DD Network
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Valedictory

The Passing of Dane County Supports for People With Developmental Disabilities Into Managed Care

John O'Brien

Don't it always seem to go
That you don't know
What you've got
'Til it's gone.
–Joni Mitchell

Accounts of organizational change are more often written from the perspective of those initiating change than from the point of view of those who are the objects being changed by those with greater power. This paper reflects the perceptions and actions of local leaders –people with DD, families, advocates, agency managers, and county administrators– who felt a moral obligation to conserve capacities they value as a process implemented by State Department of Health Services (DHS) officials replaced local government leadership with Family Care (managed long term care) operated by contracted agents of Wisconsin's State Medicaid agency. This story of change identifies differences in mindset and practice between State officials responsible for long term care administration and local people who, as they see it, have created an effective community response to people with DD. It identifies potential costs of centrally imposed change as local people identified them at the time of transition. Local leaders' perception of the risks of managed care frames a description of the relationships and structures that shaped a comprehensive local system capable of delivering many of the results that DHS and the Federal Center for Medicare and Medicaid Services (CMS) policy values.

It is far too soon to account for even the short-term effects of this disruptive change. Those results will depend on the ability of local citizens and existing provider organizations to influence the continuing practice of Family Care after it is "rolled out" (in DHS' phrase). However it seems good to document what some local leaders think has made the county managed system work and how they made sense of the early stage of Family Care implementation. Defining and trying to minimize the risks of disruption in a climate of uncertainty has sharpened local awareness of the elements and relationships that offer people with DD substantial opportunities to compose good lives as contributing citizens.

The State of Wisconsin adopted managed care to promote cost saving outcomes: employment, reduction of nursing home and institution placement, and mobilizing personal and community resources. CMS, the State's federal partner in the Home and Community Based (HCB) waivers that fund services, has issued regulations that will soon require individualized supports of the sort that Dane County now provides. It is ironic that a locally managed system that reliably produces the outcomes state and federal government value is being replaced by a system design that is, to take employment or individualized housing options for people with DD for instance, demonstrably less effective. **This is not a story of failing local efforts reformed by State intervention. It is not a story of implementing an alternative proven superior to current practice. It is a story of State policy and implementation practices shaped by an ideology that renders local means to produce good outcomes irrelevant.**

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Links are live in the pdf file. As of August 2018 DHS has taken down some links.

Thanks

Thanks to Marcie Brost of DD Network who sponsored these reflections and arranged interviews and meetings as well as thinking with me about the events and accounts that inform this paper. Thanks also to Monica Bear, Lynn Breedlove, Sarah Cutler, Dennis Harkins, Doug Hunt, Wendy Hecht, Axel Junker, Melissa Mulliken, Kim Turner, and Chris Williamson Witt, who shared their thoughts with me in late November 2017 and January 2018. Interpretation of their views and the content of this paper is my sole responsibility.

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The mission of the Developmental Disabilities Network is to inspire, inform, and point the way to best practice of daily support for people with developmental disabilities and to promote greater opportunities for people with developmental disabilities to:

- Contribute to community life
- Control their own lives
- Secure good health and a stable home
- Work and earn an income
- Learn and grow

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Disclaimers

This paper is anything but objective. I have never lived in Dane County, but since 1974 I have been regularly involved in advising, facilitating learning groups and documenting developments there. I like and admire the people who have shaped the imperfect and improving system of supports that has emerged and value the friendships and collegial relationships that have grown for me there. I believe that what the citizens of Dane County have co-created over more than a generation exemplifies a comprehensive, consistent and creative effort to understand and realize the values of self-direction and individualized support for community living. I believe that the active elements of this approach are worth conserving as the mechanism of financial administration changes. I think it remains an open question whether the move to managed care will offer people with developmental disabilities better life chances than Dane County's current culture and structure does. I align myself with those who remain skeptical about this possibility. This is not because I doubt the commitment or competence of existing Wisconsin Family Care Organizations* but because of the exceptional results achieved by Dane County citizens under their current form of local administration. There is plenty of room for improvement in Dane County, but I am unconvinced that State imposition of managed care offers a superior path to those improvements.

These reflections focus on the way leaders within the Dane County system say they have experienced the State Department of Health Services (DHS) implementation of managed care up to the point in January 2018 that managed care organizations began building their provider networks and enrollment was beginning. It is DHS policy and practice as it shows up in local experience of those involved in the transition that I consider in these pages, not the work of any operating Family Care Organization.

I have chosen to look through the eyes of those who were active in efforts to conserve what they value in the current system as managed care begins to take over (a process planned to be complete by June 2018). These reflections build on local leader's efforts to make sense of DHS's actions. Those who acted for DHS have their own experience and their own story of the process. Their perspective is very likely to differ considerably from those presented here. However, apart from attending a DHS conducted information session on the transition and reading as much documentation as I could find, I did not try to discover DHS's stories.

My ideas about what makes Dane County effective are strongly influenced by personal experience. Many of my encounters with Dane County leaders have been in planning and learning from collaborative efforts. Differences in interests, perspective, style and practice show up in these efforts, but their context is defined by common value commitments and respectful personal relationships. The story that follows is shaped by this experience and may underplay differences, conflicts, the work involved in compliance with the demands attached to current HCB Waivers and the use of County management authority.

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* For a national overview, see MLTSS Institute (2018), *MLTSS for people with ID/DD: strategies for success*. In some places such as Iowa and Kansas, the move to managed care has produced what many people with DD and their families see as negative results.

Transition is a technical problem that DHS has solved. Compliance produces success.

Transition is an adaptive challenge that requires multi-stakeholder collaboration.

*A **technical problem** can be resolved by correctly applying expert knowledge in a situation where differences in values are unimportant and there is an agreed problem definition.

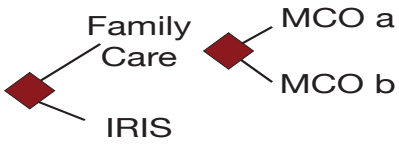
An **adaptive challenge** arises when…

- … previously successful approaches no longer produce desired results and new ways must be discovered.
- … there is threat of significant loss.
- … there is significant disagreement about how to understand the situation.
- … there are important differences in what people value.

See R. Heifetz, A. Grashow & M. Linsky (2009). *The practice of adaptive leadership.* Boston: Harvard Business Press. They argue that the most common cause of failure in change initiatives is treating an adaptive challenge as if it were a technical problem.

The challenge of imposed change

Those concerned about supports to people with developmental disabilities in Dane County face an adaptive challenge.* Since the early 1980s they have developed a comprehensive system of supports with funding from Medicaid HCB waivers, administered by Dane County Human Services Managers. In the 2015-2016 Budget, Wisconsin's Legislature decided that the time had come to complete the implementation of Family Care, a managed care approach to financing and coordinating long term care for elders, people with physical disabilities and people with DD which administers HCB waiver funds through contracts between managed care organizations and the State Department of Health Services (DHS). This legislative decision removed a requirement that Counties initiate the process of implementation and positioned Dane as the 71st of 72 counties to join Family Care through a DHS controlled transition process intended to complete enrollment by the summer of 2018.*



Wisconsin's approach to managed care offers eligible citizens an option. They can become members of a managed care organization** contracted by DHS to serve their district or they can self-direct an individual budget through IRIS ("**I**nclude, **R**espect, **I S**elf-Direct") administered by DHS. In DHS's view a successful transition solves a set of technical problems that allow people to decide which option to take and then choose either a managed care organization or a DHS certified IRIS Consultant Agency. A State run technical process establishes capitation rates, selects and contracts with managed care organizations, certifies IRIS Consulting Agencies and assures that people and guardians have disinterested information to guide their choices. DHS staff are the source of information on the transition process and Aging and Disability Resource Centers (ADRC) follow DHS guidelines to provide options counseling as the sole source of information to guide people's choice.

What is taken to be at risk

DHS staff seem to see two principal risks in the transition if County Managers and Providers fail to comply with the details of the process they have perfected as they have rolled out Family Care in other counties. People and families will be confused by multiple messages about managed care and the transition process, which could lead to unnecessary anxiety and ill informed resistance.

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*See *Dane County - Family Care, Partnership, and IRIS Transition* to see the DHS plan for change and their explanation of the options people have. www.dhs.wisconsin.gov

** Currently, people with DD can choose among three types of managed care organizations: Family Care, Family Care Partnership and PAC. While differences in benefits matter for individual choices, 95% of those who choose managed care choose Family Care, which will be the term used in this paper to include all three.

And, people's choices will be swayed by self-interested parties –especially providers– seeking gain by influencing people and their guardians and thereby driving up costs to provider advantage. DHS expect to manage both of these risks straightforwardly by technical means such as imposing defined procedures and time lines and maintaining control of messaging and information. DHS staff believe that the experience of rolling out Family Care in 70 other counties has produced a tried and true path to a successful transition. The assigned role of County managers and existing providers is to step back and cooperate with implementation protocols as DHS staff manage the transition and then implement DHS oversight of Family Care organizations and IRIS Consultants through contract, certification and quality assurance measures.

Risk: non-compliance with DHS instructions will result in…

…confusion & resistance

…self-interested providers biasing people's choice.***

Dane County leaders* see different risks which pose adaptive challenges. Numbers such as a 62% employment rate for people with DD and others enumerated on the next page signal worthy performance and underwrite county leaders' claim that an effective transition to Family Care would thoughtfully consider how to conserve and build on as much of what currently works as possible. However, county leaders have far more at stake than numbers can express. Shared experiences and struggles weave them into common stories with people and families and support workers whose effort creates the better life chances that the numbers reflect. Their own careers have unfolded locally through the creation of new possibilities in Dane County, a process that has involved many explorations and debates that have shaped a range of innovative approaches toward realizing common values. They work from personal commitment and feel an ethical responsibility to influence the transition to the advantage of the many people and families whose faces and stories they know personally.

Risk: disruption of relationships,agreements and norms that produce individualized supports & exceptional results.

As the table on the next page shows, collaborative effort has developed individualized supports that assist many more people with DD than is common to work productively in community jobs and make supported homes of their own through participation in the ordinary housing market. Investments in developing provider competence and an array of specialized services brings a job and a home of one's own within reach of a majority, though insufficient funding keeps a growing number of adults living with their parents longer than desired. Innovative partnerships with people and families have significantly decreased risk of admission to IMDs (Institution± for Mental Disease), State DD Centers and nursing homes. These shared local accomplishments are consistent with current disability policy goals** and Statements

* The term, Dane county leaders, includes those people with DD, families, advocates, agency managers, and county administrators who share an agenda to influence the transition to conserve as much as possible of current capacity. These leaders include several Dane County citizens who have retired from senior positions in DHS and Statewide advocacy organizations.

