Promoting Sustainable and Progressive Systems of Support

AAIDD Wisconsin
Real Change -- Issues, Insight, Impact
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Delivering on the promise... What promise?

How are we doing? -- What the stats say

Focus on work in Milwaukee County

What to do next

Concluding remarks
Delivering on the promise...

What promise?

“enter the functioning sphere of [people with intellectual disabilities] to teach culturally normative behavior.”

Wolf Wolfensberger

“try another way…”

Marc Gold
What do you believe? And when did you believe it?

Integration ➔ Inclusion
Independence ➔ Interdependence
Productivity ➔ Contribution

Self-Determination
Self-Direction
Supported Decision making
Integrated Supports
Person-Centered
Families!
Supports!
People First Language
Continuum Trap
Developmental Model
Normalization
Self-Advocacy!

Choice!

1960’s “Label jars, not people!”

“Who’s in charge?”

“Nothing about me without me”

“Thank you, but what you built we don’t want”

2016
Challenges Ahead

- Accelerating service demand and budget stress
- Turbulent policy responses involving enduring dependence on legacy systems and an increasing reliance on families
- Shifting administrative framework and regulatory infrastructure
- Workforce shortages
- Continued push for community integration, participation, contribution and self-direction.

Decisions Made → Future System
One question to ask...

Why are we doing this?

Why

How

What
The BIG IDEA

We believe that people with intellectual and developmental disabilities have the right to live, love, work, play, and pursue their life aspirations just as others do in their community with the support they need.

www.theriotrocks.org
Complementing Themes

A person-centered, community-oriented approach to deliver services for people with IDD. The approach emphasizes:

• That people with IDD be in charge of their lives as much as possible.

• That people with IDD have opportunities to use resources in ways that enhance their lives and help them participate in their communities.

• A shared responsibility for the wise use of public dollars and the contribution that people with IDD and their families can make.

• That the system is managed in a way that is efficient and fair to everyone.
The “BIG Idea”

*people with intellectual and developmental disabilities have the right to live, love, work, play, and pursue their life aspirations just as others do in their community with the support they need.*

Complementing Themes

- Self direction
- Good life in the community
- Participation
- Wise use of resources
- Efficient and fair
- Supports for all

Putting it Together
## Human Services & Sustainability

### Human Services

By human services, we mean the full range of services that help people at each life stage maintain or reach their full potential.

A strong human services system is critical to the well-being of a community, its residents, and society at large.

Human services not only improve the quality of life for consumers of those services, but in doing so contribute to the safety and vitality of communities and the State.

*Fair and Accountable: Partnership Principles for a Sustainable Human Services System (2010)*

[www.wallacefoundation.org](http://www.wallacefoundation.org)

### Sustainability

The capacity to endure.

The ability to maintain a certain status or process in existing systems.

A way for people to use resources without the resources running out.

The maintenance of the factors and practices that contribute to the quality of environment on a long-term basis.

Places that meet the diverse needs of existing and future residents... are safe and inclusive, well planned, built and run, and offer equality of opportunity and good services for all.
Blending Together Principles Related to Service Delivery & System Management

Services & supports that people with developmental disabilities prefer

Disciplined fiscal & management practices

A Person-centered & sustainable system
How are we doing?

What the stats say

People served per 100,000 population

Cost per person served

Where people live

Employment

Some words about that word “Choice”
Wisconsin

https://risp.umn.edu/state-profiles
In Wisconsin, it was estimated that 12,639 people live in 2,044 settings (non-family).

73% live in settings of 1-3 people, compared to the national average of 51%.

