Enhancing the Adult Intellectual/Developmental Disabilities Service System in Milwaukee County

Phase Two Final Report

Blueprint for Systems Change

September 2015

Human Services Research Institute

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Prepared for

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All opinions expressed herein are solely those of the authors and do not reflect the position or policy of the Milwaukee County Department of Health and Human Services.

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Introduction

The Human Services Research Institute (HSRI) and the Public Policy Forum (PPF) worked with the Milwaukee County Disabilities Services Division (DSD) – a division of the county's Department of Health and Human Services (DHHS) – to identify means for improving services for Milwaukee County residents with intellectual/developmental disabilities (I/DD). The project was divided into two phases.

> **Phase One** included a gap analysis to analyze the characteristics of the current system in Milwaukee County, its strengths and weaknesses, and potential opportunities for improvement. To complete Phase One, HSRI conducted a review of the contextual circumstances in Milwaukee County and an analysis of the performance of the current service system against seven performance benchmarks. HSRI reviewed relevant literature and data available at the national, state, and county level, and conducted interviews with more than 20 key informants. Findings from this analysis were compiled previously.[1]
>
> **Phase Two** involved a planning effort to develop a series of recommendations to address observed system challenges in Milwaukee County. This report details efforts pertaining to this phase and the recommendations that resulted.

Methods Applied

To complete Phase Two and compile this report, HSRI and PPF:

- Sought guidance and feedback from the Project Advisory Group. An Advisory Group was formed at the project's onset to guide the work and included representatives from self-advocacy and family advocacy organizations, service providers, IRIS (Include, Respect, I Self-Direct), Wisconsin Board for People with Developmental Disabilities, Combined Community Services Board (CCSB), Disability Rights Wisconsin, and others.

  In September2014, the Advisory Group met to review the results of the Phase One findings. Then, at the onset of Phase Two, the Advisory Group was expanded to include representatives from the Milwaukee County Behavioral Health Division, Milwaukee County Department of Family Care, Community Care, Inc., and additional self-advocates. The expanded Advisory Group met in person or by webinar in November of 2014, and January, February, and April of 2015, to review current best practice standards and develop draft recommendations for this final Phase Two report.

- Compiled five "Best Practice Policy Briefs" to inform discussion among Advisory Group participants. These papers, found in Appendix A, were shared with the Advisory Group to inform discussion and covered the following topics:

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[1] Agosta, J, Bradley, V., Kardell, Y., and Aiken, F. (2014) *Phase One Final Report System Performance Review and Analysis (Executive Summary*). Milwaukee WI: Milwaukee County Department of Health and Human Services

  - Behavioral crisis response systems;
  - Self-directed supports;
  - Peer support among people with I/DD and their families;
  - Employment for people with I/DD; and
  - Person-centered planning practices.
- Convened two topic specific webinars for the Advisory Group. The topics covered during these 90-minute webinars included *Employment First* policy and practice, behavioral crisis response systems, and issues pertaining to local system administration. The PowerPoint presentations used to guide these webinars are found in Appendix B.
- Compiled themes to form the basis for eventual recommendations. While the Phase One report outlined numerous performance targets, Phase Two involved prioritizing those areas. Some areas could not be addressed locally since they were outside the authority of county managers. Likewise, some of the Phase One topics (e.g., improved opportunity for employment for service recipients, systems of crisis prevention and support) were already being addressed by state authorities or others. Themes that emerged were initially reviewed and revised after discussion with county staff.
- Settled on four primary action areas. Based on discussions with county staff, the four resulting priority areas included:
  - Strengthening self-advocacy;
  - Promoting transparency and shared information regarding system performance;
  - Promoting mutual support through increased opportunity for peer support, exchange networks, and use of supports offered by local businesses and community-serving organizations; and
  - Governance of the local system.
- Presented descriptions of these themes along with associated action steps. Over several months, these themes and related action steps were presented to county staff and the Advisory Group through telephone discussion, webinars and on-site presentations. Finally, the themes and proposed actions were presented to stakeholders in Milwaukee through a public forum and focus group with people with I/DD. Based on the feedback provided through these activities, this final report was formed.

These steps unfolded over several months, but it is important to note that during this time important changes to the service system were approved by the legislature and governor and may be implemented after approval by the U.S. Centers on Medicare and Medicaid Services. As illustrated in the accompanying text box, these changes would significantly alter the current system structure and mechanics. Regardless of these changes, however, the recommendations offered here would still likely ring true and be relevant to the new system configuration.

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 significant changes to the long-term care structure currently operating in Wisconsin. Key changes most likely to affect services for people with intellectual/developmental disabilities and their families 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 some 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).

Report Structure

This report is divided into three subsequent parts:

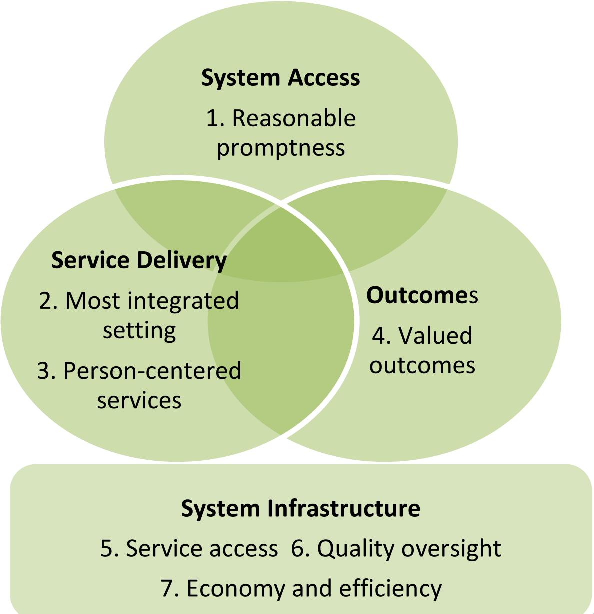
1. **Review of Phase One findings:** To provide context for the proposed action steps, we provide a summary review of findings generated through the "gap analysis" completed during Phase One.
2. **Call to Action**: For each of the four selected themes, a series of steps is presented that we believe must be taken to improve performance of the local service system for people with I/DD. Actions are called for in four areas to:
    - Invest in self-advocacy for policy collaboration;
    - Assure system transparency;
    - Invest in peer support and contribution; and
    - Provide direction and oversight.
3. **Conclusion:** We present a summary of our observations and parting remarks.

Summary of Phase One Project Findings

Prior to making a series of policy choices aimed at re-positioning the I/DD service system in Milwaukee County, it is essential to gain a perspective on the present issues confronting the system. To do so, Phase One of the project, which commenced in 2013, involved conducting a "gap analysis." *A gap analysis* compares an enterprise's actual performance to its potential, or desired, performance. It is an assessment of the distance between what an enterprise is currently doing and what it seeks to do in the future.

A gap analysis uses benchmarks to determine the level of performance achieved in relation to stated goals or best practices. For the purpose of this gap analysis, we viewed the system in relation to four primary domains including service access, service delivery, outcomes, and system infrastructure (See Figure 1). These areas are briefly defined as follows:

Figure 1: Four Domains and Seven Performance Benchmarks



- *System access* refers to the ease by which qualifying individuals with I/DD gain entry into or receive services from the I/DD services system.
- *Service delivery* refers to the array of services available to individuals, the amounts of such services a person may receive, and how these services are delivered.
- *Outcomes* refer to the impacts of these services on individuals.
- *Infrastructure* refers to the array of administrative structures and practices undergirding the system to assure smooth and effective service access and delivery. This includes, for example, rules or regulations, funding mechanisms, service reimbursement rates and protocols, and quality assurance and data management.

Within these domains are seven performance benchmarks against which we reviewed the provision of publicly-funded services and supports for people with I/DD in Milwaukee County. These benchmarks are shown in Table 1.

Table 1: Seven Performance Benchmarks

Access	1. People with intellectual/developmental disabilities have access to and receive necessary publicly-funded services and supports with reasonable promptness.
Service Delivery	2. Services and supports are provided in the most integrated setting appropriate to the needs of the individual. 3. Services and supports are person-centered and self-directed (or family-directed as warranted) to the extent possible.
Outcomes	4. The provision of services results in the achievement of preferred outcomes for people with intellectual/developmental disabilities.
Infrastructure	5. There is an adequate infrastructure to facilitate the ready access of people with intellectual/developmental disabilities and families to services. 6. Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably. 7. The system must promote economy and efficiency in the delivery of services and supports.

Summary Phase One Findings

Benchmark #1: People with I/DD have access to and receive necessary publicly-funded services and supports with reasonable promptness.

- ▶ **Summary Finding:** Wisconsin's Family Care program was implemented for persons with I/DD in Milwaukee County beginning in 2009. Milwaukee County subsequently eliminated its waitlist for services in 2012 and individuals with I/DD currently have access to services with reasonable promptness.
  - ▪ Milwaukee County reported serving 372.3 people per 100,000 in population in 2011, while the national average was 225.
  - ▪ We learned during our interviews that some stakeholders believe there was a trade-off associated with this success. Some interview respondents report that while more people are being served, the quality of services is also adversely affected.
  - ▪ Family Care organizations argue that while some service patterns could not be sustained after implementation of the managed care approach, the emerging constellation of services and supports is sufficient and responsive to meet the needs of members.

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

- **Summary Finding:** State-level data reveal an increasing reliance on smaller community residences, and less reliance on families than is the case in other states. Milwaukee County data suggest similar trends.
    - Approximately 76% of people receiving services in Wisconsin live in homes of 1-6 people and the majority of those (54%) live in homes of 3 or fewer.
    - It is estimated that in Milwaukee County 43.5% of individuals receiving Home and Community Based Services (HCBS) live at home with family and 23.7% live in their own home.
    - DHHS plans to grow capacity to address the needs of individuals with I/DD with complex needs living in the community by expanding the mobile crisis team to provide 24/7 availability for these individuals.
    - The county initiated the downsizing of the Center for Independence and Development (a.k.a. Hilltop), which serves individuals with a dual diagnosis of I/DD and mental illness, and plans to close the facility by the end of 2014.