** Consider the mandate for community integration in *The Americans with Disabilities Act* and its interpretation in *Olmstead* and following Federal Court decisions (ada,gov),

*** Remember that **DHS Sees** is an inference that one or more County Leaders make in their attempt to make sense of DHS behavior. It should always be qualified: "It seems as if DHS sees…"

Dane County demonstrates effective responses to contemporary policy goals & best practice guidelines for a majority of the 1,400 adults who rely on it's services*

People have individual, paid community jobs WIOA, CMS Settings Rule, Olmstead	62% have individual, paid community job US=19%; WI Family Care= 12%; IRIS=9%** 92% leave high school with paid jobs US=26%	• Dane County priority since 1984 as best foundation for community inclusion. • ±900 businesses employ people with DD with support from 14 supported employment providers. 48 have been employers for more than 20 years. • 49 people own micro-enterprises & small businesses. • Partnership with 12 school districts means that >90% of students with DD leave school each year with individualized, paid community jobs. • 13% spend time in a day center or sheltered workshop; 30% of these people are >65 years old.
People live in homes of their own with individualized support CMS Settings Rule. Olmstead	69% live outside their family home US=44% WI Family Care 43%** 87% use self-directed funds to purchase individualized assistance to live in their own home US=10%	• Founded by local families, Movin' Out provides housing counseling, mortgage assistance & develops & manages a variety of community integrated rental properties. • Night Owl Support Systems, a local innovation, provides a monitoring technology option.
People are free from institutionalization Olmstead	2% live in institutions by guardian choice US = 9% 00.2% admitted to IMD average stay = 11.5 days WI=1.5%**	• An array of specialized wellness, positive behavior support & crisis response supports collaborate with people & providers. • Custom designed intensive supports increase self-regulation & access to community roles.
People self-direct their supports	98% WI=35%**	• People have budget authority over an individualized rate with the option to contract with a provider they chose or hire directly. • Each person chooses among 91 independent support brokers who can provide hands on assistance as well as planning and support coordination.
People have accessible transportation for work & community membership	192,000 paratransit rides/year for 565 people –most job related– including "door to door" & "leave attended" service 95,000 specialized rides–most employment related– to 415 people Mobility training & free bus passes	• City/County funding partnership • DD Service funds for specialized rides & mobility training • Free passes from METRO
Families of adults have support to mobilize community resources.		• >300 families supported by LOV Dane to create opportunities. • 33 families have created individualized living arrangements without supported living funds. • Local capacity building initiatives created through family groups, some financed & facilitated with DD resources. • TimeBank supported to include people with DD

* Sources: *Building on the Dane County Difference* www.ddnetworkinc.org; US comparisons from fisp.umn.edu and Statedata.info Delays in compiling national data mean that comparisons are between 2015-16 and 2013 but the relative size of the difference is unlikely to change very much when national statistics catch up. Wisconsin data are more current.

** WI DHS (2017) *Long Term Care Scorecard: 2013-2015* www.dhs.wisconsin.gov/publications/p01265.pdf & DHS Data: DD Coalition.

of best practice* and rank Dane County among international leaders in integrated employment, support for people living in their own home, and self-direction of public funds.

Despite what has been achieved, county leaders are aware that of work not yet, or ever, done. They share a strong belief that much more is possible for people with DD through continued learning in a network of people committed to shared values: even better jobs; a greater range of affordable housing choices; more diverse relationships and memberships; even more effective responses to people with complex physical and neurophysiological differences; better supports to people whose needs increase with aging; more effective mobilization of personal networks and community resources. They know that this learning can only happen if there is intentional investment in innovation within well managed structures that offer self-directed, individualized assistance to employment, home life and community engagement.**

The coming of Family Care raises questions about how current capacities for individualized support can be sustained and how innovation to expand opportunities for people with DD can continue. To make sense of changing circumstances, the Dane County way is to gather and deliberate. From 2014 on County leaders have regularly discussed what Family Care and IRIS could mean for local citizens with DD, their families and the people who provide support.

Inquiry into Family Care and IRIS in Wisconsin counties and managed long term care in other States informed them. Their deliberations identified these risks.

- Family Care Organization Care Teams are responsible to find the most cost effective way to meet assessed needs and support identified outcomes, as the box to the right shows. This process is sensitive to norms and assumptions about the value and cost effectiveness of employment, living in one's own home, and self direction and about the conditions required for these to be reasonable for a person with DD. Striving to implement best practice and anticipating the demands of the CMS Home & Community Settings Requirement and the Workforce Innovation & Opportunity Act (WIOA) by many years, Dane County has assumed employment and support to live in a home of one's own as integral to service effectiveness for all adults with DD. From this commitment, they have worked to find the least costly individualized means

Nothing in the results the County has achieved stimulates curiosity or interest in searching for ways to preserve what works.

Life work that has generated capacities and alliances worth conserving through negotiation with DHS & Family Care Organizations

Care Wisconsin is responsible for supporting your long-term care outcomes, but we also have to consider cost when planning your care and choosing providers to meet your needs.

To do this, your care team will use the Resource Allocation Decision (RAD) process as a guide in making decisions about services. The RAD is a step-by-step tool you and your team will use to find the most effective and efficient ways to meet your needs and support your long-term care outcomes.

Cost-effectiveness is an important part of the RAD. Cost-effectiveness means effectively supporting an identified long-term care outcome at a reasonable cost and effort. For example, if two different providers offer the assistance you need, Care Wisconsin will purchase the more economical service.

Care Wisconsin (2017) *Family Care Member Handbook.* This document follows a DHS supplied template; other Family Care organizations will make very similar Statements.

the *CMS Home & Community Settings Requirement*, *WIOA: The Workforce Innovation & Opportunity Act*, and *The UN Convention on the Rights of Person's with Disabilities*.

* See for example The American Association on Intellectual & Developmental Disabilities position Statements on *Community Living*, *Employment* and *Self-Determination*.

** Of course this network does not encompass everyone in Dane County who cares about the wellbeing of people with DD. There are some advocates for group living, sheltered workshops and day programs who say that the County's policies and investments restrict choice and discourage effective forms of service. Guardian choice to reject alternatives accounts for the few remaining long term institutional and group living placements that the County funds.

Living & day services that serve groups of people with DD are necessary elements of a cost effective continuum of care.

Individualized supports, purchased through a self-directed individual budget are a necessary condition of good results at reasonable cost.

Services that group people impose unacceptable costs to self-direction & quality of life.

to achieve these valued ends. Dane County accounts costs of social exclusion and inefficiencies of group based services when considering the cost side of the cost-effectiveness estimate.

> Individual community employment, support for living in one's own home and self-direction can be seen as options limited by perceived impairments. If a Care Team held this view, only those assessed as meeting some standard of readiness would have these options. Dane County presumes that the system's task is to continually improve its capacity to put a job, a home of one's own and self-direction within everyone's reach. The burden is on the system to figure out how to provide and pay for what it takes to do so.

> A Care Team belief that integrated employment or supported living is only cost effective for people who need small amounts of assistance or for whom it is possible to fade assistance would unnecessarily limit access and arguably violate people's rights. This assumption discounts the proven benefits of valued community roles, especially for people who require substantial assistance and are at risk of placements that exclude them from the developmental opportunities that come with employment and the security of their own homes.

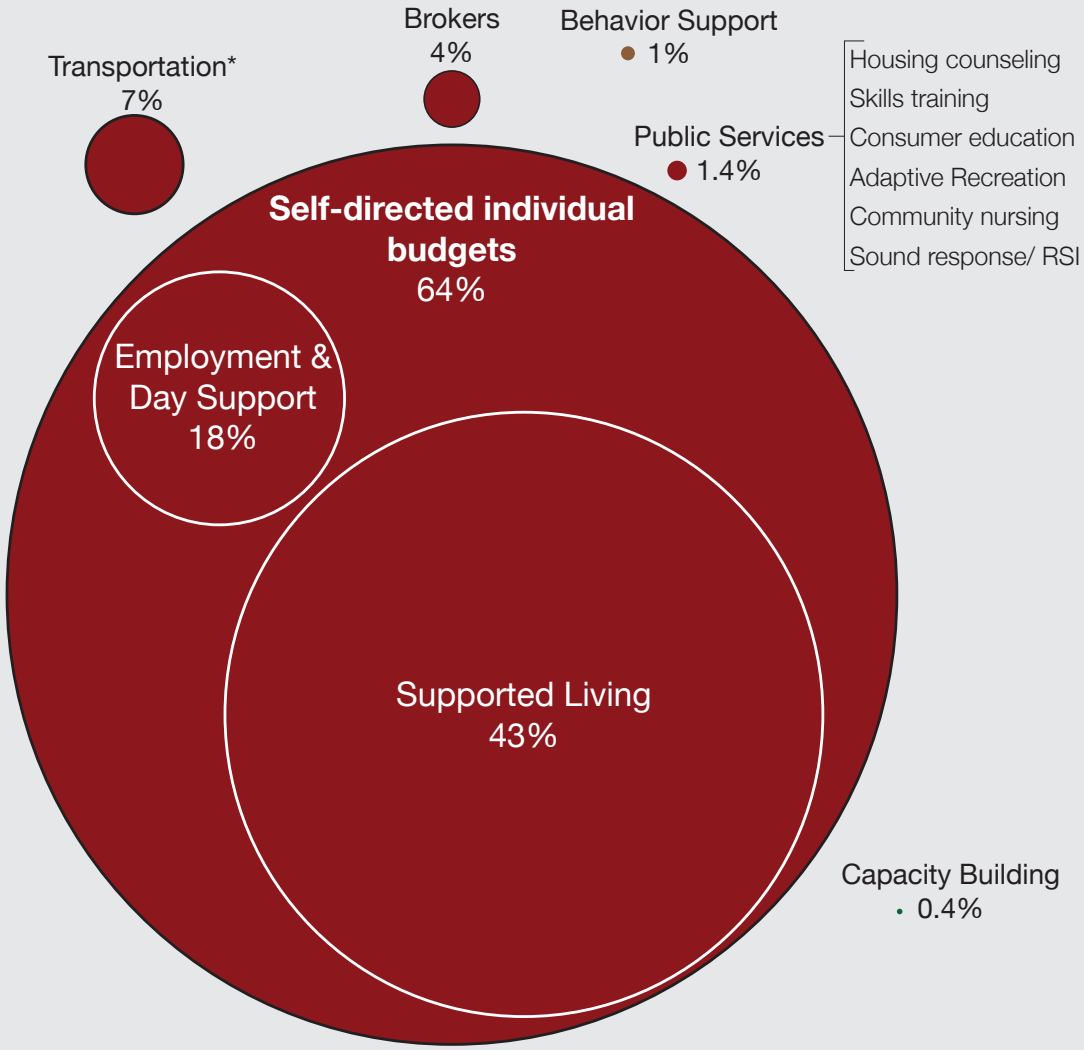
> Providers in most other areas of the State are heavily invested in services to groups of people with DD. Sheltered workshops and day programs are more common than pervasive individualized supports to community employment. Group homes or family operated adult fostering arrangements are more common than individualized, self-directed supported living, especially for people with substantial needs for support. Family Care organizations may lack experience with administering a network of individualized support providers similar to those responsible for Dane County's current performance. They might even consider group based services as cost-effective options in a continuum and seek providers of group based settings willing to complete what they understand as a menu of cost effective services.

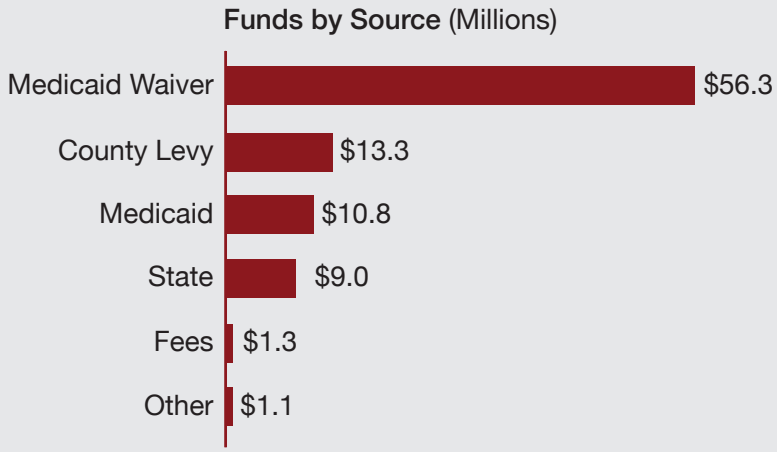
- Dane County invests in a variety of specialized supports as public services, available to people as needed. Almost everyone has a broker they have chosen to assist them in spending their individual budgets to support living a valued life in community. There are an array of positive behavior supports, community nurse consultants, access to technology and housing assistance, as well as county supported efforts to organize and support families. The 40 people who live in Certified Adult Family Homes for 1-2 people benefit from supports to home providers that considerably exceed what the State requires. There is assistance that encourages people to join funds from their individual budgets to cooperatively purchase some individualized supports.