93% live in settings of 1-6, compared to over 70% nationally.

https://fisp.umn.edu/state-profiles
Employment Services

http://www.statedata.info/statepages/wisconsin
### Trends Regarding Where People with IDD Live in Wisconsin (FY 2013)

#### Setting Umbrella

<table>
<thead>
<tr>
<th>Setting Type</th>
<th>Setting Type</th>
<th>Setting name</th>
<th>2010</th>
<th>2013</th>
<th>2013</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individualized Settings</td>
<td>Individualized Settings</td>
<td>Own Home</td>
<td>5,823</td>
<td>5,444</td>
<td>127,664</td>
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<tr>
<td></td>
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<td>Family</td>
<td>7,663</td>
<td>13,904</td>
<td>630,367</td>
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<tr>
<td></td>
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<td>Host Home</td>
<td>1,280</td>
<td>5,367</td>
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<tr>
<td></td>
<td></td>
<td>1 to 3</td>
<td>0</td>
<td>DNF</td>
<td>59,058</td>
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<tr>
<td>Congregate DD settings by size and type</td>
<td>4 to 6</td>
<td>4 to 6</td>
<td>2,858</td>
<td>DNF</td>
<td>122,262</td>
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<td></td>
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<td>1 to 6</td>
<td>2,858</td>
<td>2,602</td>
<td>181,320</td>
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<tr>
<td></td>
<td></td>
<td>7 to 15</td>
<td>2,040</td>
<td>31</td>
<td>57,709</td>
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<tr>
<td></td>
<td></td>
<td>16+</td>
<td>273</td>
<td>473</td>
<td>25,049</td>
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<tr>
<td></td>
<td></td>
<td>16+ Nonstate</td>
<td>449</td>
<td>373</td>
<td>23,854</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16+ State</td>
<td>449</td>
<td>373</td>
<td>23,854</td>
</tr>
<tr>
<td></td>
<td></td>
<td>16+ Total</td>
<td>449</td>
<td>373</td>
<td>23,854</td>
</tr>
<tr>
<td>Non-DD Specific</td>
<td>16+</td>
<td>Nursing Facility</td>
<td>153</td>
<td>34</td>
<td>24,021</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Psychiatric Facility</td>
<td>0</td>
<td>0</td>
<td>1,151</td>
</tr>
<tr>
<td>People with IDD in the System</td>
<td>All Types</td>
<td>Waiting list</td>
<td>4,783</td>
<td>2,252</td>
<td>204,336</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Estimated Total, Residence Type Known</td>
<td>20,386</td>
<td>25,226</td>
<td>1,134,133</td>
</tr>
<tr>
<td>Medicaid Recipients and Expenditures</td>
<td>HCBS</td>
<td>Waiver Expenditures per Person</td>
<td>35,420</td>
<td>33,504</td>
<td>42,713</td>
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<tr>
<td></td>
<td></td>
<td>Waiver Recipients per 100,000</td>
<td>345</td>
<td>476</td>
<td>225</td>
</tr>
<tr>
<td></td>
<td>ICF/IID</td>
<td>ICF/IID Expenditures per Person*</td>
<td>188,655</td>
<td>185,235</td>
<td>144,609</td>
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<tr>
<td></td>
<td></td>
<td>ICF/IID per 100,000*</td>
<td>14</td>
<td>15</td>
<td>25</td>
</tr>
</tbody>
</table>

https://fisp.umn.edu/state-profiles

USA

49% vs 56%
Some words about “choice”

When **choice** is a the primary consideration,

*choices that exemplify community integration or segregation are ALL equally acceptable*

When we organize around a **community for all**, 

*Policy favors options that promote community integration and discourages, even eliminates, options that segregate people from their community.*

Which is it?
Phase One of the project included a gap analysis to analyze the characteristics of the current system in Milwaukee County.

Phase Two involved these primary activities:

1. Compiling “Best Practice Policy” briefs
2. Compiling by project staff of selected themes to form the basis for the development of recommendations
3. Discussion of the Phase One report, Best Practice papers and the selected themes.
4. Settling on four primary action areas.
5. Presentation of tentative recommended actions by primary theme.
Data Sources

**Data collection process**

Collected & reviewed raw data and division policies & procedures at the county, state, and national level for performance comparisons.

Worked with county & state staff to complete data collection.

Reviewed available literature such as analyses & external reviews.

**Stakeholder interview process**

Interviewed about 30 key stakeholders: policy makers, MCO executives, providers, ADRC staff, family members, and self advocates.

The interview covered: system direction, leadership, access, service delivery, rates, and recent achievements & challenges.
Several completed surveys were reviewed


2006 UW Center for Health Systems Research assessed outcomes using PEONIES. Results were generally positive but not by service population.