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

- **Summary Finding:** IRIS offers significant opportunities for self-directed services and person-centered supports, though there are concerns over its application. Family Care organizations also seek to offer person-centered supports, but by definition are charged with managing supports and resources.
    - The opportunity to select freely among qualified providers is a bedrock principle of person-centered approaches. The Aging and Disability Resource Centers (ADRCs) provide neutral information to individuals but cannot advise for a particular managed care provider. Repeatedly during interviews, respondents observed that individuals with disabilities and their families do not have an independent source of information to assist with determining which of the managed care organizations or IRIS is most likely to meet their needs and preferences.
    - Interview respondents cite the popularity of the IRIS program, which they attribute to its flexibility and the authority that service recipients have over the supports they receive.
    - Some challenges with the IRIS program are noted, including: inadequate budget allocations; no systematic training for IRIS consultants; service recipients are on their own in managing supports; difficulty in assessing quality of supports; and requires a lot of assistance to manage.
    - Family Care organizations seek to offer self-directed options as well, but are challenged to do so given the managed care framework.

Benchmark #4: The provision of services results in the achievement of preferred outcomes for people with intellectual/developmental disabilities.

- Summary Finding: Performance on this benchmark was not definitively explored due to a lack of county-specific outcome data. Interview results suggest that the publicly-funded providers that operate in Milwaukee County are not held accountable for valued outcomes such as employment and community inclusion. As a consequence, there is no way to determine whether these outcomes are being achieved.
    - The State of Wisconsin participates in the National Core Indicators project that collects outcome data at the state level, though these findings cannot be extrapolated to the county level or any particular managed care organization.
    - Performance outcomes of MCOs providing Family Care were reviewed by the state in the past, beginning in 2000. These reviews provide information on performance across all Family Care participants, but do not offer breakdowns by service population (i.e., elders, intellectual/developmental disability, and physical disability) or by MCO or at the county level.
    - The Wisconsin Department of Health Services is working with MCO leadership and various workgroups to develop a performance scorecard related to quality management, fiscal, and performance measures.

Benchmark #5: There is an adequate infrastructure to facilitate the ready access of people with intellectual/developmental disabilities and families to services.

- Summary Finding: The ADRCs manage system access efficiently. Once the choice of program and organization is made by participants, entry into services is managed by Family Care case managers or IRIS consultants with generally satisfactory results.
    - During interviews, there were no complaints regarding access to ADRC services. Approximately 300 applicants are processed monthly with 60-65% of these applicants found eligible.

Benchmark #6: Services must continuously meet essential quality standards and there must be confidence that quality oversight systems function effectively and reliably.

- Summary Finding: Concern was voiced among interviewees regarding perceived changes in expectations over what constitutes “quality services,” and an absence of transparent quality oversight and means for comparing performance across service options.
    - Data is collected and aggregated at the state level, but is not made available by county.
    - Several respondents reported that Family Care organizations amply monitored and tracked the quality of the services they offer. However, it was difficult to find information to describe the results of these efforts.

Summary Observations

Our overarching impression was that the system for serving people with intellectual/ developmental disabilities and their families in Milwaukee County – while accomplishing important goals with respect to system access – is challenged by the fact that it is complex and comprised of a number of moving parts. Those include three managed care entities, IRIS, two county-operated ADRCs, multiple providers, and case managers or IRIS consultants.

Going forward, it is essential to consider whether new roles and responsibilities for public managers are warranted at the state and local level, as well as whether external stakeholder groups should be fortified. A complementing challenge – given the concerns expressed by respondents over the depth and flexibility of the system – is to explore ways to make the system more individually-tailored and to increase the numbers of individuals who are self-directing.

Call to Action

Wisconsin is at a crossroads. The recent legislative and executive decisions to re-shape the state's managed care system may be enacted in ways presently described or not at all. Much depends on the details associated with the envisioned system redesign and the prospective approval of the Centers for Medicare and Medicaid Services.

Regardless of the system's eventual operational and fiscal underpinnings, actions may be taken in Milwaukee County to improve the local response to people with I/DD. The impetus for these actions may be initiated within managed care organizations, the county, or service providers as part of their commitment to enhance services and supports to the individuals they serve. In addition, to further ensure consistent action to improve the system of supports across the state, the Wisconsin Department of Health could include certain requirements in its contracts with MCOs. The next sections cover recommended *actions under the following headings:*

1. Invest in self-advocacy for policy collaboration;
2. Assure system transparency;
3. Invest in peer support and contribution; and
4. Provide direction and oversight.

Table 2: Action Areas and Steps

Invest in self-advocacy	▶ Provide self-advocates increased opportunity to interact, support one another and form opinions about policy. ▶ MCOs and provider agencies should assure that self-advocates have opportunity to inform and shape agency policy. ▶ When self-advocates participate in stakeholder committee meetings, provide appropriate support. ▶ Emphasize self-direction and community integration throughout the service planning and delivery process and in ways consistent with self-advocacy positions.
Assure system transparency	▶ Milwaukee County DHHS should form or assist other stakeholders in forming a Performance Outcomes Committee.
Invest in peer support and contribution	▶ MCOs, IRIS staff, and DHHS should join together to promote participation in Peer Connection Networks. ▶ MCOs, IRIS staff, and DHHS should team up to provide opportunity for individuals with I/DD and their families to establish formal cooperatives.
Provide direction and oversight	▶ DHHS and CCSB should work together to function as a repository of information that will be shared with people with I/DD and their families and service providers. ▶ DHHS and CCSB, IRIS staff, and MCOs should team up to invest in selected progressive practices.

Action Area #1: Invest in self-advocacy

Background

People First of Oregon was established in 1973 and is recognized as the first formalized self-advocacy organization in the United States. This action spurred momentum nationally as People First organizations formed from state to state.

At first, these fledgling organizations acted more as social clubs than as centers for directed advocacy and change. The 1990s, however, brought a change in this focus as self-advocates showed a stronger interest in influencing policy and practice. Increasingly, participants rallied against the idea of individuals with disabilities being defined by a diagnosis – often described in terms of limitations. Instead, they emphasized that people with disabilities are just like everyone else and have strengths, interests, feelings, and desires for their own lives. And they demanded that their voices be heard. In 1993, at the Third International Conference on Self-Advocacy in Toronto, Roland Johnson of Pennsylvania gave a stirring speech where he asked simply: "Who's in charge? Who's in charge of your life?" This is a good question, indeed.

People First of Wisconsin was established in this same vein. Its mission is to: "work to empower people to speak up for themselves, to have their voices heard and to effect personal and societal change." More particularly, it seeks to "challenge the institutions, social policies and community attitudes that prevent people with disabilities from achieving their full potential as citizens" (http://peoplefirstwi.org/).

While overall, the I/DD field is committed to the ideal of including individuals with I/DD in shaping policies and practices, doing so over time poses numerous challenges. Many local self-advocacy organizations that once had a strong presence and influence are struggling with issues such as declining and aging membership, lack of relevance or a clear purpose, and diminishing funding. In the policy arena, their presence on councils, boards, committees, workgroups and projects might be requested. Without the appropriate support or balance of power to participate in a meaningful way, however, their involvement is only a token gesture.

The contributions of people with I/DD to discussions that affect their lives is just as important now as it ever was. Their perspective is critically important in creating systems of support that are equipped to respond to the needs of the next generation of individuals with I/DD, who may have very different life experiences and expectations than the generation of self-advocates who initiated the self-advocacy movement.

The input of self-advocates should help guide decisions about what services should be expanded and which services and supports do not contribute to desired outcomes. To participate in this way, self-advocates must have necessary skills and support on multiple levels. However, the Advisory Group noted that:

(a) It is difficult for self-advocates to participate in meetings held during the day because they work and may have trouble with transportation. During stakeholder meetings, self-advocates repeatedly voiced concerns related to the lack of reliable, accessible transportation. Also, while others may be getting paid for their participation as a function of their job, self-advocates are typically asked to volunteer their time.

(b) Self-advocates often do not get the support they need to participate effectively in stakeholder committee meetings. These meetings may be held at a level of discussion and analysis that is difficult for people with I/DD to follow, and so their voices are not often heard.

While there is a prevailing high expectation for self-advocate participation at high-level meetings, this expectation often is met through the participation of just a few of the same self-advocates. These self-advocates may or may not speak for others, given that local self-advocates, through People First, for example, have not declared unified positions on policy issues that may affect them.

Action Steps

- ▶ <u>Provide self-advocates increased opportunity to interact, support one another, and form opinions about policy</u>. In a decentralized system where people do not live close to one another, it is essential that families, providers, and MCOs bring self-advocates together on a regular basis so that they can make social connections as well as develop a collective understanding about the services they receive. From this base of opportunity, self-advocates may take action to support one another, contribute to their communities, and form policy positions.
    - ▪ People First of Wisconsin already exists and has local membership in Milwaukee County (See https://www.facebook.com/peoplefirstwisconsin). In fact, its Executive Director is a prominent local self-advocate. MCOs, local providers, and family advocacy groups should meet with the local People First leadership to determine what could be done to build this group's membership and promote collaborative action consistent with self-direction and community integration.
- ▶ <u>MCOs, in association with the state Department of Health Services, should assure that self-advocates receive training to direct their services to the extent feasible and have opportunity to shape local agency policy</u>.
    - ▪ The role of self-advocate leadership should be promoted with a "Self-Advocate Liaison" position within local MCOs to provide self-advocates with needed training or information and access to decision-makers. In accordance with 42 CFR §431.10, activities associated with this position to provide training to self-advocates may be viewed as an administrative expense found necessary for the efficient administration of the state's HCBS Medicaid waiver.[2] These types of activities, i.e., "beneficiary education," may be used to undertake quality management functions needed for the proper and efficient administration of the waiver. After all, state authorities, MCOs and ADRCs have an interest in assuring that service recipients, i.e., Medicaid beneficiaries, have the information they need to most effectively benefit

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[2] See: http://157.199.113.99/WMS/help/35/appInstrSecA.html

from Medicaid services.[3] We emphasize, however, that implementing this particular recommendation will require collaboration between DHS and MCOs.

  - There should be an increase in the presence of self-advocates on advisory boards. Self-advocates should be involved in making decisions that have a direct impact on the quality of their daily lives.
  - Provider agencies should consider forming self-advocacy decision-making groups within community residences or day programs to shape practice. In this context, providers and self-advocates could work together to weed out any rules that both parties may deem unnecessary to govern individual lives (e.g., early bedtimes, unnecessary restrictions on calling or seeing friends).