Preserving the support, knowledge and relationships that these investments represent is critical to sustaining current performance.

- An agreement with Madison METRO generates a $2.1 million dollar match for Medicaid funds that underwrites nearly 200,000 para-transit rides a year. The majority of these rides provide an essential infrastructure for employment within the area METRO serves.
- Regular investments of County Levy funds, matched through Medicaid waivers, has sustained a policy that offers every eligible young person who graduates from high school with an individual community job continuing support to stay employed along with a broker and a budget for personal and family support (respite). An agreement with Vocational Rehabilitation allows braided funding for young people's vocational supports. A partnership with all 12 of the County's school districts yields many years in which more than 90% of eligible young people leave school with integrated employment and transition successfully into the individual support necessary to sustain employment. This successful policy is vulnerable to the DHS policy for managing waiting list elimination: some graduates could find themselves on a two years long waiting list for adult services. This would interrupt the transition that they and their families have planned and disrupt support for their continuing employment.
- Recruiting and retaining a competent workforce, especially direct support workers, is a critical national issue. Dane County's low unemployment rate and higher cost of living make this even tougher. County policy requires contractors, including all DD providers, to pay a living wage. If rate calculations don't take account of local labor market conditions and the demands on staff competence that go with providing individualized support the workforce problem will become even harder to address. The cost effectiveness mandate might encourage false, short-term savings on wages, especially for direct support workers who will no longer be protected by Dane County's Living Wage Policy. Thoughtfully accounting the costs of worker scarcity and high turnover in money, competence and continuity is necessary to make good judgments about cost effectiveness.
- Brokers provide a variety of supports to people who want to self-manage their supports or negotiate individualized arrangements with provider agencies. It is not clear that the IRIS consultant role is defined and funded with the expectation that they will offer similar assistance or that people's IRIS budgets will be sufficient to hire brokers who offer the assistance that people currently benefit from.
- A significant number of adults with DD have become disconnected from their families or have legal guardians who have become distant. They, and often their guardians, rely for decision support on their broker and service workers whom they know and trust. Many active families also rely on the advice of

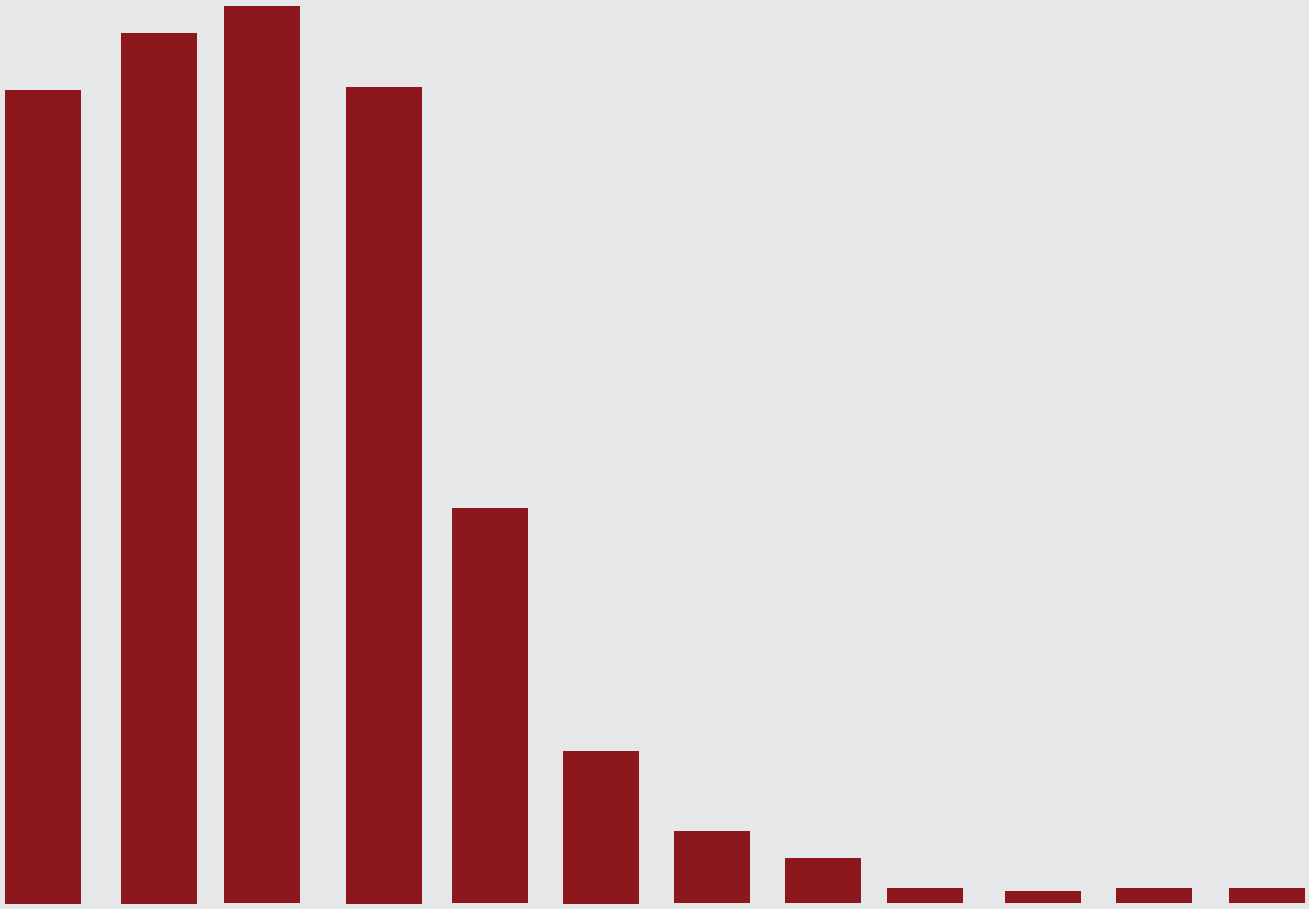
Individualized adult services as a % of total Dane County DD Budget (2015)





*Madison Metro pays local Medicaid match of $2.1M for paratransit.

Total daily cost of self-directed services & supports: number of people by amount of individual budget (2017)



People	272	291	300	273	132	51	24	15	5	4	5	5
Daily cost	$5-49	$50-99	$100-199	$200-299	$300-399	$400-499	$500-599	$600-699	$700-799	$800-899	$900-999	>$1,000
Mean cost	$28	$75	$145	$250	$339	$445	$537	$635	$747	$836	$939	$1,068

Total daily cost of supports and services for 1,377 citizens with DD who self-directed their individual budgets, which included Medicaid HCB Waiver funds and Medicaid personal care. Included the cost of transportation, brokers, contracted behavior support and public services identified on the facing page (which reflect 2015 investments).

Dane County also funded services to a small number of people who live in licensed residential settings and receive no other service. Those costs are not included in this table.

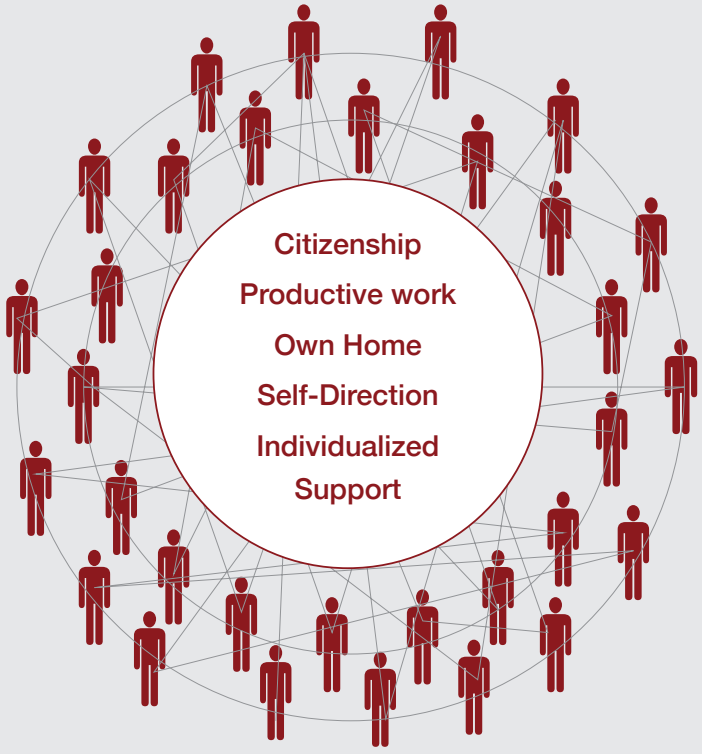
Capacity for individualized responses

- Agencies differentiate to offer distinctive competencies.
- Investment in a variety of specialized supports available as needed.
- Value on small, local agencies.
- History of innovation in response to challenges in assisting people to make their own homes & work (people with complex neurophysiological differences; people at risk of IMD admission; people with profound, multiple disabilities).

Associations

- Voluntary cross boundary coordination
- Deliberation
- Voice
- Innovation

Network with shared commitment to commonly understood values & will to innovate



brokers and support staff they trust to assist in decision making. Injunctions that forbid involvement of anyone paid with Medicaid funds in the process of managed care enrollment and planning would leave many people and families without the assistance they need and want to support good choices.

People must be insulated from staff involvement in their transition choices, regardless of the quality of their relationships, otherwise staff self-interest will bias choice & drive up cost.

The capacity is in the system

The risks identified above are enumerated as a list but each identifies potential erosion of an element in a closely linked system that currently produces results that Dane County citizens value. Charts often reflect contractual or regulatory connections among service elements; these bring hierarchy into focus. The system map on the facing page highlights networks of relationships that are critical to Dane County's performance.

Supported by a broker they hire, people with DD, and often their families and guardians, form agreements with service providers and use system funded specialist services when they need them. **Capacity for individualized responses** (the top of the diagram), emerges through multiple collaborative relationships among people with DD and their families and allies, their brokers and those who offer assistance. Providers, Behavior Consultants and Community Nurses often have years long relationships with people and their key support workers and have built the trust necessary to good support. **Associations** create platforms for action and forums for learning, collective sense making, problem solving and innovation (three of several such associations are central on the diagram). A **Person-to-person network** of those committed to the value of providing individualized, self directed support to work, making one's own home, and diverse personal and civic relationships forms the system's foundation (the bottom segment of the diagram). Members of this web of relationships have diverse perspectives and ideas about how to realize what they value and sufficient common understanding of what they are seeking to accomplish to provide direction and set boundaries. Over years they have developed a way of collaborating that significantly reduces the need for top-down commands, imposed conflict resolution and transactional regulation.

People must be free to choose involved decision support from anyone they trust regardless of their role. This is not only typical for anyone making an important decision, it is a reasonable accommodation to cognitive impairment

It's relationships all the way down.