2009 DHS oversaw survey of random sample of 3,606. 81-95% were satisfied always or most of the time, but no outcome data by population or MCO.

2011 State Legislative Audit Bureau evaluated Family Care. Findings presented by population & MCO & generally positive but don’t include outcome data by population & MCO.

2012 MetaStar conducted quality review report, findings show that agencies are performing well.

- The trouble is there is no data on outcomes made readily available to the public that can be performance-tracked in the county by population or managing entity.
From Applying to Service Delivery
Family Care, Partnership or IRIS Services in Milwaukee Co.

Individual Seeking Services

Aging & Disability Resource Center

Community Care Inc.
Milwaukee Co. Family Care
iCare

Care Coordinator

Services Delivered

IRIS

IRIS Consultant

Services Delivered
Family Care in Wisconsin

Created in 1998 in response to concerns over costs, long term care service system complexity, & intended to:

- **Give** better options for residence, and services & supports
- **Improve** access to services
- **Improve** quality focused on health & social outcomes
- **Create** a cost effective system for the future

**Programs Initiated**

- **Family Care** primarily provides long-term care services for people with physical disabilities, people with I/DD, and frail elders. Doesn’t pay for health care costs. Available in 57 of 72 counties, including Milwaukee County.

- **Partnership Program** is an integrated health & long-term care program for frail elders & adults with I/DD or physical disabilities. Available in 19 of 72 counties, including Milwaukee County.

- **PACE** is an optional benefit under both Medicare & Medicaid focusing on older people to provide medical & social services. PACE is available in 2 counties, including Milwaukee County.

Table 2: Number of People Served in Milwaukee County by MCO & Program (2013)

<table>
<thead>
<tr>
<th>Managed Care Organization (MCO) - Program</th>
<th>Intellectual/Developmental Disabilities</th>
<th>Frail Elderly</th>
<th>Physical Disabilities</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Community Care – Family Care</td>
<td>778</td>
<td>567</td>
<td>422</td>
<td>1,767</td>
</tr>
<tr>
<td>Community Care Health Plan - PACE</td>
<td>7</td>
<td>606</td>
<td>37</td>
<td>650</td>
</tr>
<tr>
<td>Community Care Health Plan - Partnership</td>
<td>55</td>
<td>101</td>
<td>59</td>
<td>215</td>
</tr>
<tr>
<td>Independent Care (iCare)</td>
<td>124</td>
<td>239</td>
<td>354</td>
<td>717</td>
</tr>
<tr>
<td>Milwaukee County Department of Family Care</td>
<td>1,330</td>
<td>5,956</td>
<td>757</td>
<td>8,043</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>2,294</strong></td>
<td><strong>7,469</strong></td>
<td><strong>1,629</strong></td>
<td><strong>11,392</strong></td>
</tr>
</tbody>
</table>

IRIS Program

*Include, Respect, I Self-direct*

Established statewide in 2008 as an alternative to Family Care, counties have less freedom over local IRIS policy/practice

Budget determined by a ‘functional screen’

IRIS consultants are provided by specialized agencies (Connections, The Management Group)

Service users manage chosen supports, goods, & services

Users can independently manage or have IRIS Consultant Agency or Financial Services Agency help

The Milwaukee Center for Independence manages direct support staff payments

Table 3: Number of Participants and Consultants for IRIS Program in Milwaukee County (2013)

<table>
<thead>
<tr>
<th>Category</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Active Participants I/DD</td>
<td>1,025</td>
</tr>
<tr>
<td>IRIS Consultants</td>
<td>63</td>
</tr>
<tr>
<td>IRIS Consultant Supervisors</td>
<td>3</td>
</tr>
<tr>
<td>Orientation Consultants</td>
<td>5</td>
</tr>
</tbody>
</table>

In Milwaukee Co, 4,009 people used IRIS
Of these 4,009 people:
549 (13.7%) frail elderly,
2,435 (60.7%) physical disability,
1,025 (25.6%) I/DD

[1] IRIS enrollment data: Wisconsin Department of Health Services, Division of Long Term Care, Nov 2013
Proposed Changes to Wisconsin’s Long-Term Care Services and Supports System

In February 2015, as part of the 2015-17 Biennial Budget, Governor Walker proposed changes to the long-term care structure currently operating in Wisconsin. These included:

- Elimination of long-term care districts.
- Administration of Family Care statewide by January 2017.
- A provision allowing the Wisconsin Department of Health Services (DHS) to contract with any applicants that it certifies as meeting the requirements to be a CMO.
- Elimination of the IRIS program.
- Addition of primary and acute health services to the Family Care benefit.
- Elimination of the Family Support program.
- Elimination of the requirement for long-term care advisory committees and resource center advisory boards.
- Creation of the Children’s Community Options Program.