- ▶ <u>When self-advocates participate in stakeholder committee meetings, provide appropriate support.</u>
  - In advance of meetings, the facilitator of the meeting should secure appropriate supports for self-advocates to participate. This support should include: (a) education to help self-advocates understand the issues being discussed and to deliberate these issues in ways that reflect the positions held by self-advocates; (b) help to form "key messages" that self-advocates agree should be pressed at meetings; and (c) practice among self-advocates who will be attending meetings to help each participant get comfortable with his or her role.
  - During meetings, particular self-advocates could be assigned a support person to help him/her understand proceedings and make contributions. The support person would need to be familiar with the proceedings and content, and comfortable assisting people with disabilities to follow along.
  - After meetings, participants should be given opportunity to review the meeting proceedings and outcomes, with potential for follow-up action by self-advocates.
  - Selected self-advocates may also be provided a self-advocate "mentor" to offer information on policy issues and answer questions. The supporting organization would be responsible for identifying self-advocate mentors and matching them with other self-advocate members.

- ▶ <u>Emphasize self-direction and community integration throughout the service planning and delivery process and in ways consistent with self-advocacy positions</u>. Clearly, there is a commitment at all levels to promote ideals such as self-direction and community integration. Still, more might be done to assure that this commitment translates into common policy and practice.
  - MCOs should assure that its individual supports planning processes routinely promote a "community first" ideal regarding residential options, day services and

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[3] Self-Advocate Leadership Institute (2006). *Using Medicaid to fund trainings for self-advocates.* Tualatin OR: Human Services Research Institute.

employment, and other life domains. For instance, during individual support planning meetings, the first day support option discussed and offered should focus on employment. Center-based or segregated options might be suggested afterwards. Likewise, discussion regarding residential or leisure activities options should focus on the most integrated options possible.

Transparent

: *able to be seen through*
: *easy to notice or understand*
: *honest and open, not secretive*

Merriam-Webster dictionary

- MCOs, provider agencies, and family and self-advocacy entities should work together to offer ongoing educational opportunities for provider staff and others regarding ways to maximize opportunity for self-direction and community integration.

Action Area #2: Assure System Transparency

Background

As public intellectual/developmental disabilities systems have evolved over the past several decades, there has also been a growth in the use of data to more intentionally manage state systems. For many years, states collected data on issues such as licensing and incidents but did not use the data in a systematic way to improve performance. Nor did states make the data available to the public in ways that would assist stakeholders and others to make judgements about the effectiveness of the system. Several factors over the past several years have changed both the way that public managers use data and the extent to which performance data is available to the public. These factors include:

- CMS requirements that states solicit public input prior to the submission of new HCBS waivers;
- The growth of the self-determination movement and the need to provide performance information to assist participants to make choices;
- CMS requirements that states submit evidence to support their compliance with HCBS requirements;
- The rapid expansion of community services, which necessitated the use of aggregate data to chart progress;
- Pressure from families and self-advocates regarding the transparency of system performance information;
- The adoption of the National Core Indicators by an increasing number of states and the public availability of all NCI data on individual and family outcomes;
- Increasing transparency in other related areas such as the federal posting of performance indicators for nursing homes and hospitals;
- The growth of quality improvement methodologies that rely on aggregate data; and

- The development of incentives in some state rate methodologies that reward providers that achieve valued outcomes, such as employment.

As more and more states move to managed long-term supports and services, there is a concern that performance data at the local provider and state level will no longer be publicly available since many MCOs consider this data to be "proprietary." Even though the funds expended are public tax dollars, it is not incumbent on MCOs to release data unless they are required to do so in their state contracts.

In Wisconsin, individuals are informed of their option to select from multiple managed care organizations or IRIS, and then from among various service providers. 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. Yet, such outcome data either is not available or is not commonly shared.

During project Advisory Group deliberations, some asserted that such information might be available, but is not being compiled and circulated. Others noted that it is difficult to reach a consensus over what outcome domains should be targeted. Methodological difficulties were also cited as a barrier that makes outcome measurement difficult.

Still, the Advisory Group noted two types of outcome data that could be collected relatively easily and made available to consumers and their families:

a) Outputs: Such information pertains to particular notable outputs such as:

   Employment: Examples include the number of people receiving supported employment services or holding competitive jobs, average numbers of hours worked per week in such jobs, average pay per hour, or types of jobs secured by individuals.

   Residential options: This could include, in staffed community residences, the average number of people living together. Other examples could include the number who own their own home, or the number receiving supports while living with families.

   Health and well-being: Examples might include notable incidents (e.g., altercations with staff), frequency of wellness visits to the doctor or dentist, or percentage of people using psychotropic medications for behavior.

   Staffing: Staff turnover rates, or numbers of hours per year of training.

b) Personal observation and opinion. Such information could be generated from surveys of individuals and families to gauge their observations and opinions regarding the services they receive. An example of such a publicly available survey is from the Rehabilitation Institute of Chicago (http://www.ric.org/app/files/public/3598/CPI-commnity-participation.pdf). The form includes questions to collect demographic information as well as a series of "community participation" indicators.

Action Steps

- ▶ Milwaukee County DHHS should form, or assist other stakeholders in forming, a Performance Outcomes Committee to define, collect, and disseminate information regarding the performance of MCOs and service providers that is deemed necessary for informed decision-making by adults with I/DD and their families. Members of this committee should include self-advocates, family members, county staff, MCO staff, providers, and members of the (CCSB. The committee should:

- Establish the performance domains or topics that will be targeted for data collection;
- Identify specific "output" data that will be collected related to these domains;
- Identify the "personal observation and opinion" topics that will be targeted and questions that individuals and their family members may respond to;
- Establish means for collecting and analyzing this information locally; and
- Disseminate the results to individuals and families.

We recognize the political, logistical, and fiscal barriers to such work. For instance, there is no legal obligation for MCOs and others responsible for service delivery to participate, and those providers may be wary of doing so because of concerns about the portrayal of their performance. There are also numerous data collection challenges that may require a commitment of resources from providers to resolve. Finally, if DHHS is the entity that organizes and manages this initiative, then it likely would need to invest both staffing and financial resources, and it may wish to seek outside assistance from an objective third party to gather, interpret, and disseminate performance data as a means of offsetting any perception of bias.

However, it would behoove all system participants and stakeholders – including the Wisconsin DHS – to enhance their collective ability to gauge performance through publicly available information. This is desirable not only as a means of facilitating better decision-making, but also as a mechanism for ensuring that there is constant and ongoing consideration of system improvement strategies. To succeed, all those involved with service delivery in Milwaukee County, including DHHS, MCOs, and providers, will need to contribute their time and resources. In addition, it may be critical for DHS to participate in this effort and ensure the compliance (in terms of data collection and dissemination) of entities with whom it contracts for services.

Action area #3: Invest in Peer Support and Contribution

Background

Service systems across the nation are challenged to accommodate increasing demands for service while enduring difficult fiscal times. In the face of these challenges, states continue to support a "services first and only" approach, funded primarily through Medicaid. Lost in this response are opportunities for promoting a spirit of personal reliance and contribution, mutual support, and community connection.

One of the strongest assets any community has is its people. People volunteer daily to do any number of tasks for others, through structured groups or individual initiative. In addition,

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 on the one hand, and the array of community assets available to find additional means of support on the other.

Going forward, policy makers at all levels must complement existing public services by establishing sustainable networks of mutual support so that individuals with I/DD and their families may:

- Make efficient and effective use of public services, such as those funded by Medicaid;
- Work cooperatively to achieve common goals;
- Utilize supports available from local businesses or community-serving organizations;
- Provide supports to one another, as in an exchange network or peer support group; and
- Contribute in meaningful ways to the community.

Operationally, this suggests action to develop peer connection networks where individuals offer one another mutual support, as well as formal cooperatives where participants work together to manage the services they receive.

Two approaches gaining prominence nationally include: (a) peer connection networks; and (b) formal cooperatives or federations where participants work together to manage the services they receive.

- Peer Connection Networks. These networks are not meant to provide services that will take the place of HCBS services. Rather, they are intended to generate additional, complementary supports within communities. In a Peer Connection Network, participants unite voluntarily to address common needs through mutual support and/or joint action. Networks can be composed of individuals with disabilities, family members, or both. A staff person or "organizer" is typically required to advise and organize the network, though it should ultimately be shaped by the needs and preferences of its members. This person may be employed by a service providing agency or in Milwaukee County by an MCO, the IRIS network or DHHS. Financing for this position might be secured person to person and noted as "goods and services" tied to their service plan, funded as a cost of doing business by MCOs or by DHHS discretionary funds. Alternatively, multiple entities might pool resources together and make this support available to any with IDD in the area, regardless of their affiliation with a particular MCO or IRIS.

  Peer Connection Networks blend together three essential sources of support:

  - Disability-oriented public services: Individuals with I/DD may be receiving support services already through a community services network. These actions may also be complemented by other public services (e.g., local ride sharing programs sponsored by local transit agencies). These services often provide significant support, but may be insufficient to address all of the unmet support needs among individuals with lifelong disabilities.

  - Peer support: Peer support associations are created to link people through a voluntary exchange of support. This can include simple forms of help that individuals offer one another (e.g., temporary respite, a car ride, emotional support, information). Peer support may also be organized more formally through a "time bank." A time bank organizes participants within an exchange network where everyone's contributions are valued equally and tracked. The hours a participant gives to others are credited to his or her account, and hours of help the person receives are "debited" from the account. After each service exchange, the participants notify the office of how many hours were given.
  - Community assets. The network can also collaborate with other community assets, such as faith-based and other community service organizations (e.g., churches, civic or hobby clubs, recreational centers). Local chambers of commerce and community businesses may also prove helpful.

- Formal Cooperatives. In the current service system, families are counted on in a number of ways to manage the supports provided to the family member with disabilities. By working together, participants can form a strong alliance within a "cooperative." Within the context of a self-directed service option, the cooperative itself may function as a provider agency, performing any number of functions collectively for its members, including:
  - Recruiting direct support staff;
  - Acting as an employer of record;
  - Monitoring paid staff and assuring that supports are properly delivered and accounted for;
  - Purchasing services, durable equipment or other needed supports; and
  - Acting as a fiscal intermediary to ensure that providers are paid, and also to offer providers workers' compensation and other benefits.