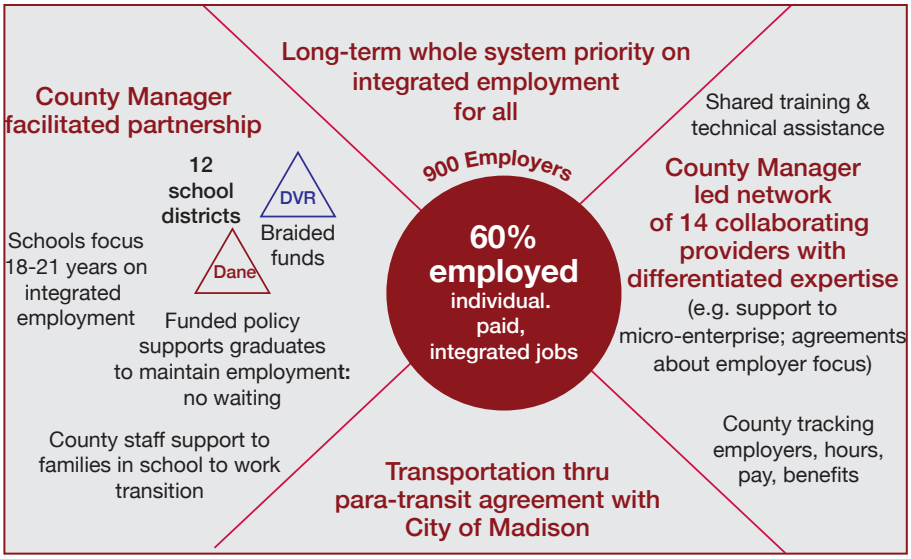
Strong collaboration with State DD leadership extended Dane County's person-to-person network beyond its administrative borders. From the mid-1970s to 2016 DHS had a specialized Bureau or Office to manage interactions with Counties responsible for administering services for children and adults with DD. For most of this time, most State managers at this level had personal experience in services to people with DD and shared commitment to the values held by Dane County leaders. State and county staff often worked as partners in learning how to realize the values they shared, problem solving around individuals and groups in challenging situations and testing ways to make the best of available resources. Collaboration formed the context for resolving the inevitable conflicts that arise from different interests in assuring compliance with the condi-

tions of HCB waivers and managing scarce public funds. The means by which Madison Metro currently provides the match to Medicaid payment for 192,000 rides a year was developed through this County-State collaboration.

Each relationship and element of Dane County's system has developed over time in response to local conditions and changing ways of understanding what more is possible. Changing one element effects the others. This connectedness results in better performance. Its disruption could result in a breakdown of capacity, especially if elements or relationships disappear in the transition.

An example. The diagram highlights the system sector that currently produces one of the highest reported rates of employment for people with DD in the US. County management influences performance in multiple ways: defining policy and directing public funds; administering contracts with providers; leading a collaborative network of providers; facilitating agency specialization; creating partnerships with school districts and vocational rehabilitation; developing ways to multiply resources; convening shared learning opportunities.

In turn, the effectiveness of the employment sector depends on connections external to work that the system makes possible. Broker and supported living provider alignment with the value of employment provides a context for planning and problem solving that gets people to work and supports families and those who assist people in their own homes to deal with difficulties that employment or unemployment poses for them. Specialized services decrease barriers to employment for people with complex impairments. Managers skilled in understanding Medicaid funding in past collaboration with State HCB waiver managers have reduced costs and multiplied flexible resources. Local advocacy sustains the State's highest level of investment of County levy funds in supports to people with DD.



Multiple interdependencies account for Dane County's capacity to continually improve its outcomes. Failure to conserve them under Family Care is very likely to undermine that capacity.

Promised rewards of managed care

Dane County's current system performs well enough on socially valued measures of performance to deserve recognition as one effective way to manage resource constraints and organize and coordinate supports to people with DD. Like every other approach to managing supports it impos-

es costs. Dane County priorities have nearly eliminated long term institutional or nursing home placements by offering supported living to people whose families are in crisis and by acting affirmatively to co-create effective supports for people with complex impairments. New high school graduates are assured continuity of employment; a very high proportion of people have the support of a broker and access to personal and family support (respite). Overall, the current system sustains high rates of employment and supports more people with DD to live outside their parental home than the combined Family Care average (69% vs 44%).

There are good reasons for these priorities, but they systemically restrict options for, and impose costs on, people whose families remain able to provide adequate support for them to continue to live in the family home. More, perhaps many more, people would choose to move out and establish their own homes than current priorities for available funding allow. As well, some family members say that singular focus on ordinary housing with support and development of integrated employment unfairly restricts choice for families who would prefer group living, sheltered workshops or day centers.

Advocates for Family Care, including a number of Dane County citizens, point to benefits that they have concluded will reduce current disadvantages without compromising performance.

- Chief among these benefits is the elimination of waiting lists once Family Care is fully implemented in 2021.
- Family Care simplifies and streamlines access to needed services by bringing some Medicaid State Plan Services and Home and Community Based Waiver Services together into a single benefits package under Care Team management.
- Family Care members have the option to self-direct almost all of their services with support from Family Care organization staff.
- Those who choose to self manage all their services have the option to enroll in IRIS.
- Family Care assures uniformity and portability. Regardless of zip code and no matter where they move in Wisconsin people have access to the same set of Family Care benefits.
- The process for determining eligibility, assessing need and identifying cost effective services is transparent and uniform throughout the State. Eligible people choose their services based on objective information provided by ADRC staff, who are free of conflict of interest and guided by DHS procedure.
- Political commitment to Family Care and assurances to CMS insure that public investment in supports will keep up with assessed need, entitling eligible people to cost effective services.
- Family Care caps a growing burden on county taxes and improves predictability for local and State political decision makers.

Cross agency alliances are not worth maintaining.

Alliances around employment & transportation are essential resources.

- Family Care controls public expenditure by applying of actuarial methods and other cost management and quality assurance strategies to the whole State population.

Oppositions

Many Dane County leaders don't accept the argument that replacing the current system with Family Care will bring benefits to people with DD that outweigh potential disadvantages, even if promised rewards can be delivered. As they have learned more about managed long term care as an evolving policy they have identified important differences between the ideas that guide Family Care and the ideas that guide Dane County's approach.* From their point of view, these narratives are different enough to describe them as oppositions. These oppositions form the root system for the risks threatening Dane County's current capacities (see page 5).

The rest of this section contrasts the DHS narrative of Family Care (as Dane County leaders understand it from documents,** meetings and State staff responses to inquiries) with the narrative that guides Dane County. The focus is on the State government narrative because DHS controls the transition process and because DHS exercises strong control over the structure and performance of Family Care Organizations through requirements for selection, contract, and setting capitated payment rates. On learning journeys with Family Care Organizations, Dane County leaders encountered good people doing good work guided by values similar to their own. This good work appears to depend on the Family Care Organization's ability to generate its own distinctive narrative and practices rather than simply following the DHS storyline.

In the idea of who the system serves that informs system design

Policy makers act from an image of who they intend to serve. In its report to justify Family Care expansion, DHS presents a very strong image of the typical Family Care member, a description that leaves people with DD nearly invisible. The report visualizes a frail elderly person, usually with a family who can offer assistance and often with some funds to expend on care. The person is very likely to be dealing with one or more medical conditions that affect their need for assistance, so including a nurse on each person's care team makes sense. The person is housed when they contact the ADRC and would, as long as nec-

What about IRIS?

IRIS is a crucial option for people and families and a significant number have chosen it. However, it plays a minimal part the DHS managed care narrative. The oppositions discussed here also apply to DHS thinking about IRIS.

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* Managed care advocates sometimes talk as if Dane County has been unmanaged. It seems closer to the facts to see Dane's current system as managed, but according to different guiding ideas, including thoughtful strategies to manage scarce resources and concern for cost-effectiveness.

** I take this document, which made the case the case for Family Care expansion, as a good expression of the DHS mindset: DHS (2013) *Long Term Care Expansion Report to Joint Committee on Finance*. www.dhs.wisconsin.gov/publications/p0/p00590.pdf No more recent account is apparent on the DHS website. Proposals for Family Care 2.0 in the 2015-2016 State budget intensify and expand the thinking in this document.

essary services are available, prefer remaining at home to moving into a nursing home. The need for long term care comes later in life, for a limited time. For this person, early availability of low intensity services, including encouragement and support to unpaid caregivers, will defer the need for more costly, publicly funded services. Increasingly intensive interventions that offer the right service at the right time to meet growing needs will prevent or significantly delay nursing home admission. The option to move into lower cost group accommodation (AFH or CBRF) can further delay or eliminate demand for a high cost nursing home bed. Reducing and delaying demand for nursing home placement with cost effective alternatives that make the most of natural (i.e. unpaid) support is the key to bending the long term care cost curve. Attention goes first to controlling the boundary between the person and publicly funded services to minimize use of publicly funded services consistent with maintaining health and safety.

Dane County designs individualized supports from an image that includes adults of all ages with very diverse support needs and a common right to community living. Flexible, competent support tailored to individual situations greatly expands all people's options. Because DD refers to a variety of life long impairments that begin before age 18, needs for assistance will vary significantly among the whole group of eligible people and through the lifespan for each person. A substantial number of people are institution survivors, many of whom are separated from their families. Needs for more costly assistance to age in place are increasing as lives lengthen and, for some, the bodily consequences of institutional neglect catch up. New generations of adults have grown up in their family home with developmentally powerful early intervention, competent education and good personal and family supports. As a result they expect opportunities to choose supports for opportunities in community roles. Only a minority are dealing with conditions that require ongoing nursing and these people are very likely to benefit from a continuing relationship with a specialist nurse health advocate who has been a part of their history. A small number of people present extremely complex needs that will result in institutionalization unless committed providers learn with them how to support them well. The focus is on managing the boundary between individuals and community opportunities to actively support access to valued social roles. Families, mostly parents, continue to provide housing and substantial amounts of support to about a third of adults. For those of working age, integrated employment offers the best foundation for citizenship. Enforced poverty, racism and social devaluation of DD remain strong influences on people's life chances and demand attention and innovative responses. Overcoming disability discrimination and assuring access to benefits and services outside the HCB funded system –such as housing benefits and first rate primary and acute health care– is an effective approach to increasing people's assets.

"Frail elders" who use services for a limited period. The right service at the right time reduces costs to taxpayers.

A highly diverse population who require life-long support to live as contributing citizens.

[Wisconsin's] aging population is projected to grow from just over 900,000 people in 2015 to over a million people by 2020.This growth in the aging population will require a cost-effective system of quality supports to manage limited public resources to ensure that the needs of Wisconsin's most vulnerable citizens are addressed. The goal of Wisconsin's managed long-term care system is to provide the right service, in the right amount and in the right setting. Critical to the Department's success in bending an otherwise rapidly increasing cost curve is the promotion of:

- *The wise use of personal resources to delay entry into publicly funded supports;*
- *Healthy aging and achieving the best health possible for people with complex needs; and*
- *Coordinated, community-based supports that help people to maintain better health and independence.*

–Long-Term Care Expansion Report, p. 2

In core purpose

DHS justifications of Family Care appeal to reduction of the growing expense to tax payers created by a growing population eligible for Medicaid long term care.* If not diverted by prudent use of personal resources and timely community supports, growing numbers will swell the population eligible for Medicaid and thereby entitled to nursing home care at public expense. Eliminating waiting lists for less expensive services ultimately eases taxpayer burden. Expending public funds for long-term care is treated as an expense that can be reduced by entitling eligible people to assistance that meets assessed need in a cost-effective and timely way. Member satisfaction is an important asset for Family Care Organizations to manage and its measurement is a key focus of quality assurance.