After deliberating on the governor’s budget proposal, the legislature made some modifications, including new requirements for stakeholder input, but left the thrust of the governor's proposals largely intact and included a revised package of changes in its version of the biennial budget.

Subsequently, Governor Walker made additional changes with vetoes to the budget bill, and set in motion action to settle on the operational details of the new proposed system structure. Before implementing, the state will need to gain approval for its plan from the Centers on Medicare and Medicaid Services (CMS).
Phase 1 Summary Findings

Domains & Performance Benchmarks

System Access
1. Reasonable Promptness

Service Delivery
2. Most Integrated Setting
3. Person Centered Services

Outcomes
4. Valued Outcomes

System Infrastructure
5. Service Access
6. Quality Oversight
7. Economy & Efficiency
Milwaukee County Redesign Benchmarks

1. People with I/DD have access to & get necessary publicly-funded services & supports with reasonable promptness.

2. Services & supports are provided in the most integrated setting appropriate for the individual’s needs.

3. Services & supports are person-centered & self-directed (or family directed as warranted) to the extent possible.

4. Providing services results in achieving preferred outcomes for people with IDD.

5. There is adequate infrastructure that facilitates ready access to services for people with IDD & their families.

6. Services must continuously meet essential quality standards & there must be confidence that quality oversight systems function effectively & reliably.

7. The system must promote economy & efficiency while delivering services & supports.
Findings
System Access

**Benchmark 1:** People with intellectual/developmental disabilities have access to & receive necessary publicly-funded services & supports with reasonable promptness.

Milwaukee County *eliminated* their waitlist for services in 2012 & people with I/DD have access to services with reasonable promptness.
Findings
Service Delivery

**Benchmark 2:** Services & supports are provided in the most integrated setting appropriate to the needs of the individual.

State data show an **increasing** reliance on smaller community residences & **less** reliance on families than is the case in other states. Milwaukee County data suggest similar trends.
Figure 2: Place of Out-of-Home Residence Wisconsin 1977-2011

Source: Larson et al., 2013
Figure 3: Percent of People Receiving Services While Living at Home with Family

<table>
<thead>
<tr>
<th>Year</th>
<th>Wisconsin</th>
<th>US Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>2005</td>
<td>31%</td>
<td>57%</td>
</tr>
<tr>
<td>2006</td>
<td>33%</td>
<td>55%</td>
</tr>
<tr>
<td>2008</td>
<td>44%</td>
<td>57%</td>
</tr>
<tr>
<td>2009</td>
<td>42%</td>
<td>58%</td>
</tr>
<tr>
<td>2010</td>
<td>38%</td>
<td>57%</td>
</tr>
<tr>
<td>2011</td>
<td>38%</td>
<td>58%</td>
</tr>
</tbody>
</table>

Source: Larson et al., 2013
Findings
Service Delivery

**Benchmark 3:** Services & supports are person-centered & self-directed (or family-directed as warranted) to the extent possible.

IRIS offers significant **opportunities** for self-directed services & person-centered supports, though there are concerns over its application. Family Care organizations also **seek** to offer self-directed supports but by definition are charged with managing supports & resources.
Overall Observations

There is no clear advisor who provides individualized advice about service choices to service recipients.

Due to the complexity of the decision-making process, family members often serve as proxy decision-makers which may detract from self-direction for the person & instead become family-directed.

Family Care organizations notice IRIS’s popularity & are establishing ‘self-directed’ options. These options must still be managed within a managed care framework- the MCO is ultimately responsible for services & amounts delivered and prices paid.