When families work on their own, such responsibilities can prove burdensome over time. If families and individuals work together, however, many of the associated responsibilities they assume may be more efficiently and effectively managed. This can be accomplished by promoting partnerships within the public and private sectors – for example by forming a "Human Services Cooperative (HSC)."

HSCs are recognized by the Federated Human Service Cooperative, an organization whose goal is to "assist in the creation of Human Services Cooperatives" (See http://www.federatedhsc.coop/). This national entity certifies local cooperatives that are directed by individuals and families who use disability services to provide supports that benefit their membership. Once certified, a cooperative essentially operates as a provider agency, delivering services based on policies formulated by member owners. This type of cooperative is typically built on partnerships developed between agencies and community-service organizations in the public and private sector. These partnerships create a responsive network to offer self-directed services to address member needs.

Action Steps

- MCOs, IRIS staff, and DHHS should work together to promote participation in Peer Connection Networks. To complement traditional Medicaid-funded services provided through Family Care or IRIS options, individuals and families could be actively encouraged to participate in local Peer Connection Networks. In this regard, the *Milwaukee Area Time Exchange* (http://mketimeexchange.org) already exists in the area and involves people with I/DD and their families. Indeed, DHHS already invests modestly in this effort.

  What is needed is a greater commitment to enterprises such as these. In particular, these networks require support to develop and later to pay for staffing to organize and maintain the effort. Toward these ends, MCOs, DHHS, and providers should pool resources to establish a variety of peer networks across the county.

- MCOs, IRIS staff, and DHHS should team up to provide opportunity for individuals with I/DD and their families to establish formal cooperatives where participants work together to manage the services they receive. Within the context of a self-directed service option, the cooperative itself may perform a number of functions collectively for its members, including:
  - Recruiting direct support staff;
  - Providing opportunity to share paid staff and assure that supports are properly delivered and accounted for; and
  - Acting as a purchasing alliance to secure services, durable equipment or other needed goods (e.g., food) and support.

  Throughout Wisconsin, there is already an underlying culture of mutual support as evidenced by the extensive array of farmer cooperatives across the state. In particular, *In Control- Wisconsin* is an organization that prioritizes the importance of establishing peer and family networks across the state. (http://www.incontrolwisconsin.org/what-we-do/community/). As a result, this organization may provide unique and essential expertise to MCOs, IRIS staff, and DHHS to help establish local cooperatives and networks.

Action Area #4: Provide Direction and Oversight

Background

Many Advisory Group members observed that over the past several years, local policy and practice is increasingly less influenced by the “driving principles” that guided actions previously. These principles were built on constructs such as community integration, self-direction, and community participation. One member wondered if policy today was about these principles or “more about simply managing care.” Other members stated that these principles still guide policy decisions, but that there is a need for greater fiscal discipline, which requires some mediation between cost efficiency and ideology.

As illustrated by the Phase One study findings and discussion among Advisory Group members, the need to reinforce key values in the provision of supports is a priority. The current administering agencies, including state authorities, ARDCs, MCOs, and service providers, are meeting support needs, but the current managed care structure within which these supports are delivered may be contributing to an erosion of these values. In part, this may also help explain the continued and growing interest in IRIS, which was established as an alternative to the managed care option.

Further discussion among Advisory Group members also focused on the greatly diminished role that DHHS and the CCSB play in policy-making. In fact, it no surprise that the perceived decreased influence of driving principles in today's service system has coincided with the elimination of input by the two local policymaking bodies that once established those principles, and that once were publicly accountable for upholding them.

Going forward, establishing a mechanism for Milwaukee County and the CCSB to gain more oversight and influence on policy and practice may be desirable, particularly as a means of ensuring that there is system oversight from publicly elected and appointed individuals at the *local* level, where an understanding of the needs and desires of citizens is taken into account. Doing so would require an approach that contemplates current constraints, including contractual requirements between state agencies, ARDCs, MCOs, and service providers. It also would require careful consideration of whether this enhanced role would conflict with the very nature of a managed care approach, whereby a significant amount of policymaking leeway is delegated to MCOs.

Given the current service model, the county's input would need to be limited to influencing, rather than directing, policy and practice. Specifically, DHHS and the 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 valued ideals. An

> One Advisory Committee member wondered if policy today was about [driving guiding principles] or “more about simply managing care.”

important consideration related to this is to ensure that Milwaukee County and the CCSB have the necessary resources to hire staff or make investments to have a significant role in the system.

Such information should be targeted to:

- Service demand: Often, policy makers emphasize what and how services are delivered. Just as important is what people with I/DD and their families expect of the services they receive. If these individuals demand services that are consistent with best practice principles, then the MCOs and service providers would be pressed over time to alter what is offered in response. After all, a next-generation of service recipients may not want what was offered to individuals 15-30 years ago. The challenge to any service network is to have the capacity to adapt to changing demands for services. Such adaptations cannot take place unless service recipients have the information necessary to modify their expectations.
- Service delivery: The supply of services could also be altered by offering information directly to MCO and provider staff. Some providers may be rooted to practices that were once, but no longer are progressive. Offering information on current or emerging practices could help providers to change their practices and adopt new business models. Likewise, MCOs should not continue to fund outdated ways of doing things, and should seek instead to invest in progressive approaches that reflect shifting service demands.
- Program outcomes: As noted earlier, information pertaining to outcomes related to MCO and provider performance should be available to people with I/DD and their families. Such information will help individuals to make an informed choice between IRIS, managed care options, and service providers.

Action Steps

- ▶ DHHS and the CCSB should work together to function as the providers of information that will be shared with people with I/DD and their families and service providers. Specifically, this information should:
    - Inform expectations among service recipients: This might include making available selected speakers on a variety of topics, such as person-centered planning, supported employment options, shared living, assistive technology, supporting families, or positive behavioral support. The idea is to educate people about what to expect of their service system, which will prompt MCOs and service providers to adjust the services offered accordingly.
    - Promote progressive best practice among service providers: To meet shifting demand, it is essential to provide MCO staff and service providers with a steady stream of information on present and emerging best practices. We recognize that

  training opportunities are routinely made available to staff, and this action is not meant to replace those efforts. Rather, the intent is to offer information to suggest new practices or business models. For instance, information might be provided on best practice employment strategies or on how an MCO or provider network might establish cooperatives or purchasing alliances.

  - Make outcome or performance-related data available to service recipients and their families. As noted earlier, it is essential that individuals with I/DD and their families have easy access to outcome-related data. Once such information is available, it must be disseminated effectively to inform the service related choices people make.

- <u>DHHS, CCSB, IRIS staff, and MCOs should team up to invest in selected progressive practices</u>. The responsibility for establishing and sustaining a dynamic, ever-evolving system cannot fall to any single entity. DHHS, CCSB, IRIS, and MCOs all must share in this responsibility. In this context, these main service entities should identify particular practices where pooled effort and resources could work for the benefit of all. Examples include working together to:

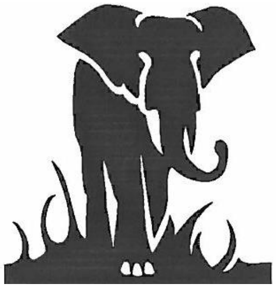
  - Establish a crisis prevention and intervention network;
  - Establish a county-wide purchasing alliance among service recipients so that they might realize discounts when purchasing certain goods (e.g., food purchased from participating supermarkets);
  - Work with Milwaukee Time Exchange to expand the number of participants; or
  - Strengthen People First of Wisconsin locally.

  We understand that IRIS and MCOs are competing for business and so may be suspicious of collective action involving their competitors. MCOs may also be wary of diluting their authority over the services they deliver through collective actions involving DHHS or the CCSB. Yet, a commitment to a “community-centered” response to disability requires some amount of collective action among all involved. The current dynamic where each entity acts independently has resulted in a diminution of transparency and previously established values. In part, the remedy requires that common ground be found among all those involved, including competitors, to achieve a greater common good for all.

Conclusion

Milwaukee County's Disabilities Services Division and Department of Health and Human Services once had primary responsibility for assuring that the needs of county residents with intellectual and developmental disabilities were met. With the advent of the Family Care and IRIS service framework, however, the county's role in overseeing and guiding services was greatly reduced. This new reality provided the context for this study's Phase One report, in which the following general observations were made:

- The system for serving people and their families in Milwaukee County has become very complex and is comprised of a number of moving parts, including three managed care entities, IRIS, the ADRCs, multiple providers, and care coordinators or IRIS consultants.
- Participants attempting to negotiate this complex system are at a disadvantage given that:
    - The ADRCs are prohibited from giving potential service recipients any advice regarding which organization has the best track record in serving individuals with the same or similar needs and preferences;
    - Very little information on the outcomes experienced by people receiving services is available to the public;
    - Case managers ultimately work for or on behalf of a managed care organization and may not be free of potential conflicts; and
    - IRIS consultants vary in terms of the amount of training and orientation that they receive.
- These circumstances are complicated by the absence of publicly accountable leadership at the state or county level that is responsible for dictating and articulating the outlines of best practice.



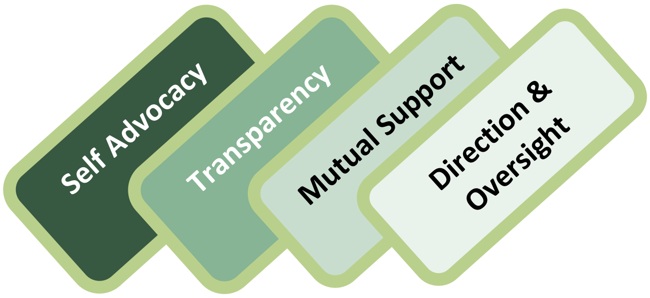
When an elephant stands still, it is more bothersome for the person underfoot than for the rider on top.

Indian proverb

The recommendations and associated activities offered here are meant to address many of the issues outlined during Phase One of this study. The actions we have proposed, which are organized into four cornerstone themes, would establish a more prominent role for the county in influencing local policy and practice. Those enhanced roles include strengthening self-advocacy, assuring transparency, promoting mutual support and community participation, and actively promoting compliance with best practices.

To move forward on these actions, DHHS and other stakeholders in Milwaukee County will need to act collectively.