Dane County frames supports to people with DD as an investment in citizenship. People with DD gain access to jobs and employers benefit. Parents who provide a home and support can continue to choose work outside the home. People with DD have necessary assistance to fulfill the responsibilities and rights recognized by the Americans with Disabilities Act and the State and federal rules governing the HCB waivers that multiply Wisconsin State tax dollars. It's a worthy use of public funds to pay for the personal assistance, technology and specialist interventions that offer people with DD good life chances because the lifetime accumulation of these costs is well beyond the material resources of almost every family. Cost consciousness, rigorous negotiation of individual budgets, and underwriting innovation to mobilize collective and community assets outside the DD budget stretches available funds by promoting engaged citizenship.

Purpose: reducing taxpayer burden.

Purpose: investing in contributing citizenship.

In logic of organization and administration

Services to people with DD are best managed as a form of state managed health insurance. Effective relationships are transactional and recognize the importance of harnessing and disciplining Family Care Organization and provider self-interest through contractual requirements, incentives and penalties. The DHS role is to construct and manage a quasi-market in care** that controls costs to the State and maximizes the flow of federal HCB waiver dollars by assuring compliance with CMS requirements. Minimizing the number of public

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* It will not escape the notice of anyone familiar with Wisconsin politics that there are substantial differences between the majority of Dane County citizens and the State government now responsible for implementing Family Care. Both Republican and Democratic administrations have promoted Family Care, but severely limiting public expenditure, reducing numbers of public servants, and privatization of services are distinctive priorities of the current Administration. Managed care could look different in a different political context.

** For more on quasi-markets –where services are coordinated and offered by competitive providers but financed from public funds– see, for example, Julian LeGrand (2011). Quasi-market versus State provision of public services. *Public Reason 3*, 2 pp. 80-89.

employees involved in system management is a state government priority and there is no expectation that DHS Family Care administrators will have expertise or involvement in service provision. Contract assurances guarantee that Family Care Organizations and providers come prepared to do the necessary work. DHS defines the structure of the system, selects Family Care Organizations, administers a standard contract that specifies Family Care Organization performance in detail, sets the capitated payment structure, and enforces licensure and quality assurance requirements.

Family Care is managed for uniformity. No matter where in Wisconsin a person lives they have access to the same benefits from a Family Care Organization governed by compliance to the same detailed contract. An economy of scale logic favors the growth of Family Care Organizations in member numbers and geographic scope and encourages bigger networks of bigger providers. At the Family Care Organization level innovation responds to DHS rate signals and rules that reduce State expenditure. Future opportunities for cost savings lie in bringing primary and acute care for Family Care members under unified management, opening the market to national health insurers and allowing for-profit enterprises to be Family Care Organizations. Service definitions are standardized, simplified and reduced to the smallest possible increments to allow cost analysis, encourage competition among providers on price and minimize demand for skilled direct support workers.

Family Care Organizations are designed to provide what is taken as otherwise missing: a service coordination mechanism, separate from service provision, that assesses members' needs and desired outcomes, matches them with the right services from their provider network, and assures their health, safety and satisfaction, adjusting services to meet changing assessed needs. Family Care Organizations manage people eligible for long-term care, a grouping based on the source of payment for services. Concern for cost effectiveness and member satisfaction is incentivized by a capitated rate structure, certified by actuaries, which puts Family Care Organizations at financial risk for meeting all assessed need among their members without resorting to waiting lists. Family Care Organization performance is driven by the negative reinforcement of avoiding loss of money through loss of members to competitors and consequent failure to maintain the reserves required to stay in business.

Over the years of Family Care growth and development these themes have grown stronger. Pilot Family Care Organizations held sole responsibility for a smaller, naturally defined populations and were governed by citizens naturally identified with the communities their organization served. The Department saw itself as a partner in innovation and maintained distinct organizational entities, staffed by experts in services to elders, services to people with physical and sensory disabilities, and people with developmental disabilities. These disability focused programs where merged into the Division of Medicaid Services in 2016.

Self-interest channeled through financial incentives in a state managed market will produce cost effective services.

Good support comes from committed relationships among people who highly value the full citizenship of people with DD.

DHS Design

- Quasi-market for long term care population modeled on managed medical care.
- Self-interest based transactions drive cost-control through fiscal incentives & competition.
- State control through rate setting, selection of management organizations, contract & regulation.
- Economies of scale create efficiencies.
- High value on uniformity across the state.
- High value on eliminating a wait for cost-effective services that meet assessed needs.

There are now at least two Family Care Organizations to choose from in each district. Operating Family Care Organizations report growing concern about the adequacy of capitated payment rates. Two Family Care Organizations have bankrupt and three have merged to attain a more competitive scale.

The Governor's 2015-2016 Budget proposed Family Care 2.0, a restructuring that indicates the Administration's desired direction of travel. It would expand the scope of Family Care to include managing Medicaid benefits for member's primary and acute care, open the market to health insurance companies including for-profit entities, and replacing IRIS with increased local competition among Managed Care Organizations. The legislature suspended implementation of Family Care 2.0, but DHS announced the intention to move Family Care in the direction of Family Care 2.0 as opportunities permit.

Dane County manages its DD system relationally by intentionally cultivating a culture that sustains collaborative relationships and actively supports innovation. The culture is shaped by shared values among people and organizations with diverse capacities. Values set strong boundaries that focus resources on individualized supports offering good opportunities for people with DD to self-direct the supports they need to work, participate in community life, and inhabit their own homes. Within these boundaries, providers develop distinctive competencies and discover niches of specialization. This culture has strong local roots. Leaders are committed to the places of Dane County and many have spent their entire career developing and delivering innovative supports that include people with DD in the County's neighborhoods and villages. Local provider organizations that set limits to growth in numbers are valued. A network of moderately and tightly connected relationships forms a container for negotiating the inevitable conflicts generated among people with strong views who share responsibility for managing scarce resources. This culture provides the context for establishing contracts and complying with the rules and requirements that accompany HCB waiver funds. Within its Human Service Department Dane County maintains specialist units that differentiate supports for elders from supports to people with DD. Senior managers have personal knowledge of many of the people and families the system serves. Dane County provides the greatest possible flexibility for tailoring supports to individualized services by billing for services under the most flexible service codes in the HCB waivers it uses. Dane County employs a small number of Case Managers with specialist case loads, but most coordination is accomplished by Brokers chosen and employed by people with DD to assist them in getting the best from spending their self-directed individual budget and mobilizing the many civic and publicly funded assets that Dane County offers its citizens. The people who provide direct support are valued, offered learning opportunities, and paid at least at the level set by the County government's living wage policy. The obligations created by relationships and shared values are primary motivators

Dane County design

- Culture shaped by collaborative relationships & common values.
- Single focus on the diverse population of people with DD & their families.
- Self-directed individual budgets, negotiated with broker support, offer the best chance of fair allocations & effective supports.
- Encourage high expectations for valued social roles.
- Local responsibility within Medicaid rules.
- Small & local providers are valued.

for County managers and providers alike. Formal contracts, policies and procedures and inspections play a real but secondary role in coordinating the work. Compliance makes it possible to stay in the game, it can never generate new winning plays; their source is respect for people's capacities and desires for a good life.

In confidence in finding efficiencies

Family Care assumes that because Family Care Organizations are at risk for serving all eligible people within an actuarially determined capitated rate they will discover efficiencies sufficient to meet their obligations and build their reserves. The transition process keeps people who are receiving services at the point of enrollment in a stable situation for a few months while rate negotiations with providers and network development go forward. Within six months Care Teams will use the Resource Allocation Decision (RAD) process with members to assure the most cost effective services to meet assessed needs. This process discriminates between needs, which entail entitlement to cost-effective services, and wants, which do not. People coming off the wait list will begin with cost effective services. When full entitlement is achieved, advice on best use of personal resources and immediate access to needed services will further reduce costs. DHS is sufficiently confident that the press release announcing the expansion of Family Care to the final seven counties predicts a cost saving of $550 per member, per month.*

Dane County leaders don't share DHS' confidence. They note that the effects of managed care structures are still contested in primary and acute care where they have been applied for longer and at greater scale.** Managed Care is still uncommon in administering long term care for people with developmental disabilities. Less than half the states applying capitated rates to long term care through Section 1115 Waivers include people with developmental disabilities.*** Model legislation governing managed long term care prepared by ALEC –an organization of state legislators committed to limited government, free markets

Significant reductions in Medicaid investment can be made by prioritizing cost-effectiveness. Quality & satisfaction will improve.

There is no way to make cuts of this extent without radically redefining quality.

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* DHS, July 28, 2016. *Family Care and IRIS Program to expand statewide*.

** See for example, Michael Porter & Robert Kaplan (July- August 2016). How to pay for health care. *Harvard Business Review*. They contend that "under this system cost reduction gravitates toward population-level approaches targeting generic high-cost areas, such as limiting the use of expensive tests and drugs, reducing readmissions, shortening lengths of stay, and discharging patients to their homes rather than to higher-cost rehabilitation facilities. As a response to the failed experience with capitation in the 1990s, current capitation approaches include some provider accountability for quality. However, 'quality' is measured by broad population-level metrics, such as patient satisfaction, process compliance, and overall outcomes such as complication and readmission rates.
This all seems good at first blush. The trouble is that, like the failed FFS [fee for service] payment system, capitation creates competition at the wrong level and on the wrong things, rather than on what really matters to patients and to the health care system overall."

*** Mary Watts, Mary Beth Musumeci, & Petry Ubri (2017). *Medicaid Section 115 Managed Long Term Services & Supports Waivers: A survey of enrollment, spending & program policies.* KFF.

and federalism– does not include people with DD* ALEC includes them in a different model bill that would commit states to a system very similar to IRIS.** The evidence base that Family Care can draw on to underwrite its confidence is thin. DHS has done little to develop evidence beyond what is required by CMS.*** People with DD in Iowa have experienced significant risks as their system has moved farther in the direction set by proposals for Family Care 2.0.****

As CMS requires, DHS contracts with actuaries to assure that capitated rates meet technical requirements. While the adequacy of funding depends on actuarial methods, from the citizen's point of view the process functions as a black box stuffed with recondite models and formulae imported from the insurance industry.***** It is difficult to trust a process that one is expected to accept on blind faith, especially when it sits alongside a projection of significantly decreased funding. A handout, "Care Efficiency Assumptions", from DHS circulated as the transition began. It asserts that the "Dane Acuity Adjusted DHS PMPM [per member per month]") will decrease from $4,640 in 2018 to $3,675 in 2020, a decline of 20% in two years.

The practical question, Where will efficiencies come from? DHS staff assure citizens that no one will lose services that they need. The Family Care mandate excludes waiting for services that meet assessed need. Immediate availability of services is one of the Family Care keys to cost control, along with minimizing use of nursing homes and institutions, delivering services in people's own homes, encouraging employment, employing as much natural support as possible, coordinating services and community resources, and achieving administrative efficiencies through such measures as improved control through information technology. Dane County makes minimal use of nursing homes and institutions; most people who live with their families have respite and access to contracted resources; a high percentage of people with DD employed; brokers assist people to negotiate and make good use of their individual budget, coordinate services and access benefits and community resources.