Several interview respondents noted the heavy reliance on Medicaid-funded supports. Some mentioned community assets should be used to improve the user’s quality of life. Peer support or exchange networks were also mentioned as a way to support one another within their communities.
Focus on Concerns Regarding IRIS

Present budget allocations per person are not enough to support community-based residential facility services.

IRIS consultants’ training isn’t systematic or standardized. There is considerable variance in skills, experience, & effectiveness.

No organized means for people to share info about service providers exists.

IRIS users are not supported (unless using a consultant) to recruit or manage staff or are referred seek possible help from community-serving organizations or businesses.

Taking part in IRIS requires a lot of assistance such as: apply for employer federal taxpayer identification, buy Worker’s Comp insurance, process timecards, issue checks, submit taxes & manage returns, & provide monthly reports.
Findings
Service Outcomes

**Benchmark 4:** The provision of services results in achieving preferred outcomes for people with intellectual & developmental disabilities.

Benchmark performance couldn’t be explored due to a lack of *county-specific* outcome data. Consequently, there is no way to determine whether these *outcomes* are being achieved. There is speculation among those interviewed that expectations are adjusting to a managed care framework.
Interview Findings

There is no overarching direction regarding best practice & what expected outcomes should be.

There’s agreement the behavioral crisis support needs to be expanded.

Like other states, Wisconsin struggles to provide integrated employment services -20% of those served are getting this service.

Transitioning to work after graduation is increasingly difficult for high school students.

Service providers report reimbursement rates for employment services are presently sufficient.

There’s wide variance in opinion for ‘contemporary’ day service options. ex: from the continuum or ‘readiness model’ to employment.

Some observe that quality of services has slipped for transportation, social opportunity, and skills development.
In 2013, 6,602 Family Care members & IRIS participants on employment settings- State-wide:

26% of respondents reported working in an integrated environment for an average wage of $8.01 an hour,

5% worked in a work crew or enclave environment with an average wage of $6.39 an hour, and

77% worked in facility base employment averaging $2.33 an hour.

Data couldn’t be broken down to county level.

Findings
System Infrastructure

**Benchmark 5:** There is adequate infrastructure to facilitate ready access for people with ID/D & families to services.

The ADRCs manage system access **efficiently**. Once participants choose the program & organization, entry into services is managed by Family Care care coordinators or IRIS consultants with generally **satisfactory** results.
Interviewees suggested that there have been changes in what defines “quality services.” The lack of transparent quality oversight and means for comparing performance across service options makes this observation difficult to evaluate.

**Benchmark 6:** Services must continuously meet essential quality standards & there must be confidence that quality oversight systems function effectively & reliably.
Findings
System Infrastructure

**Benchmark 7:** The system must promote economy & efficiency in the delivery of services and supports.

Annual HCBS costs per person in Milwaukee County are **less** than the national average but **more** than the state average. Financing is perceived to be adequate for essential services, but with concern for the loss of services that were previously available to enhance individual quality of life.

<table>
<thead>
<tr>
<th></th>
<th>Average HCBS Waiver Costs Per Person Per Year (2012)</th>
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</thead>
<tbody>
<tr>
<td>United States Average</td>
<td>$45,294</td>
</tr>
<tr>
<td>Milwaukee County</td>
<td>$40,068</td>
</tr>
<tr>
<td>Wisconsin</td>
<td>$35,420</td>
</tr>
</tbody>
</table>

*Source: WI Department of Health Services (2013); Larson et al., 2013*
A Closer Look:....

From 1998 to 2011

Wisconsin increased the number of people receiving HCBS services by 266% from 7,373 to 19,361 people.

- Nationally, the number served increased by 257%.

Wisconsin increased spending (adjusted to 2014 dollars) by 260% from $280.7 million to $729.9 million.

- Nationally, the amount spent increased by 284%.

In Wisconsin the cost per person (adjusted to 2014 dollars) decreased 3.61% from 1998 to 2011 from $38,601 to $37,208 per person.

- Nationally, the cost per person rose by 10.58% to $47,580.

While Wisconsin increased the numbers served and is spending more overall than it did in 1998, the cost per person, adjusted to 2014 dollars, actually decreased modestly during the period.

https://risp.umn.edu/
Overall Observations

The system is complex & comprised of a number of moving parts: three MCOs, IRIS, ADRCs, multiple providers, and care coordinators or IRIS consultants.