Cornerstones



Milwaukee County DHHS Call to Action

Over the past few years the new system framework, involving Family Care and IRIS, has taken root in most of the state. The changes have resulted in notable success, such as the elimination of a 30-year-old wait list for services, but they also have created new challenges. Moreover, recent executive and legislative action calling for significant statewide restructuring of the state's long- term supports and services system would have unknown impacts on transparency and individualized supports.

The complexities presented by the current system, however, should not constrain local stakeholders and elected officials from continuing to seek positive and practical reforms. As systems change they also expose new opportunities. The Wisconsin system for people with I/DD at the state and county level has, for many years, been an example of best practice. Too much has been invested and accomplished to simply accommodate change. To protect the I/DD legacy will require that DHHS and stakeholders in the local system seize the opportunities outlined in this report to guide the shape, content, and outcomes of services and supports to people with intellectual and developmental disabilities and their families.

The recommendations offered and their associated activities provide the county with several suggested actions steps that can serve as a "blueprint" to guide the way. Now, county leaders must decide whether a new and enhanced role in the service system for individuals with I/DD is practical, affordable, and consistent with the county's overall mission and vision.

The best way to predict the future is to invent it.

Alan Kay

Appendix A

Five Best Practice Papers

Person Centered Practices
Self-Direction
Peer support Practices
Employment First Policy and Practice
Behavioral Crisis Response

Redesigning the Adult Intellectual/Developmental Disabilities Service System in Milwaukee County

Information Brief on Person-Centered Planning

November 2014

Person-Centered Planning

People with intellectual and developmental disabilities (I/DD) expect to live a life in the community with the supports they need. As users, the supports they need are matched by services. Essential to receiving services, a plan lists out what they need: services delivered, and how often or how much of a service is to be delivered. In the past, plans too often were developed by paid support staff or by others around the person (such as family members). Contemporary thought places the person with I/DD in charge of their own service planning.

Person-Centered Planning is:

a planning process directed by the person for whom the plan is for, resulting in steps and ways to achieve the person's goals with the objective to also do so as integrated as possible in their local community.

Reinforcing this, in March 2014 the Centers for Medicare and Medicaid Services (CMS) issued new requirements for states regarding the delivery of Home and Community Based Services (HCBS).[4][5] These rules emphasize community integration, person centered planning and services, and choice, including self-direction. Examples of the new requirements relevant to person-centered planning include these:

- The participant actively contributes to the development of their service planning.
- The support coordinator asks the participant what they want and helps the participant get what they need.
- Did your family member help develop the plan?
- Did you or another family member help develop the plan?
- Ensures the individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS.
- Provides opportunities to seek employment and work in competitive integrated settings, engage in

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[4] Retrieved from: http://www.medicaid.gov/

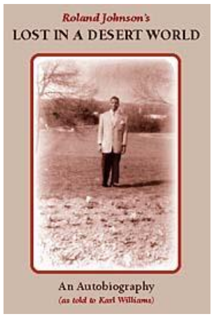
[5] Retrieved from: http://www.nasddds.org/news/cms-releases-hcbs-transition-plan-guidance/

community life, and control personal resources.
- Respects the participant's option to choose a private unit in a residential setting.
- Ensures right to privacy, dignity and respect and freedom from coercion and restraint.
- Facilitates choice of services and who provides them.
- Optimizes autonomy and independence in making life choices.
- Offers choices to the individual regarding the services and supports the individual receives and from whom.

In Milwaukee County

In 2013-14, HSRI conducted a review of the present contextual circumstances in Milwaukee County and an analysis to assess performance of the current service system against seven benchmarks in four primary domains. No specific benchmark focused on person-centered planning, however several benchmarks touched on the construct. What was found were two main approaches, Family Care and IRIS:

- Family Care was designed to foster the individual's independence and quality of life while recognizing the need for interdependence and support in addition to providing cost-effective long term care[6]. Individuals enrolled (or their guardian if applicable) in the Family Care program are required to participate in developing a care plan that reflects the individual's values and preferences[7]. Concerning person-centered planning, Family Care has improved flexibility for residence, services, and supports, fosters the individual's independence, and has improved focus on the quality of the individual's health and social outcomes.
- IRIS, designed as an alternative to Family Care, is a self-directed long-term care program option in which the participant manages supports and services using natural supports and services to meet their long-term care needs and outcomes within the guidelines of allowable supports and services[8]. The program is based on the five core principles of self-determination[9]:
    1. Freedom to decide how an individual wants to live their life.
    2. Authority over an individual budget.
    3. Support to organize resources and direct services in ways that are life enhancing and meaningful to the person and that recognize the contribution that individuals with disabilities can make in their communities.
    4. Confirmation of the important role that people with disabilities have in being self-advocates and affecting change.



In 1993 at the Third International Conference in Toronto, Roland Johnson gave his most famous speech. In his speech he asked self-advocates, *"Who's in charge? Who's in charge of <u>your</u> life?"*

His autobiography, "Lost in a Desert World", tells his story at Pennhurst State School where he endured sexual abuse and worked without pay.

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6 Retrieved from: http://www.dhs.wisconsin.gov/LTcare/generalinfo/whatisfc.htm
7 Family Care Statutes: DHS 10.44(2)(f) and 46.284(4)(c) retrieved from: http://docs.legis.wisconsin.gov/statutes/statutes/46/284
8 IRIS Policy manual: 1.1B retrieved from: http://www.dhs.wisconsin.gov/publications/P0/P00708.pdf
9 IRIS Policy manual: 1.1D retrieved from: http://www.dhs.wisconsin.gov/publications/P0/P00708.pdf

5. Responsibility for the wise use of public dollars.

Best Practices Elsewhere

Elements of Person-centered planning have been around for decades. John O'Brien and Herbert Lovett in "Finding a Way Toward Everyday Lives: The Contribution of Person-Centered Planning"[10] describes the following as person-centered planning's foundational beliefs:

- The person at the focus of the planning, and those who love the person, are the primary authorities on the person's life direction.
- Person-centered planning is experienced as learning through shared action. Those involved with the planning process may be uncertain about what is possible or desirable for the individual and may disagree about supports or decisions based on the participant's personal values and beliefs; but the planning process serves as a forum for negotiating such conflicts.
- Person-centered planning aims to change patterns of community life by integrating the individual into the community and by challenging oppressive or restrictive thoughts and actions to the individual's community integration.
- Person-centered planning requires collaborative action and fundamentally challenges practice that separate people and perpetuate controlling relationships.
- Honest person-centered planning can only be achieved by respecting the dignity and completeness of the individual.
- Those who treat person-centered planning as simply a technique and those who fail to provide their own development and support will offer little benefit to the people they plan with.

These foundational beliefs are still put forth and followed today as evident by the new CMS regulations and several states' recent adoption of person-centered planning principals intro their service systems. According to the Guidance for Implementing Standards for Person-Centered Planning and Self-Direction in Home and Community-Based Services (HCBS) Programs for Section 2402(a) of the Affordable Care Act, several elements of the person-centered process include:

- The individual living where they choose, integrated in the community with opportunities to work, engage in community life, control personal resources, and receive services in the community to the same degree of access as individuals not receiving HCBS services
- The individual's positive attributes must be considered and documented up front, at the beginning of the plan.
- Consider the individual's right to assume some degree of personal risk, and include measures available to reduce risks or alternative ways to achieve their personal goals.
- Elements of self-direction must be addressed whenever a self-directed service delivery system is chosen.
- The plan must be written in the plain language of the individual receiving services, and be understandable to the individual or their guardian.

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[10] O'Brien, J., & Lovett, H. (1992). Finding a Way Toward Everyday Lives: The Contribution of Person Centered Planning. Retrieved from: http://files.eric.ed.gov/fulltext/ED356596.pdf

Redesigning the Adult Intellectual/Developmental Disabilities Service System in Milwaukee County

Information Brief on Self-Direction

November 2014

Self-Direction

Terminology regarding the concept of "self-directed" services varies depending on the population being considered. Phrases such as person-centered, participant-driven, self-directed, consumer-directed, stakeholder involvement, and person-directed are all used to refer to services and supports identified as:

> *Necessary and useful by the person who needs them, and controlled and managed by that person.*

The essential constructs to this concept center on the idea that each individual with disabilities decides what supports are needed, based on his or her dreams or aspirations and need for support to meet day-to-day life demands. Moreover, embedded within the construct is a presumption that the individual has authority over the resources made available to address identified support needs. This may include resources made available through the public sector, such as through a service provider delivering Medicaid-financed services, or the "informal" or private sector involving non-paid supports.

Regarding individuals with intellectual disabilities, however these constructs must be balanced against the impact of the disability on an individual's capacity to make independent decisions that affect his or her safety and well-being. Overall, the greater the level of intellectual disability, the greater the need for oversight and supervision, thereby reducing the individual's potential for self-direction in some facets of life. For many individuals this reality plays out so that others (e.g., family members, guardians, paid staff) act as proxy decision-makers for the individual, even in "self-directed" systems. The challenge in this context is to find an appropriate balance so that individuals have maximum authority over their life, but without unacceptably risking their health and well-being.

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Note that in March 2014 the Centers for Medicare and Medicaid Services (CMS) issued new requirements for states regarding the delivery of Home and Community-Based Services (HCBS).[11][12] These rules emphasize community integration, person-centered planning and services, and choice, including self-direction. Examples of the new requirements relevant to self-direction include the following:

- The option to use a self-directed option is made available to all individuals who receive HCBS.
- HCBS recipients must have access to information and counseling and information on self-direction through a variety of sources as need or desired, so they can make an informed decision when choosing a self-directed service delivery model.
- People must be able to choose their paid and unpaid direct care workers and/or medical support staff.
- People must have flexibility to seamlessly change their service plans and budget allocations, based on different needs and preference with an assurance of health and safety.
- People must be supported in taking risks associated with pursuing their goals. There must be a back-up plan for assumed risks, and for a variety of emergency situations.