Cost cutting tactics

- Tighten eligibility criteria.*
- Limit expenditures to restrictively defined services to meet "assessed need."*
- Restrict investment to system assessed standards of "health & safety".*
- Assume a distinction between "wants" & "needs" that reduces or eliminates focus on support to valued social roles in favor of narrowly defined tasks.
- Interpret "cost-effectiveness" to discount personal and community costs of social exclusion & group management.
- Lower expectations for individualized support to integrated jobs, making one's own home and civic engagement.
- Simply announce rate reductions.

* As much as possible replace human judgment by those who know people with instruments & procedures that claim to be "objective".

* ALEC (2017) *Medicaid Managed Long-Term Services and Supports Act*.

** ALEC (2013) *Medicaid Consumer-Directed Care Act*.

*** See Family Care Program Monitoring & Evaluation. The Government Accountability Office (2018) criticizes CMS and the states: *Medicaid Demonstrations: Evaluations yielded limited results*. In 2010 DHS commissioned a technical assessment of rate setting and capacity to maintain required reserves that does not concern member experience.

**** See for example *Des Moines Register,* June 13, 2017. *Disabled Iowans fed up with cuts under privatized Medicaid, sue Gov. Reynolds.*

***** DHS provides annual reports on the calculation of the capitation rate. The 2018 report includes this paragraph. "The results of this report are technical in nature and are dependent upon specific assumptions and methods. No party should rely on these results without a thorough understanding of those assumptions and methods. Such an understanding may require consultation with qualified professionals." From the citizen's perspective no truer words were ever written.

Its hard to think that DHS staff and Dane County citizens share a common understanding of terms like “assessed need” and “the right services, at the right time, in the right place”. It is hard to see how joining management of services for elders and people with physical disabilities will generate sufficient economies to hold public funds steady for people with DD.

In where language is grounded

“Will I still get supported employment after Family Care comes?” Repeated variations of this question at a public information session expressed a grave concern shared by many people and family members attending a DHS sponsored public information session. Answers from DHS representatives consistently reassured the questioners that things will stay the same for them. Responses always included the same phrase: “Supported employment is in the benefits package.” Question and answer use common English words but are grounded in different language worlds.

The person with DD asks the question from a thickly textured daily experience. For 60% of adults in Dane County services this means a job in a particular place. It may be a job they love or a job they want to move on from. A setting with familiar co-workers. A job they travel to with a Metro para-transit driver they are acquainted with. A job they do with the support of a job coach from a provider that has assisted them for years through multiple ups and downs in their life.* The work this person wants to conserve has familiar smells, sounds and smiles. And, if they are dissatisfied with their provider, their broker will help them choose among choice of supported employment providers who have different styles but share a common commitment to get to know them and earn their trust through a search for a job that makes a good fit with their interests and capacities.

Bureaucratic language produces adequate services. Writing a requirement into a contract or rule justifies a promise that people will experience its benefits.

Reliable words come from sense-making conversations among committed people searching for valued experiences in the local life of specific people.

DHS representatives don’t answer from the same ground that the wheels of the questioner’s chair rest on. Their answer references the written provision of a contract, it does not assure continuity of lived experience. There are multiple contingencies in the machinery of Family Care. The provider the person trusts may not be in the network of the Family Care Organization that enrolls the person. Their rate for what the Care Team sees as equivalent assistance may not be competitive. Consultation on positive behavior support that has kept difficult situations together may be missing. After an initial period of maintaining the services a member has at the point of transfer, a Family Care Organization controlled planning process aimed at implementing efficiencies will begin. Employment might be assessed as a want rather than a need. Individual supported

* The effects of successful Dane County supported employment agency relationships, some of which have lasted for more than 20 years, are reported in Lou Brown, Betsy Shriaga & Kim Kessler (2005). The quest for ordinary lives: The integrated post-school vocational functioning of 50 workers with significant disabilities. *Research and practice for persons with severe disabilities. 31*, 2: 93-121

employment may not be judged the benefit that offers the most cost effective path to meeting assessed needs. The Family Care Organization may adopt a different approach to work-related transportation. The response –"The benefit is in the package"– is accurate but grounded in a world constructed by policy, contract, and reporting procedures alien to the questioner. The benefits package lives in a document that informs a chapter of an Family Care Organization's handbook and in servers tended by authorization specialists who store entries into cells on spread sheets. Whether or not the benefit's actualization smells familiar to any particular person is beyond the reach of this form of language.

The language the State finds adequate to implement Family Care is thin and abstract, a matter of statistics on targets met on time, member satisfaction scores, and rates of contract and regulatory compliance revealed by inspections and audits. Much Family Care language comes down from CMS as DHS accommodates and interprets CMS demands to comply with HCB waiver assurances. Stories from people's lives are of primary value for quick cuts in marketing videos.* There is reference to evidence based practices but minimal citation of the extensive literature on services to people with DD. In these rarefied terms any willing provider who meets applicable standards is interchangeable with any other. This mindset views providers of defined services as equivalent and choice weighted to price as legitimate. A unit of home care is the same whether delivered by someone with whom you have a longstanding and trusting relationship or a succession of strangers in scrubs. To say this form of language is thin does not mean it lacks effect. It encodes and effectuates power over people and organizations. In the IRIS Program it authorizes contracted nurses who know nothing more of a person than can be learned on a computer screen to decide the legitimacy of calling on the assistance of a community nurse consultant who has a years-long relationship with a person and their physician. It introduces the people and families who appeal a denial of that support to a complicated and often exhausting bureaucratic exercise conducted in DHS language.

Dane County leaders ground their language in their experience of life as they live it in relationships with people with DD and their families, direct support workers, employers, neighbours and landlords. They favor thicker, more detailed descriptions that bring in more perspectives, acknowledge uncertainties and support a search for even better possibilities in community life. Everyday words and images open discussions to more people and support their commitment to exercise power with people rather than power over them. The grammar incorporates biases toward self-determination and inclusion that alert them to the ever present risks that people with DD will be isolated or pushed into staff controlled groups at the margins of community life. Statistics track performance

* View a two minute video example at www.dhs.wisconsin.gov where a member's declaration about Family Care is captured on screen: "A MIRACLE"

of the system as a whole, which helps assess strategies for employment and life in one's own home. Stories testify to the diversity of individual and family experiences of DD and the importance of individualizing supports and investing in good relationships. Stories are situated in familiar Dane County places, like the approximately 900 places people with DD are employed with support. They invite engagement and empathy. Stories provide reference points, reveal breakdowns, and generate practical knowledge for the work of strengthening people's voice, mobilizing assets and building community.

Conservation efforts*

As DHS set transition to Family Care in motion Dane County leaders moved from discussing uncertainties to begin the work of conservation. Dane County intertwines supports delivered by provider agencies with a set of County funded supports that provide specialist supports as needed. Many people with significant impairments depend on the agreement with Madison Metro for a safe ride to work. The WIN Nurses and the psychiatry clinic, available at the point of need, offer specialized supports tailored to community life that are rare to the vanishing point in typical nursing or psychiatric practice. These and many other interdependencies shape a County agenda for transition that reaches far beyond a person's choices of Family Care or IRIS and one Family Care Organization or IRIS Consultant Agency or another. Conserving specialist capacity is necessary to maintain continuity of support. Loss of specialist capacity risks what is good in peoples' lives and what produces desired system outcomes.

So far this paper has emphasized the values and relationships that unify Dane County leaders. There is no better expression of this group's diversity than the multiple paths to conservation that they produced. Based on their roles, their affiliations, their personal influence networks, their interests and their talents, they generated six streams of action. DHS responses to these initiatives filled out County leader's picture of Family Care as the State understands it and led to further action.

Preparing people and families for the choices at transition

Conserving continuity of support holds priority for most people and families. Self-determination is a core value of the Dane County system. The process of transition is technically complex, as this locally designed poster demonstrates. It is also disrupting: there are important uncertainties about whether the services a person counts on will continue and the loss or potential loss of relationships with brokers and providers they know and trust.

Specialized Capacities

- METRO Transportation Partnership.
- Community Nursing.
- Crisis Response.
- Consultation on positive behavior support & communication.
- Counseling.
- Psychiatry clinic.
- Community Connecting.
- Housing Counseling; home modification & housing development.
- Independence skills training.
- Technology assistance & support.
- Advocacy & support for crime & abuse victims.
- Organizing people & families.
- Unified staff training & learning groups.

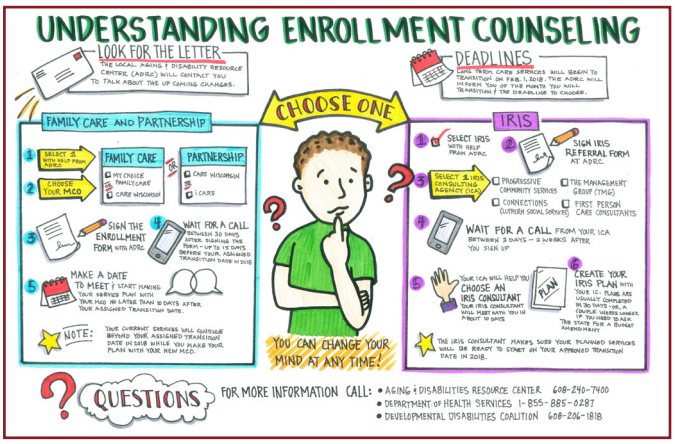
Family Care Organizations will purchases specialized clinical supports from their provider network as individuals are assessed to need them.

Enabling functions, like those in the box above, are best financed & delivered as distinct elements of the whole system.

* The idea that the greatest flexibility of response to a rapidly and unpredictably changing environment comes from clear and energetic focus on sustaining the values worth conserving is developed in Humberto Maturana & Pille Bunnell (1999) The biology of business: Transformation through conservation. *Reflections: the Society for Organizational Learning Journal 1*, 1: 82–86

Local retired citizens with long term care expertise were an important asset for people with DD and their families who must make sense of the change and their new options. They offered a series of well attended trainings on Family Care and IRIS and developed information sheets and guides shaped by the questions arising among people and families as the transition moves forward.

The DD Coalition maintained a website that presented it's members' views on the Family Care Transition.* In addition to sponsoring a number of information sessions, LoV Dane, a grassroots organization of people with DD, family members and citizens, disseminated planning tools and guides to negotiating desired supports, and initiated a learning circle to support self-direction.**



Brokers assisted people to produce one page profiles that clearly identify the supports they currently rely on and the benefits that these supports provide. This process helped people clarify what works for them. The profile could inform meetings with an Options Counselor and their IRIS Consultant or Care Team.

Local leaders encouraged participation in DHS sponsored information sessions. This resulted in what DHS staff said was the biggest expression of local interest they have encountered in transitions to date. They had to schedule extra sessions to accommodate the numbers of interested citizens.

DHS accounts of the IRIS Option seemed excessively narrow to several local citizens who have considerable experience with IRIS. They think DHS statements contrasted IRIS with Family Care in terms that discouraged its choice. IRIS, as they heard the DHS account, was presented as an option for people who want to take full responsibility for employing their own staff, without support or back up. On the other hand, Family Care was presented as offering members the option of self-directing any approved service with the continuing support of a full team. Local IRIS experts say that this gravely understates the variety of supports that a person can purchase with an IRIS budget. They produced materials and presentations that told a bigger story about IRIS.

Organizing personal support for transition

The people who organized and presented locally sponsored information sessions encouraged people and families to connect with friends and allies and support each other to understand their options and choose. This support matters after enrollment, as people make their plan with a Family Care Organization Care Team or negotiate their IRIS budget.