Users that want to navigate the system are disadvantaged:

- **ADRCs** are prohibited from giving any advice about an organization’s track record in serving individuals with the same/similar needs & preferences
- **Very** little info is publically available on outcomes experienced by people receiving services
- **Care** coordinators work for or on behalf of an MCO & may not be free of potential conflicts
- **IRIS** consultants vary in terms of the amount of training & orientation they receive
It’s a complicated system.

Outcomes are ‘member driven.’

The driving ideology now seems to center on safety & health-related supports & its someone else’s job to provide other elements of life.

… We don’t do enough to break away from our reliance on Medicaid-funded services. There is not enough emphasis on what people can give to each other & the value of what people with disabilities can give.

There are no expectations regarding outcomes from any of the funders. We are on our own.

... managed care companies are charged with... well... managing care... and they do.
What’s next?

Recommendations
Offered in Milwaukee

Four Primary Themes

1. Invest in self-advocacy
2. Assure system transparency
3. Invest in mutual support
4. Provide direction and oversight
1. Invest in Self Advocacy

Summary:

Self-advocates are essential to activities to shape the service system.

Input from self-advocates should help guide service decisions.

To inform policy self-advocates must have necessary skills and support on multiple levels.
Invest in Self Advocacy

Potential actions:

- Increase opportunities to interact, support one another and form opinions about policy.
- MCOs (with WI DHS) should assure that self-advocates receive training to direct services and shape policy.
- Provide appropriate supports for self-advocates to participate in decision-making processes and meetings.
- Emphasize self-direction and community integration throughout service planning and delivery consistent with self-advocacy positons.
Invest in Self Advocacy

What issues most excite self-advocates?
What do young people think?
Local actions lead to wider actions
what can we do individually and collectively to improve our lives.

- Language
- Silly rules!
- Peer support
- Exchange Networks

www.theriotrocks.org
Some Examples of Silly Rules

Won’t let me be home by myself.
Say we are supposed to eat brown bread.
Make us go to bed at 9pm
Lights out at 10pm on weekends, and we can’t sleep in
Won’t let me out on a date or let us have a boyfriend or girlfriend.
Make me go bowling just because the others are going.
Say I can’t smoke, even during free time.
Won’t let us eat popcorn in the TV room even when we are watching movies.
Say we can’t stare at each other during meals
Say we can’t watch scary or X-rated movies
Can’t make or receive phone calls.
Won’t let us cuss, even though staff do.
We can’t wear makeup
2. Assure system transparency

Summary:

Delivery of I/DD services should result in desired outcomes for individuals and families.

To make informed choices, individuals and their families must have information that they can use to assess the strengths, weaknesses, and overall performance of the service entities from which they are choosing.

Such outcome data is not commonly available.

Service systems should be held accountable to achieving outcomes and routinely assessed against mission-critical performance standards. Related data should be commonly available.
Assure Transparency

Two types of outcome data should be collected and made available:

• Outputs (residential options, employment, health and well-being, staffing)
• Personal observation and opinion
Considering Outcomes

8 Questions Plus 1

1. Do individuals design and direct the supports they receive to the extent possible?

2. Are services delivered in ways to respect cultural, ethnic, economic and spiritual differences?

3. Do individuals and families receive combinations of supports that are publically or privately funded or involve natural supports?

4. Do individuals and families access community supports available to any other citizen?

5. Do individuals and families offer support to one another within “peer support” or exchange networks or human service cooperatives?

6. Are individuals and families involved in policy making?

7. Do individuals and families receive services and supports with reasonable promptness?

8. Is public funding is allocated to individuals and families in ways that are fair to all?

*Bottom line...* Do individuals receive supports the supports they need to live, work and play in the community like others?
Potential action:

- Milwaukee County DHHS should form a Performance Outcomes Committee to develop ways of collecting and disseminating information regarding the performance of MCOs and service providers serving adults with I/DD.

- The Committee should be charged with:
  
  - Establishing the performance domains or topics that will be targeted
  
  - Identifying specific “output” data that will be collected.
  