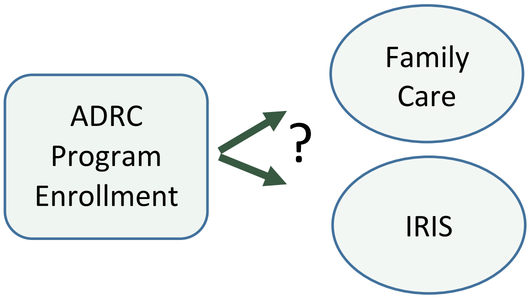
  For more information on the guidance issued by CMS: http://www.acl.gov/Programs/CDAP/OIP/docs/2402-a-Guidance.pdf

In Milwaukee County

In 2013-14, HSRI conducted a review of the present contextual circumstances in Milwaukee County and an analysis to assess performance of the current service system against seven benchmarks in four primary domains. One benchmark pertained specifically to self-direction.

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

- **Summary Finding:** IRIS offers significant opportunities for self-directed services and person-centered supports, though there are concerns over its application. Family Care organizations also seek to offer person-centered supports but by definition are charged with managing supports and resources.
  - The opportunity to select freely among qualified providers is a bedrock principle of person- centered approaches. The ADRC provides neutral information to individuals but cannot advise for a particular managed care provider. Repeatedly during interviews, respondents observed that individuals with disabilities and their families do not have an independent source of information to assist with determining which of the managed care organizations or IRIS is most likely to meet their needs and preferences.



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[11] http://www.medicaid.gov/

[12] http://www.nasddds.org/news/cms-releases-hcbs-transition-plan-guidance/

  - Interview respondents cite the popularity of the IRIS program, which they attribute to its flexibility and the authority that service recipients have over the supports they receive.
  - Some challenges with the IRIS program are noted, including: budget allocations not ample enough; no systematic training for IRIS consultants; service recipients are on their own in managing supports; difficulty in assessing quality of supports; and requires a lot of assistance to manage.
  - Family Care organizations seek to offer self-directed options as well, but are challenged to do so given the managed care framework.

Best Practice

In the 1990s, the ideals of "self-direction" were relatively new to a field where services to people with I/DD were largely predicated on the premise that these individuals required significant oversight and direction, coupled with habilitative instruction. The idea that they might expect to "be the boss" of their own life, however, took root so that presently many states offer "self-directed" options within their service configurations. A well-designed and implemented self-directed service system is one that has: (a) strong principles to guide what is done, and how, (b) structures to provide context for the system to function, (c) processes to govern day-to-day operations, and (d) expectations tied to what outcomes are expected regarding what will happen to people and systems. [13][14]

- **Principles to guide what is done, and how**. These values, or principles, provide an overarching framework within which all structures and processes (i.e., policies, design elements, and practices) are consistent.
  - <u>Individual authority to plan and pursue their own vision</u> – Self-direction values and embraces the concept that the individual is in the best position to know what he or she wants and needs, and that the individual should have power over factors that can help them realize their vision.
  - <u>Individual authority to direct services</u> – Self-direction values people being in charge of what happens, what services and support they receive and who provides them.
  - <u>Community membership</u> – Self-direction values and promotes inclusion and participation in a community, recognizing that "promoting community membership" represents something different for each person.
  - <u>Collaborative support delivery</u> – Self-direction values personal networks of individuals, friends, family, co-workers, neighbors, and others, and connects service delivery systems with these "individual communities" to support individuals in achieving their goals.
  - <u>Meaningful leadership roles for individuals and families</u> – Self-directed models value and assure meaningful leadership roles for individuals at all levels of the service system. Has necessary design elements in place to support self-direction.
  - <u>Flexibility in support delivery</u> – Self-direction constantly refers back to what the person needs

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[13] Melda, K., Vorderer, L., Bradley, V. & Agosta, J. (2003). *Best practices in self-directed services and supports: Key elements across the intellectual and developmental disabilities, behavioral health, and elderly and physical disability fields.* Tualatin OR: Human Services Research Institute.

[14] http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Delivery-Systems/Self-Directed-Services.html

  and wants. Utilizes best practices in delivering services and supports.
  - Access to satisfactory support options – Self-direction means that people not only have the power and authority to make support choices, but also that there are options available to them that are appropriate and desirable. Anticipates what people want to lead a meaningful life.
  - Commitment to excellence and personal outcomes – Self-direction values and assures a sustained commitment to achieving service excellence and individual outcomes for recipients.

- **Structures** – Structures are the key design and policy elements essential to a self-directed system. The connection between structures and processes is inextricable. That is, each process or best practice must sit within a structure that not only allows for, but promotes its availability and opportunity to be implemented successfully. Essential structures include:
  - Fair and reliable means for assessing support needs;
  - Fair and ample individualized budget allocations based on need;
  - Fair and ample rates of service reimbursement for providers;
  - Effective means to inform individuals about how to self-direct;
  - Person-centered supports planning;
  - A qualified and available workforce to provide supports;
  - Means of assuring quality in service delivery and assurance of safety and well-being of individuals; and
  - Means for assuring public transparency to illustrate what has been to whom, to what effect, and at what cost.
- **Processes** – Self-directed models must employ current best practices to deliver services and supports to individuals. Across fields, self-directed models universally include key practices such as a person-centered plan, an individually determined and controlled budget, a qualified workforce and a method for assuring quality of services. Equally important, though, as *what* happens in a self-directed model, is *how* things happen. Essential processes include:
  - Individuals feel welcome and heard
  - The exchange of information is adequate; yet not burdensome
  - Practices are culturally competent
  - Individuals control their budget allocation
  - Planning is person-centered
  - Individuals choose and manage supports and providers
  - Money and services/supports are portable
  - Supports are flexible to meet changing needs
  - Supports are available in a crisis
  - Informal community resources are utilized
  - Peer support/mentoring is available
  - Quality of supports is measured
  - The public is kept informed
- **Quality of Life Outcomes** – The delivery of self-directed services should result in the achievement of valued outcomes for individuals. When services and supports are targeted and customized around the needs and preferences of individuals, better outcomes are achieved. In fact, the outcomes that a system can achieve are affected by the services that the system offers, the allocation of resources

within the system, and the extent to which a system promotes the achievement of valued outcomes. Several desirable outcomes refer to:

- Relationships –People want to feel connected to others, to experience friendships, relationships, and a sense of belonging (within a family or otherwise). For some, it may be a wide network of casual relationships, while for others, fewer more significant relationships are important. Individually-defined, people want to be supported to participate in social relationships, religious activities, recreational opportunities and other community-oriented activities.
- Meaningful things to do – People want a meaningful life, and to spend their time in meaningful ways.
- To be safe – People want to feel and be safe. This includes having a safe and stable place to live, a safe place to work, and a sense of personal security.
- To feel valued – Individuals want to be valued in their personal relationships, relationships with their communities, and within society as a whole.
- To have access to a community life – To be a full participant in community life, one must be assured access. Individuals want their choices to live an inclusive community life to be individually accommodated physically (e.g., transportation, physical access to buildings and parks), linguistically (e.g., ready access to interpreters and translators), and culturally competent (e.g., public and community supports that are culturally responsive).
- To be as healthy as possible – Individuals want to be as healthy as possible (given their specific age or disability) and supported to create or maintain a healthy lifestyle. Individuals want to be adequately informed to make choices about their own health, and when opportunities for improving health exist, individuals want ready access to those resources (e.g., medical services, medications, assistive technology).
- To have an ample amount of money – Many people with I/DD, physical disabilities, behavioral health issues and/or those who are elderly experience short or long-term poverty. This poverty affects individuals’ sense of themselves and their ability to “make their way in the world”. For some, economic security means knowing more about the benefits to which they are entitled or eligible, and being able to manage them. For others, it means having the same chance to hold down a meaningful job as someone who does not have a disability. And for others, it means moving into retirement not worried that their plans for economic security in their later years will fall apart.

Redesigning the Adult Intellectual/Developmental Disabilities Service System in Milwaukee County

Information Brief on Peer Support and Cooperatives

November 2014

Peer Support and Cooperatives

Service systems across the nation are challenged to accommodate increasing demands for service while enduring difficult fiscal times. In the face of these challenges, states continue to support a “services first and only” approach, funded primarily through Medicaid. Lost in this response are opportunities for promoting a spirit of personal reliance and contribution, mutual support and community connection.

Yet, one of the strongest assets any community has is its people. People volunteer daily to do any number of tasks for others, through structured groups or individual initiative. In addition, 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.

Going forward, a more favorable response to present challenges requires that policy makers at all levels complement existing public services by establishing sustainable networks of mutual support so that individuals with I/DD and their families may:

- Make efficient and effective use of public services, such as those funded by Medicaid;
- Work cooperatively to achieve common goals;
- Utilize supports available from local businesses or community serving organizations;
- Provide supports to one another, as in an exchange network or peer support group; and
- Contribute in meaningful ways to the community.

Operationally, this suggests action to develop peer connection networks where individuals offer one another mutual support, as well as formal cooperatives where participants work together to manage the services they receive.

> *In a peer support network or cooperative, participants unite to address common or individual needs through mutual support and/or joint action.*

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In Milwaukee County

In 2013-14, HSRI conducted a review of the present contextual circumstances in Milwaukee County and an analysis to assess performance of the current service system against seven benchmarks in four primary domains. One benchmark pertained to person-centered planning and self-direction. In this context, control over one's overall life was explored, including supports that may be provided outside the public sector (i.e., Medicaid financed services).

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

- **Summary Finding:** Aside from differences in administration between IRIS and Family Care, interview respondents also lamented the unrelenting reliance on Medicaid-funded supports. Some noted that other community assets should be tapped to improve participants' quality of life. After all, every community has businesses and organizations with members that offer support to each other.[15] These may include churches, schools, colleges, businesses, libraries, neighborhood associations, clubs, recreational entities and other community serving organizations. In addition, people might be encouraged to support one another through peer support or exchange networks whereby individuals contribute their own time to support another and are supported by others in return. Indeed, some respondents noted that a more frugal use of resources may actually stimulate more creativity and a greater use of other available resources.

Best Practice

Two approaches gaining prominence nationally include: (a) peer connection networks; and (b) formal cooperatives or federations where participants work together to manage the services they receive.

- Peer connections. To complement traditional Medicaid-funded services provided say through Family Care or IRIS options, individuals and families may be encouraged to participate in local Peer Connection Networks. These Networks are not meant to take the place of HCBS services. Rather they are intended to generate additional, complementary supports within communities.