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* ,www.whatdoesfamilycaremeanfordanecounty.com

** (lovdane.org/fcandiris/)

Pathfinders, a small voluntary association, emerged and engaged a modest number of people and families who want an opportunity to clarify what matters most to them in conversation with someone who will listen, support their thinking through what is possible and accompany them through the transition. Pathfinders also maintained channels to get and share DHS staff answers to family questions.

Citizens volunteered as community allies free of conflict of interest to accompany people who would otherwise lack support in the enrollment process.

People with expertise volunteered to meet one-to-one to assist people to understand their options before Options Counseling and sometimes to accompany them to meetings if the person and family choose.

Sustaining threatened capacities

Preserving specialist functions, training, and community organizing meant developing new relationships with Medicaid and other potential resources. The organizations that have been contracted to be available when needed explored assisting IRIS participants, joining Family Care Organization provider networks, and offering Medicaid fee-for service, as well as providing services, consultation and training outside Dane County. They found ways to reduce costs. They explored other funding streams.

Each move affects organizational and personal identity and relationships with people with DD and their families, with direct support workers and provider management, and with professional networks and community partners. Adapting to multiple new resource environments calls for thoughtful effort to conserve what makes current offerings work.

Dane County maintains responsibility for administering publicly funded supports to children and young people up to age 18 with DD and their families. This could offer a home for some employment agreements currently managed as adult services. Even under Family Care, Counties continue to hold responsibility for institution costs. This gives Dane County a stake in assuring that crisis supports to people at high risk for institutionalization remain available and effective. To allow time for adaptation to the new environment, the County invested some bridging funds in critical services.

Inviting collaboration with DHS

The Department's assurance that people would not lose services under Family Care made it reasonable for County Mangers to think that DHS staff would be interested in conserving the local capacities that generate high rates of integrated employment, low rates of institutionalization, and high rates of prospective compliance with the CMS rules governing residential settings and person-centered planning. They offered DHS staff responsible for Family Care a variety of invitations to collaborate in conserving the capacities that make the Dane County system work.

- They arranged tours that gave DHS staff the chance to meet people at work and at home and hear from them, their families and support staff about what works for them.
- They reached out person-to-person to engage DHS staff in conversation about issues of mutual interest and options for making progress.
- They wrote an account of *The Dane County Difference*[*] that documents high levels of outcomes consistent with DHS priorities and describes the interdependencies that produce those outcomes.
- Through all available channels, they persistently raised questions and offered feedback that raised the issues on their conservation agenda.
- The raised questions about how the capitated payment rate takes account of local labor market conditions as well as current and projected service costs.

None of these efforts interested DHS staff in collaboration on the County's desired agenda.

County leader's desired conservation agenda with DHS

- Maintain the transportation agreement with METRO.
- Continue the policy of supporting graduates in jobs & maintain the alliance with VR & schools.*
- Maintain the network of specialist supports to health & behavior.
- Make broker functions available to IRIS participants.*
- Assure a living wage for Direct Service Workers.
- Maintain a capitated payment rate that sustains individualized support to people at work & in their own homes.
- Let people choose who supports them in enrollment & planning meetings.*

* Some progress on these issues.

Political engagement

Those with connections to local and State political figures kept them aware of risks and enlisted their advice and help.

Contesting

DHS showed little enthusiasm for collaborating on Dane County's agenda. As enrollment approached DHS control of information became a point of conflict.

DHS staff did not welcome local initiatives to support decision making. They took the position that a successful transition depends on DHS having complete control of informing people about the transition process and their options within it. On their view, DHS staff have sole authority to offer all the information people and providers need on the transition, when DHS staff judge they need it. For individual people, staff of the local ADRC structure a free choice among options based on the objective information DHS deems sufficient to inform their choice. County managers were instructed to step back from responding to citizen inquiries and refer all questions and concerns to DHS staff. Providers were admonished to avoid attempts to influence the process in any way. DHS saw locally originated messages as sources of misinformation and confusion that stirred unnecessary anxieties and created false expectations. Most important, local efforts to support decisions risked violating stringent Federal conflict of interest rules by exposing people to undue influence by self-interested parties seeking to profit from people's choices. DHS threatened stiff penalties, including loss of Medicaid funding.

Those Dane County citizens not bound by DHS's formal authority and not liable to threats of fines and sanctions continued to exercise their First Amendment

* Read *Building on the Dane County Difference*

rights to assemble, teach and comment. They believed that they had two good reasons to contest DHS information control.

First, DHS forbade Family Care Organizations and IRIS Consultancies from engaging with people and families and answering their questions before a person enrolled with them. But learning about an option by talking to the people whose services you are considering seems like a reasonable strategy for making important decisions. In Dane County people met and questioned candidates before choosing their brokers and service providers. It seems oddly disrespectful of people's judgment and Family Care Organization and IRIS Consultancy integrity to enjoin inquiry in the name of protecting free choice. As well, the denatured "objective" information that ADRCs were authorized to share about the Family Care Organizations made the basis for good decisions even thinner.

Second, DHS forbade allies from accompanying people in enrollment counseling meetings if they are in paid roles like broker or support provider. These policies reflect such a shallow understanding of the realities of life for people with DD that it became a conflict that involved an attorney and the Dane County legislative delegation.

Many people and families have good relationships with brokers and support providers. They trust these paid workers and count on their knowledge of the person's history, what matters to them, and what works to support them. It makes sense that some people and families would welcome trusted help in making sense of the choices in front of them. Furthermore, those who understand DD recognize that a best practice is at stake here. Supported Decision-Making* recognizes that people with DD have far greater decision making capacity when they have well organized decision supports. These supports must be chosen to include people committed to their well being and aware of their information processing and communication preferences. When a paid provider is an important part of a person's decision support system, it seems a reasonable accommodation to their disability to involve them.

Excluding allies disadvantages people who have no one other than paid staff who know them well enough to assist them in decision making. A history of institutionalization has cut many people off from family. Aging, disability and distance leave some guardians reliant on information and advice provided by paid people they trust; some are not even in a position to attend enrollment counseling or Care Team meetings. It seems arbitrary to lock out those a person relies on for every other decision in their life from the choices presented in enrollment counseling.

DHS held that the controlling authority in this situation is an iron-clad CMS rule forbidding conflict of interest. DHS had, they said, no choice but to rigorously enforce this rule.

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* See National Resource Center for Supported Decision-Making.

A citizen and parent with a lifetime of encountering allegedly unquestionable rules retained an attorney with substantial experience in health and human services. The attorney's study of DHS position and inquiry with CMS revealed that it is Wisconsin DHS interpretation of conflict of interest requirements that results in these exclusionary and controlling practices. CMS does require states to minimize conflict of interest, but leaves it to the states to specify the details.

Others concerned with this and other issues enlisted the whole Dane County legislative delegation.* Legislators engaged the DHS Secretary. This resulted in a meeting, hosted by a legislator, that brought the Secretary and her staff together with a number of Dane County stakeholders. Ultimately these interventions led DHS to a partial compromise. Brokers were allowed to accompany people in enrollment counseling when the person or guardian requested their presence.

Transition management: Ideal and experienced

It's possible to imagine a transition to managed care in which State officials recognized that existing capacities produce results that both State and County value and entered into collaboration to conserve and build on those capacities. In this case both DHS staff and County leaders would recognize that they share the adaptive challenge of responding to uncertainty in generative ways while they manage technical problems to implement managed care and accommodate CMS requirements. They would learn enough about each other's worlds to develop a shared sense of what is possible and how to achieve it. Mutual respect, curiosity, enthusiasm for learning and focus on discovering and realizing the highest potential in the transition would characterize their interactions.

As County leaders experienced the early stages of transition it became clear that DHS staff act from a different image of transition management. State officials treat Family Care as a finished product beyond modification regardless of local accomplishments, concerns and questions. They had no need to learn from the local system that Family Care will replace. They dismissed current practice as no longer relevant because Family Care offers unquestionably superior alternatives, especially the entitlement that eliminates Waiting Lists and the opportunity to choose among managed care options. In public meetings they responded to every question with a complete and certain answer that promised that change equals improvement. They met concern with reassurance that aimed to sooth anxiety by asserting that what is needed will be provided and everything necessary will continue unchanged. Their bottom line when County leaders raised questions: we have the authority and we control the Medicaid money that you are completely dependent on, and you don't.

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* Read correspondence on this topic between members of the legislature and the DHS Secretary here.

Individual DHS staff varied in the courtesy they displayed in listening to local concerns. Some expressed interest in the information and issues that local leaders raised with them. Others dismissed Dane County's accomplishments, discounted local expertise to near zero and sometimes acted disrespectful or even punishing or threatening. County managers were accused of manipulating waiting lists and making improper use of Medicaid funds in transportation agreements (even though these agreements were made in collaboration with DHS officials responsible for HCB waiver administration at the time). Providers were threatened with fines and sanctions should they be apprehended offering advice to people who count on them to make sense of their options. Gaining partial responses to County concerns about maintaining an uninterrupted transition for employed graduates and allowing Brokers to support people in options counseling required persistent effort in a difficult climate.

From County leaders perspective, regardless of the degree of courtesy they exhibited, DHS staff responsible for transition shared these qualities. None had relevant experience in services to people with DD and none seemed to regard this as a disadvantage or a reason to learn from Dane County's expertise. None had been involved in the long collaborative relationship between previous DHS staff and Dane County's DD system. All seemed at least somewhat influenced by long standing stories promoted by some in DHS. One such story says that services for people with DD enjoy unfair advantages over services to elders. Another says that Dane County's DD System has been indulged rather than authoritatively managed. While empowered to dictate the details of transition, none saw themselves as able to negotiate even minor changes. They said that obedience to CMS rules ties their hands. They typically adopted a public posture of transmitting authoritative answers to every question, often with a "We know what is best for you" tone which sometimes sounded patronizing and sometimes sounded exasperated. The phrase, "We have done this 70 times in other counties and we know how to do it" occurred frequently to parry proposed modifications, though many DHS staff member's personal experience of actual transitions since 2000 was limited.

Some County leaders felt resonance when told Thucydides' account of the Melian Dialogue* From County leaders' point of view the transition they experienced was a matter of State imposition of power over the lives of people and families, a great many of whom they know and care about. Questions of how to conserve effective means of producing the results that DHS says it values failed to penetrate veils of disconnection that lie between Dane County citizens and DHS staff. Heartfelt concerns about preserving good working relationships failed to travel the distance imposed by bureaucracy. Grief at the loss of innovative and functioning structures built with care over entire careers did not penetrate the defenses erected around public service roles that are themselves devalued by those currently in political ascendancy.

*Found in Chapter XVII of Thucydides *History of the Peloponnesian War* (411 BCE), this case study reconstructs negotiations between leaders of the neutral island of Melos and Athenian representatives who demand that Melos join their confederation. To support their appeal to preserve their independence and neutrality the Melians appeal eloquently and persistently to the Athenian's sense of what is right and decent. The Athenians reject their appeal, invade Melos, subjugate its people and colonize its territory. An Athenian representative to the negotiation refutes the argument from respect for what is right this way. ***Right, as the world goes, is only in question between equals in power, otherwise the strong do what they can and the weak suffer what they must.***

Why?

This question deserves thoughtful answers from many voices. Views from a later time, when the effects of changes that now provoke concern, grief, anxiety and anger are more clear, will be cooler and more thoughtful. My initial speculations on a short answer and a longer answer are here.

A short answer

There is a season for everything,
a time for every occupation
under heaven.
–Ecclesiastes 3

The season changed.