  - Identifying the “personal observation and opinion” topics that will be targeted.
  
  - Establishing means for collecting and analyzing this information locally.
  
  - Disseminating the results to individuals and families.

- It would be helpful for the State of Wisconsin Department of Health Services to participate in this effort.
One of the strongest assets any community has is its people. Beyond individual efforts, any community also has an array of community-serving entities, such as churches, schools, and clubs. Future systems must seek to forge alliances between individuals with disabilities and their family members, and the array of community assets available to find additional means of support.
An Overall View...

Lives of people with IDD & their families

Community assets & individual efforts

People with IDD & their support needs

Possibly shrinking available public services... in face of growing demand.

Harkins, Green, Jacobson & Agosta 2011
Invest in Mutual Support

Potential action

Existing public services should be complemented by establishing networks of mutual support so that individuals with I/DD and their families may:

- Make efficient use of public services (Medicaid).
- Work cooperatively to achieve common goals.
- Utilize supports available from local businesses.
- Provide supports to one another (exchange network).
- Contribute in meaningful ways to the community.
The Way Things Are...

Services are provided to people living in isolated households.

Dependency on services

Isolation

Fail to build culture & capacity to increase opportunity for mutual support & use community resources
The Way Forward...

Public services work together to use community assets with mutual support.

Rely on multiple sources of support

Kinship

Establish culture & capacity to increase opportunity for mutual support & use community resources

Purchasing alliance
Invest in Mutual Support

Potential actions:

MCOs, IRIS staff and the County DHHS should:

- Join together to promote participation in Peer Connection Networks.
  
  In this regard, the *Milwaukee Area Time Exchange* ([http://mketimeexchange.org](http://mketimeexchange.org)) and involves people with I/DD and their families. What is needed is a greater commitment to enterprises such as these.

- Team to provide opportunity for individuals with I/DD and their families to establish formal cooperatives.
Start Here to discover how the TimeBanks circle of caring keeps growing and growing!

- childcare
- transportation
- eldercare
- handyman services
- homework help
- cooking
- respite care
- office assistance
- tutoring
- yard work
- companionship
- house-cleaning
- neighborhood watch

We have what we need if we use what we have.
—Dr. Edgar Cahn, Founder
Summary:

Committee members note that:

- Over the past several years, local policy and practice is increasingly less influenced by “driving principles” that guided actions previously.
- County DHHS and CCSB have diminished role in policy making.
- The current managed care structure may be contributing to an erosion of these values.
- Given the current service model, their input will be limited to influencing rather than directing policy and practice.

County DHHS and CCSB can influence policy and practice and provide information on “best policy and practice.”
Direction and Oversight

Summary:

The County DHHS and CCSB might serve as anchoring points for the local system by providing information continually to all involved regarding “best policy and practice” that is consistent with the principled ideals most valued.

Information should be targeted to influence: service demand, service delivery and program outcomes.
Direction and Oversight

Potential actions:

County DHHS and CCSB work together to:

- Provide information to people with I/DD and their families and service providers to:
  - Inform and elevate expectations among service recipients
  - Promote progressive best practice among service providers (e.g., supporting families, employment)
  - Make outcome or performance data available

- Invest in selective progressive practices (e.g., crisis prevention, exchange networks and purchasing alliance, self-advocacy)
Concluding Remarks

• Much has been accomplished but new challenges have emerged
• Participants are at a disadvantage presently.
• The complexities presented by the current system should not constrain local stakeholders and elected officials from seeking positive and practical reforms.

When an elephant stands still, it is more bothersome for the person underfoot than for the rider on top.
Indian proverb
Maintain high expectations

- Where imagery leads, policy follows and behavior results.
- What is your image?
- What do you believe.

*We believe that people with intellectual and developmental disabilities have the right to live, love, work, play, and pursue their life aspirations just as others do in their community with the support they need.*

*Lead On!*

Justin Dart
Dancing with Dragons

“The final act in performing a creative act is letting go. ... As we create new support practice, the proverbial beast is provoked. We are knocked off our centers as we move into unknown territory without the anchor of our legacy services. This requires... as Rebecca Chan says, [that we] Dance with our Dragons.”

Hanns Meissner, Blue Space, p. 146