A Peer Connections Network

  In a Peer Connection Network, participants unite voluntarily to address common needs through mutual support and/or joint action. Networks can be composed of individuals with disabilities, family members, or both. A staff person or "organizer" is typically

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[15] Green, M. (2010). ABCD in action: When people care enough to act. Denver CO: Engaging Communities.

required to advise and organize the Network, though it should ultimately be shaped by the needs and preferences of its members.

Peer Connection Networks blend together three essential sources of support:

- <u>Disability-oriented public services</u>: Individuals with I/DD may be receiving support services already through a community services network. These actions may also be complemented by other public services (e.g., local ride sharing programs sponsored by local transit agencies). These services often provide significant support, but may be insufficient to address all of the unmet support needs among individuals with lifelong disabilities.
- <u>Peer support</u>: Peer support associations are created to link people through a voluntary exchange of support. This can include simple forms of help that individuals offer one another (e.g., temporary respite, a car ride, emotional support, information). Peer support may also be organized more formally through a "time bank." A time bank organizes participants within an exchange network where everyone's contributions are valued equally and tracked. The hours a participant gives to others are credited to his or her account, and hours of help the person receives are "debited" from the account. After each service exchange, the participants notify the office of how many hours were given
- <u>Community assets</u>. The network can also collaborate with other community assets, such as faith-based and other community service organizations (e.g., churches, civic or hobby clubs, recreational centers). Local chambers of commerce and community businesses may also prove helpful.

- <u>Provide opportunity for individuals with I/DD and their families to establish formal cooperatives or federations where participants work together to manage the services they receive</u>. In the current service system, families are counted on in a number of ways to manage the supports provided to the family member with disabilities. By working together, participants can form a strong alliance within a "cooperative." Within the context of a self-directed service option, the cooperative itself may function as a provider agency, performing any number of functions collectively for its members, including:
  - Recruiting direct support staff;
  - Acting as an employer of record;
  - Monitoring paid staff and to assuring that supports are properly delivered and accounted for;
  - Purchasing services, durable equipment or other needed supports; and
  - Acting as a fiscal intermediary to ensure that providers are paid, but also to offer providers workers' compensation and other benefits.

Working on their own, such responsibilities can prove burdensome over time. If families and individuals work together, however, many of the associated responsibilities taken on by families may be more efficiently and effectively managed. This can be accomplished by promoting partnerships within the public and private sectors – for example by forming a "Human Services Cooperative (HSC)."

HSCs are recognized by the Federated Human Service Cooperative, an organization whose goal is to "assist in the creation of Human Services Cooperatives" (See http://www.federatedhsc.coop/). This national entity certifies local cooperatives that are directed by individuals and families who use disability services to provide supports that benefit its membership. Once certified, a cooperative essentially operates as a provider agency, delivering services based on policies formulated by member owners. This type of cooperative is typically built on partnerships developed between agencies and community-service organizations in the public and private sector. These partnerships create a responsive network to offer self-directed services to address member needs.

Resources in Wisconsin

In Wisconsin, there is already interest in establishing approaches such as these to complement the public system. Indeed, throughout Wisconsin there is already an underlying culture of mutual support as evidenced by the extensive array of farmer cooperatives across the state.

In particular, *In Control- Wisconsin* is an organization that readily recognizes the importance of establishing mutual support networks:

> *We believe that the true potential and sustainability for self-directed supports lies within the involvement and expertise of individuals, families and communities. In Control Wisconsin prioritizes the development and strengthening of peer and family networks across the state, while creating opportunities for people to be contributing members of their communities.*
>
> *Our work is focused on looking at how to connect and support people – through the creation of circles of support and community networks, as well as connecting circles and networks with each other across the state.*
>
> http://www.incontrolwisconsin.org/what-we-do/community/

In addition, we discover that there are numerous time banks sprinkled across Wisconsin, including one in Milwaukee. The *Milwaukee Area Time Exchange* seeks members across the community, and so does not focus on people with disabilities.

> *Milwaukee Area Time Exchange is a network of neighbors building safe and vibrant communities through the exchange of our greatest natural resources: our knowledge, skills and talents. One hour of service equals one time credit, exchangeable for other members' services. Members might provide a music lesson, take care of someone's pet, do a home repair, volunteer at a community center, or help someone get to a doctor's appointment. With timebanking, we all have currency. Let us cultivate our safe and vibrant communities, one hour at a time.*
>
> http://mketimeexchange.org/

Redesigning the Adult Intellectual/Developmental Disabilities Service System in Milwaukee County

Information Brief on Employment

November 2014

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Employment

The purpose of this brief is to describe circumstances and best practices pertaining to employment policy and outcomes for people with intellectual and developmental disabilities (I/DD). Ideally, the adoption of best practices results in increased opportunities for people with I/DD to achieve and maintain integrated employment at prevailing wages in the community. What follows is: (a) a snapshot of national, state, and county status regarding employment services provided to individuals with I/DD, and (b) elements of best practices that promote employment.

Background

People with intellectual and developmental disabilities often express a desire to work in a "real job." Self-Advocates Becoming Empowered (SABE), a national advocacy organization for people with developmental disabilities, plainly states, "We have been prepared enough. Get us real jobs. Close sheltered workshops" (www.sabeusa.org). SABE's resolve stems from an enduring disappointment in the lack of opportunity that people with developmental disabilities are afforded to work at real jobs in integrated settings at competitive wages. Data are provided below to illustrate the national status of individuals receiving integrated employment and other related services including facility-based work.

National Status

Data collected by the Institute for Community Inclusion at the University of Massachusetts Boston show that in 2012 I/DD agencies reported 18% of people received integrated employment services.[16] Still, progress in many states is being made. Six states including Connecticut, Maryland, New Hampshire, Oklahoma, Washington, and West Virginia all reported that at

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[16] Butterworth, J., Smith, F. A., Hall, A.C., Migliore, A., Winsor, J., & Domin, D. (2014). StateData: The national report on employment services and outcomes. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion

least 40% of individuals receiving day and employment services were receiving integrated employment services.[17] The percentage of people served in facility-based work was approximately 27% nationally.[18]

According to the National Core Indicators (NCI) Project, survey data from 25 states and one sub-state entity revealed that 14.7% people with I/DD participated in integrated employment during the 2012-2013 data collection year[19]. The majority of individuals in integrated employment work part-time. Of those in integrated employment 46.1% also took part in another type of day/employment service. For example, in addition to integrated employment, 29.1% participated in unpaid community activities, 16.5% had a paid facility-based job, and 22.3% were in an unpaid facility-based activity.[20]

A number of initiatives have contributed to the national context regarding opportunities, supports, and expectations related to employment of people with I/DD including:

- **U.S. Department of Justice (DOJ)**
  The U.S. Department of Justice filed motions in two states, Rhode Island and Oregon, related to employment service options offered to individuals with I/DD in settings commonly known as sheltered workshops. In both cases, the DOJ cited violation of the Americans with Disabilities Act (ADA) and the Supreme Court's decision in *Olmstead v. L.C* by failing to provide day activity services in the most integrated settings. In Rhode Island, the resulting Consent Decree mandates that the state must transform its service system over the next 10 years and provide supported employment services to three target populations including individuals currently served in sheltered workshops, facility-based non-work programs, and students with disabilities transitioning from high school.[21] The class action lawsuit in Oregon, in which the DOJ has intervened as a plaintiff, is still pending.
- **Home and Community-Based Services Regulations**
  In 2014, the Centers for Medicare and Medicaid (CMS) issued new regulations related to Home and Community-Based Services (HCBS) in order to enhance the quality of HCBS and provide additional protections to individuals served. The final regulations establish definitions for what constitutes home and community-based settings. The rule identifies other settings that do not meet the threshold of HCBS including, (a) publicly or privately-owned facilities providing inpatient treatment; (b) settings on the grounds of, or immediately adjacent to, a public institution; or (c) settings that isolate individuals receiving Medicaid-funded HCBS from the broader community.
  States currently operating settings that do not meet the new HCBS criteria must propose a transition plan describing how they will come into compliance within specified timelines.
- **State Employment Leadership Network**

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[17] Ibid.

[18] Ibid.

[19] Butterworth, J., Engler, J., & Hiersteiner, D. (2014, October). *National Core Indicators: Employment Trends for Adults With ID/DD and Suggestions for Policy Development.* Ancor Webinar Series. Retrieved from: http://www.nationalcoreindicators.org/upload/presentation/ANCOR_Employment_Oct_2014.pdf

[20] Butterworth, J., Engler, J., & Hiersteiner, D. (2014, October). *National Core Indicators: Employment Trends for Adults With ID/DD and Suggestions for Policy Development.* Ancor Webinar Series. Retrieved from: http://www.nationalcoreindicators.org/upload/presentation/ANCOR_Employment_Oct_2014.pdf

[21] Consent Decree, United States v. State of Rhode Island and City of Providence (No. 1:13-cv-00442, D.R.I. July 11, 2013) available as a document at http://www.ada.gov/olmstead/olmstead_cases_list2.htm

> In 2006, the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Institute for Community Inclusion at the University of Massachusetts Boston (ICI) launched the State Employment Leadership Network (SELN). The SELN is a national initiative dedicated to improving employment outcomes for adolescents and adults with intellectual and other developmental disabilities. The SELN had 30 member states during the 2013-2014 year.

Circumstances in Wisconsin

In Wisconsin, in 2012, 22% of people were served in integrated employment, 20% were served in community-based non-work, 46% were served in facility-based work, and 50% were in facility-based non-work.[22] While data show that Wisconsin serves a slightly higher percentage of people in integrated employment than the national average, there are many more people receiving facility-based services compared to the national average.

In 2013-14, HSRI conducted a review of the present contextual circumstances in Milwaukee County and an analysis to assess performance of the current service system against seven benchmarks in four primary domains. One benchmark that included discussion related to employment outcomes.

Benchmark: The provision of services results in the achievement of preferred outcomes for people with intellectual/developmental disabilities.

- ▶ **Summary Finding:** Interview results suggest that the publicly-funded providers that operate in Milwaukee County are not held accountable for valued outcomes such as employment and community inclusion. Interview respondents in Milwaukee County also expressed concern regarding: (a) employment opportunities for students transitioning from high school, (b) potential reduction of reimbursement rates for integrated employment service options, and (c) the wide variance of employment practices provided in the county, including dated continuum-based "readiness" models.[23]

Stakeholders are concerned about the status of employment services in Wisconsin as evidenced by the Autistic Self-Advocacy Network's[24] response letter to CMS stating clear disagreement with the position of the Wisconsin Department of Health Services that all current pre-vocational and day program settings should remain as part of the compendium of service options available.