The Dane County system evolved in a State administrative environment that began to diverge from Dane County's approach to system development and management in the late 1990s and early 2000s as Family Care was designed and piloted. As Family Care developed, and especially since 2010, DHS has moved Family Care in a direction summarized as **Oppositions** (page 16 and following). Until 2016 the County was buffered from accumulating changes in the State's long term care environment. DHS administered the HCB waivers Dane County has used for decades separately from the Family Care waiver, in a DHS Bureau distinct from Family Care administration and focused on people with disabilities. As the number of Counties joining Family Care grew, Dane and with six other (much smaller) counties became outliers. The Legislature pushed these Counties into Family Care. Though County leaders had anticipated the change for some time, its impact was multiplied by recent modifications of Family Care and changes in DHS structure and staff.

Stories of system change are often told as reform of the dysfunctional or modernization of the outmoded. The end of the Dane County system fits neither pattern. Measured against outcomes that Federal and State policy establish as desirable, Dane County currently out-produces Family Care by substantial margins (see page 6). State projected cost/effectiveness ratios are speculative and debatable. Dane County's system passed into Family Care and IRIS simply because it no longer fit the policy environment formed by a stream of political decisions over the past twenty years. Its season has passed.

A longer answer

Our politics fail us.

It is difficult for our governments to support citizens to make progress on complex issues that are hard to understand, seen and defined differently from very different perspectives, and threaten disruption and loss of what we value and benefit from in the short term. Some of these issues are often in the news, though this does not in itself make progress possible: climate change, income inequality, the unjust effects of racism and sexism…. Even proper naming

demonstrates differences in perspective that must somehow be reconciled in order to make progress.

Setting support for people with disabilities on a policy foundation that assures adequate public investment in support for full citizenship is not a headline issue. It may rate a mention in news items that highlight the effects of the baby boom on the cost of health care or the impact that growth in Medicaid expenditures has on a state's budget. Occasional human interest stories identify the effects of care-taking on family life, more often emphasizing family burden than the positive contributions of people with DD. But the political deliberation necessary to set long term support on a firm policy foundation that justifies and directs adequate public investment seems beyond us, at least for now.

An exercise in imagination.* To my mind a satisfactory long term support policy would provide answers to these questions that meet the standard of justice established in The UN Convention on the Rights of Persons with Disabilities.**

- What kind of community do we want to be? Given the contributions that people with DD can make to community life when they have individualized, adequately funded support, do we choose to recognize their dignity, the worth of their presence and participation and the justice of supporting their full citizenship through public investment?
- What claims on public funds are people with DD and their families entitled to as a matter of right and what corresponding duties are required?
- How will effective responses to these claims be sufficiently funded?
- Which forms of support offer people and families the best life chances and the greatest respect for their dignity? Which do not?
- What compensation and terms of employment are fair for workers who offer direct support and effective in recruiting and retaining sufficient numbers of capable people to do the work in the ways that people and families deserve?

Just answers are most likely when these questions are considered from the perspective of support for full citizenship.*** This matters because significant money

Neanderthal extinction
A metaphor

Stories of change are often formed by the pattern of superiors replacing inferiors. A change in the way paleo-anthropologists explain Neanderthal extinction provides an alternative to this pattern.

Social Darwinist stories of species extinction, told in colonial times and terms, cast Neanderthals as a completely separate, inferior species, designed and destined to be replaced by superior humans.

Contemporary Darwinism tells a more interesting story. Available evidence suggests that Homo Neanderthalis had at least as much intelligence and skill as Homo Sapiens. Their extinction is best explained as a result of overspecialization. They were adapted so successfully to their Ice Age environment that climate change gave Homo Sapiens a reproductive advantage.

Perhaps hopefully for the Dane County legacy, many humans alive today carry Neanderthal DNA in their genes.

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* This is not an entirely impossible dream. Australia's Commonwealth Parliament and State Governments have constructively engaged these questions from a disability rights perspective in legislating and beginning to implement the National Disability Insurance Scheme. Though initiated from a cost control perspective, policy development and implementation have been strongly influenced through grass roots, broad based organizing by, among others, Every Australian Counts. Implementation difficulties and contradictions abound, but within a clear policy framework, distinct from health care, based on positive values.

** Once these are answered a cascade of technical questions arise. How is disability defined and determined? How is sufficiency of funding established? Etc.

*** "Citizen" is a troubled term today, but it is fundamental to my understanding of the questions our politics must engage. I believe that responses to disability founded, as they should be, on support for full citizenship should be available to any resident, regardless of legal status.

and social costs are involved. Too little tax money, poorly directed, sacrifices social benefits and accumulates compounding social costs for people and their families, workers who offer support and their families, communities and the State's economy. Proceeding as if disability were a chronic medical condition is discredited by history and current effective practice. The Americans with Disabilities Act and The UN Convention on the Rights of Persons with Disabilities are both founded on recognition of equal citizenship. Specifying the answers to policy questions from the citizenship perspective develops the structures necessary to redeem the promise of these laws for those disabled people who require long term support.*

Today's DHS structure and administration of Family Care, focus far too much on technical fixes alleged to reduce tax money costs and far too little on the social and relational dimensions of good long term support. Client interests are assumed protected through paper assurances and bureaucratic processes that claim to assure compliance with detailed rules and policies. From a full citizenship perspective the most influential current policy reads as if it were intended for those on the Other side of an us/them divide between taxpayers and takers. Workers who hold people's wellbeing in their hands are treated as if they were a low skilled labor expense whose low income doesn't affect the quality of their work, their family and community life, as well as their local economy.

No doubt these are hard questions to take on from a full citizenship perspective. Demographic trends –growing numbers of elders acquiring disabilities, longer lives for people with DD and physical disabilities, increasing diagnosis of autism and other disabilities– imply tax-increasing costs that freeze brains. Persistent, principled disagreement about individual and family responsibility, collective responsibility and the role of each level of government, which are obvious in continuing national debates over health insurance, social security and the minimum wage, put good enough agreements to assure adequate funding for long term support at a distance. Financing and managing health care and support to people with DD are so deeply entangled as to stymie creative imagination. The State depends so much on Medicaid as to make independent State action almost unthinkable. There are differing interests and preferences at stake in determining the forms of support worth public investment. This includes loyalty to service forms that some see as incompatible with individualized support for full citizenship, such as nursing homes and congregate living arrangements. Many services have substantial sunk costs in buildings.

Though a citizen movement may be the best route to securing effective political attention, the time has not been ripe for advocates to organize broad based,

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* To explore a citizenship-for-all foundation for public investment it can help to study the idea in different national contexts. For a thoughtful and provocative exploration in the UK context, see the work of Simon Duffy. To connect internationally join Citizen Network.

grass roots discussion and action to define and claim sufficient political attention to a full citizenship approach to assure adequate public funding. The work involved truly embodies Max Weber's observation, "Politics is a strong and slow boring of hard boards."* Such organizing, when it comes, will generate a positive narrative of long term support that tests and influences twin limiting but usually unstated assumptions. One, that most citizens want to be on their own to pay for long term support and see publicly funded long term support for their family members and neighbors as a burden that they want lifted regardless of the social costs. Two, that most people agree that whatever public funds prove necessary are best managed by large scale organizations, structured on the model of health insurance companies with the option of operating for profit.

In the meantime advocates with different views and values have long allied and organized political action to eliminating waiting lists. They have seen entitlement to State controlled managed long term care as the prize worth the price of disruptive change. Uniform availability also attracts broad support: no matter where in Wisconsin a person lives, the same package of benefits is guaranteed to anyone eligible whose assessed needs justify them. DHS has mirrored the federal system and taken delivery on these advantages to be technical problems, resolved by specification of benefits, properly drawn contracts that demand effective performance, actuarially sound rates, and well formed and enforced regulations.

Save IRIS is a hopeful example of citizen action in Wisconsin. The Governor's initiative to replace IRIS in the move to Family Care 2.0 led IRIS participants to organize and persuade the legislature to delay the change indefinitely.

Building from saving a current benefit to shaping a more comprehensive policy is a leadership challenge.

Looking ahead

People and families in counties waiting for services or confronted with unresponsive services have surely and immediately benefited from Family Care.

Current issues

As all 72 counties reach entitlement, several issues require attention, including these.

- Family Care is a complicated experiment in technical approaches to cost containment and quality. No evidence base underwrites its effects on the life chances experienced by people with DD. The adequacy of rates has a powerful effect on the nature and quality of what people no longer have to wait for. Limits on DHS demands for economies have not been clearly and transparently set. Actuaries define themselves as practitioners of the science of managing financial risk. They don't claim to do moral assessment or outcome evaluation. Investments in external evaluation of the quality of supports under different rate structures are missing.
- Tested against the standard set by The UN Convention on the Rights of Persons with Disabilities the nature of the managed care entitlement is ambiguous. There is no defined entitlement to support for the choice of integrated employment or life with support in one's own choice of home.

* Max Weber (1918 [1946]). Politics as a vocation. P. 48.

- Variations in performance (page 6) show that statewide availability of the same waiver defined benefits doesn't necessarily mean that people can access supports of similar quality and effectiveness no matter where they live.
- Family Care Organizations and IRIS participants hold responsibility to do the creative, adaptive work of creating sustainable supports to a good life within State set rates. This work requires space and resources to innovate. DHS exerts centralized control through increasingly detailed contract requirements and rules that decrease the differences among Family Care Organizations and IRIS participants that allow learning. DHS expectations of increasing cost savings decrease money available to try and learn from new approaches. Centrally initiated re-organizations and changes to Family Care demand attention, increase uncertainty and shrink the space for innovation.

Reasons for hope

There are good reasons for hope. Progress in the lives of people with DD has never happened under optimal conditions. Family Care Organizations and the IRIS program can work with people with DD and their families and providers to make progress on these issues without an adequate State policy or sufficient funding. But work to build a better policy foundation is worth doing, even while dealing with short term effects of the changing Family Care environment.

Dane County's system as a locally managed, tightly coupled, interdependent network of organizations and alliances passes into history as a comprehensive response to the desire of adults with developmental disabilities and their families and allies for a good life. Their desire for a good life remains. The provider organizations that have well developed relationships and capacities to offer individualized supports remain. The leaders who hold the values that have guided more than 40 years of local development remain.

As of June 2018, more that twice as many Dane County citizens had chosen to self-direct their supports through an individual IRIS budget than is the case in the rest of Wisconsin. How this substantial number of people and families organize themselves for mutual benefit and collective action will shape the future of inclusion in Dane County communities and workplaces.

The coming months will show how effective Family Care Organizations and IRIS Administrators can be in conserving and building on the structures and knowledge they inherit from a generation of collaboration oriented to support self-direction and create opportunities to do a job and make a home and a life in community. It should be possible to conserve good relationships between people and providers and relationships among providers and advocates if people have the will. It is some of the structures and agreements that have made a system that works are most in doubt.

The chances for a good future depend, as they always have, on relationships that hold commitment to the dignity and value of people with DD and generate person and community scale innovations. Dane County has many assets in networks of committed people, the remarkable capabilities of its providers, and the abundance of opportunities for engagement in the life of its communities, as well as whatever resources Family Care and IRIS have to offer. From the resilience of committed people, a new system de-centered from County government administration of Medicaid funds, will emerge as people with DD, families and allies organize to make the most of all of these assets.

Choices of People with DD		
	Dane County	The rest of Wisconsin
Family Care & Partnership (Managed Care)	45%	**78%**
IRIS (Self-directed individual budget)	**55%**	22%