilities and their families to live. Join in. You have much to contribute.

Beginning to take action will help make Family Care or IRIS stronger and ensure that what's important to you is valued.