Elements of Best Practices Related to Employment

The presence of the following elements increase the likelihood of successful employment outcomes for people with I/DD.

- ✓ Employment First policies at the state level. *Employment first* policies are based on the presumption that people with developmental disabilities can and should work and that integrated

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[22] Butterworth, J., Smith, F. A., Hall, A.C., Migliore, A., Winsor, J., & Domin, D. (2014). *StateData: The national report on employment services and outcomes*. Boston, MA: University of Massachusetts Boston, Institute for Community Inclusion

[23] Agosta, J., Bradley, V., Kardell, Y., & Aiken, F. (2014). *Redesigning the adult intellectual developmental disabilities service system in Milwaukee County, phase one final report*. Tualatin, OR. Human Services Research Institute.

[24] Autistic Self Advocacy Netwrok. Letter to Honoroable Marilyn Tavenner, Administrator Center for Medicare & Medicaid Services. October 7, 2014. Available at http://autisticadvocacy.org/wp-content/uploads/2014/10/2014-10-07-Wisconsin-Sheltered-Workshop-Letter.pdf

employment at competitive wages is the *first or preferred* option considered for service recipients. Individuals may choose a service option other than employment, but the organizing framework of the service approach presumes employability and establishes an expectation of successful employment. An Employment First policy stance provides a fundamental and necessary underpinning to a service system that seeks to increase employment outcomes for people with developmental disabilities.

- ✓ Community based non-work options tied to gaining community employment. Complementing integrated work, many states now also encourage "community-based non work" (CBNW). The Institute for Community Inclusion defines CBNW as including all services that are focused on supporting people with disabilities to access community activities in settings where most people do not have disabilities. Volunteering and community service activities fall into this CBNW category as these kinds of community contributions are proven avenues through which individuals with disabilities can gain skills, explore career paths and develop the social networks necessary to gain meaningful employment or postsecondary education. Still, CBNW does not include paid employment, and it can be applied in ways that do little or nothing to promote later employment for participants.
- ✓ Reimbursement rates adequate to achieve integrated employment outcomes. States can encourage service providers to expand integrated employment activities by establishing higher rate of payment for integrated employment than for other day services.
- ✓ Transition strategies and services for youth exiting high school. A recent suggests that youth who began transition services by age fourteen rather than sixteen had better employment outcomes.[25] Preparing youth with disabilities to participate in the workforce begins long before planning for what life after high school entails. It begins with experiences typically associated with high school age youth such as doing chores, managing school responsibilities and homework, participating in extracurricular activities, engaging in activities to increase independence, and interacting with peers. These experiences provide the foundation for the skills and opportunities necessary for future employment for all youth, including youth with disabilities.
- ✓ **Use of assistive technology for employment supports.** Since the early 1970's, assistive technology or rehabilitation technology has emerged and opened unlimited employment opportunities for people with disabilities. Individuals who at one time faced enormous barriers concerning accessibility, communication, and mobility can now optimize their intellectual and physical capabilities through use of technology.
- ✓ **Core competencies for employment**-related staff. Investing in highly skilled and competent staff who are well-equipped to support individuals to gain and maintain employment is a key component. These staff should have knowledge and skills related to person-centered employment strategies, conducting skills assessments, identifying and securing appropriate job-related supports, developing

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[25] Cimera, R.E., Burgess, S., & Wiley, A. (2013) Does providing transition services early enable students with ASD to achieve better vocational outcomes as adults? Research and Practice for Persons with Severe Disabilities, 38(2), 88-93

relationships with local businesses, assisting individuals to pursue entrepreneurial endeavors, and implementing individualized job development strategies.

- ✓ **Commitment to phasing-out reliance on sheltered workshops**. States can discourage reliance on sheltered workshops by restricting capacity, limiting new admissions, and/or reducing funding for this type of service option. Enacting a plan with specific targets and timelines sets expectations and accountability.
- ✓ Data and performance measurement to monitor employment outcomes. Data collection practices enhance the ability to evaluate system performance related to employment outcomes. Data elements can include employment service utilization, delivery, and satisfaction.
- ✓ Support for family members to plan for and support the individual's employment goals. Family members can contribute significantly to the successful employment of their loved one with I/DD. They may benefit from assistance with navigating formal services, planning, and securing appropriate supports for the individual with I/DD to reach their employment goals. In addition, networking through friends and family may present job opportunities in the community.

Redesigning the Adult Intellectual/Developmental Disabilities Service System in Milwaukee County

Information Brief on Community Supports for Individuals with Complex Behavioral Challenges

November 2014

Community Supports for Individuals with Complex Behavioral Challenges

Prepared For

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A critical measure of the effectiveness of a community intellectual/developmental disability service system is how well it supports individuals with especially challenging behavioral conditions. To the extent that the needs of such individuals can be appropriately addressed, their lives will be more stable and higher service costs will be avoided. Toward this end, it is vital that individual needs be met without resorting to unnecessary placement out of the person's community residence or family home. The purpose of this information brief is to describe (a) the scope of the issue, (b) circumstances in Milwaukee County, and (c) encouraging practices to support individuals with I/DD with complex behavioral needs to live in their community.

Background

Nationally, in 2012, the majority of individuals with I/DD lived in small community residences with three or fewer people (22%) or in the home of family members (55% Family Home), rather than congregate settings with four or more residents (23%)[26]. A subset of people with I/DD living in these community residences have extensive behavioral support needs associated with their disability or due to co-occurring mental illness. Behavioral challenges can include self-harm, physical injury to others, or destruction of property. This raises the question of how to meet the needs of individuals in the community who experience challenging behavioral conditions, and prevent placement in more restrictive settings (e.g., psychiatric hospital). States including Maine, Oregon and Vermont recognized the need to respond quickly and expertly to the needs of individuals with challenging conditions in their home communities and avoid

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[26] Larson, S.A., Hallas-Muchow, L., Aiken, F., Hewitt, A., Pettingell, S., Anderson, L.L., Moseley, C., Sowers, M., Fay, M.L., Smith, D., & Kardell, Y. (2014). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2012*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

placement within developmental centers – placements that in some cases become permanent because of lack of community capacity.

In Milwaukee County

In 2013-14, HSRI conducted a review of the present contextual circumstances in Milwaukee County and an analysis to assess performance of the current service system against seven benchmarks in four primary domains. One benchmark included discussion related to the needs of individuals living in the community with complex behavioral support needs.

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

- ▶ **Summary Finding:** The Department of Health and Human Services plans work with the Behavioral Health Department to grow capacity to address the needs of individuals with I/DD with complex needs living in the community by expanding the mobile crisis team to provide 24/7 availability specifically for these individuals. The county initiated the downsizing of the Center for Independence and Development (a.k.a. Hilltop), which serves individuals with a dual diagnosis of I/DD and mental illness, and plans to close the facility by the end of 2014.

Best Practice

The presence of the following elements increase the likelihood that people with I/DD with complex behavioral needs will have the supports required to live in their community.

- ✓ <u>Interdisciplinary approach with focus on prevention:</u> An effective community-based strategy often requires a collaborative approach that brings together expertise from an array of resources such as mental health, positive behavior supports, person-centered planning, community supports, respite, and supports to families. Steps can be taken to proactively support people to live meaningful lives in the community, and minimize challenging behavior.

    - **Support and training for staff and family members.** Throughout, it is essential to consider that behavioral difficulties are not always best responded to with behavioral intervention directed at the individual. Staff or family members may inadequately respond to individual needs or make unreasonable demands on the individual, prompting undesired behavior. There may be any number of "silly rules" pressed on individuals by staff members that foster conflict and so problem behavior. Examples include arbitrary early bed times and restrictions of all sorts, such as on phone use, television viewing, dating, leisure activity or diet. Staff and family members may benefit from specific training on how to appropriately prevent and alleviate challenging behaviors.

    - **HCBS wavier services to cover consultation and specialized environmental design.** Through careful planning and design it is possible to adapt homes that in part address individual needs in ways to reduce the potential of behavioral events. The right physical environment can change the relationship between a person and people providing support, reducing conflict while enhancing opportunity for positive interaction.[27] See Creative Housing Solutions: http://gbcchs.com

- ✓ Robust local crisis support response. Preventative efforts are worthwhile, however, it is anticipated that, some number of these individuals may experience crisis. To respond to situations such as these, local teams must be able to offer a mix of supports, including assessment, positive behavioral support planning, staff or family training, respite services and referral to companion service systems.

  Community crisis response systems should include at least these three forms of support:

  - *Emergency* – Situations where, because of an individual's challenging behavioral issues, there is a need for: (a) immediate specialized services; or (b) crisis/respite service for family members or staff.
  - *At Risk* – Situations where a specific or time-limited problem resulting from behaviors or situational factors disrupts an individual's optimal functioning in his or her place of residence or habilitation program and causes the person to be at risk of losing his or her services.
  - *Short-Term Assistance* –Situations where 24-hour linkage and referral services are needed for ongoing services by the family or primary caregiver to address an individual's behavior or situation.

- ✓ Collaborations with first responders and other emergency community resources. Community resources such as law enforcement, fire and rescue services, community mental health or other community-based organizations that may provide emergency response or treatment may be called on to intervene in crisis situations with these individuals. Working collaboratively across community organizations increases opportunity to develop responses that are appropriate and effective for individuals with I/DD. While these emergency responders often have extensive training and expertise related to their line of work, they may benefit from additional training on how to effectively interact and address the unique needs of individuals with intellectual/developmental disabilities who are experiencing crisis.

- ✓ Trauma-informed care perspective. Trauma-informed care (TIC) is a systems-based approach that considers the lasting impact that traumatic events or circumstances can have on individuals. It offers a framework for delivering services that applies to the general population as well as people with I/DD. This approach is worth exploring, particularly in the context of creating a culture of support for individuals with I/DD with complex behavioral needs, and may also have an increased risk for abuse or neglect.[28]

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[27] See Creative Housing Solutions: http://gbcchs.com

[28] Kessler, J., (2014). A call for the integration of trauma-informed care among intellectual and developmental disability organizations. *Journal of Policy and Practice in Intellectual Disabilities*, *11* (1) 34-42.