



A Wisconsin Conversation with IHAs

Best Practices in Medicaid Managed Long-Term Care for People with Developmental Disabilities

March 31, 2016
Madison, Wisconsin

Sponsored by Wisconsin's Administration on Intellectual and Developmental Disabilities (AIDD) Partnership:



WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

disabilityrights | WISCONSIN



WAISMAN CENTER
UNIVERSITY OF WISCONSIN-MADISON
University Center for Excellence in Developmental Disabilities
www.waisman.wisc.edu

Meet Your Administration on Intellectual and Developmental Disabilities (AIDD) Network Partners in Wisconsin

Each state and territory has three organizations, known as the state DD Network, that are uniquely positioned to meet the diverse needs of individuals with developmental disabilities in their state. Each entity serves specific, but overlapping, goals that create collaboration. Each partner is committed to the core values of the federal Developmental Disabilities (DD) Act and its core values: self-determination, independence, productivity, integration and inclusion in all facets of the community. In Wisconsin, the three partners are:



The Wisconsin Board for People with Developmental Disabilities is comprised of people living with developmental disabilities, their family members, and representatives from state agencies and our two state partner agencies, Disability Rights Wisconsin and Waisman Center. The Board advocates for and develops innovative projects that improve the independence, productivity, and integration of people with developmental disabilities. Independence means having choices available, being able to choose, and exercising control over one's own life. Productivity means making a contribution to one's own household, neighborhood and community. It means working in the community and earning a living. Integration means being present in the community, participating in the life of the community and being valued as a person, friend, family member and neighbor. The Board is also charged with supporting statewide self-advocacy organization and self-advocates themselves. People can learn more about the Board at www.wi-bpdd.org

disabilityrights | WISCONSIN **Disability Rights Wisconsin** is the statewide protection and advocacy agency for all persons with disabilities in Wisconsin with offices in Madison, Milwaukee and Rice Lake. DRW's vision is for all persons with disabilities and their families to be empowered to exercise and enjoy the full extent of their rights and to pursue the greatest possible quality of life. DRW challenges systems and society to achieve positive changes in the lives of people with disabilities and their families by providing advocacy assistance to individuals with a variety of disabilities; engaging in systems change and providing training and information. DRW is focused on helping people to live, work, and attend school in the most integrated setting; confronting abuse and neglect; addressing problems within managed care; assisting people to obtain benefits; and helping people overcome discrimination and barriers. DRW employs a variety of skilled attorneys, advocates and other experts and engages in litigation when it is necessary and helps people become more independent. DRW offers services including information and referral, advice and guidance in self-advocacy, investigating, negotiating, mediating or representation in legal proceedings. Consumers and families can access our assistance in person or through our toll free number: **800-928-8778**.



The University Center for Excellence in Developmental Disabilities, whose mission is to support the full inclusion and self-determination of people with developmental disabilities and their families, is one of a nationwide network of independent but interlinked centers, representing an expansive national resource providing a research-base to addressing issues, finding solutions, and advancing research supporting the needs of individuals with developmental disabilities and their families.

TABLE OF CONTENTS

Self Direction	page 1
Community Supported Living	page 4
Support to Families	page 7
Community Integrated Employment.....	page 10
Community Integrated Day Supports	page 13
Disability Informed Acute and Primary Health Care	page 16
Behavioral Supports and Behavioral Health Services	page 19
Transportation	page 22
Speaker Directory	page 25



SELF-DIRECTION

People who manage their own care manage it better and more cost-effectively. Anyone, regardless of level of disability, can self-direct, as long as their decisional support network is in place and committed.

Self-Direction means that the participant controls his or her own long term care services. The individual has the flexibility to design and implement a cost-effective and personal plan because he or she is in the best position to know the type of support needed to help meet outcomes, how much support is needed, when it is needed and who is best qualified to provide it. The participant manages an Individual Services and Supports Plan within an individual budget and the guidelines of allowable supports and services to meet his or her long term care needs.



How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

- ▶ People who control their own lives spend less than people to whom care is dictated because they are getting exactly what they know they need. They are prudent stewards of long term care dollars.
- ▶ There are more than 13,000 people fully self-directing in IRIS and an additional 1,300 who exclusively use Self-Directed Supports within Dane County who will be new enrollees to managed care. An IHA that fully embraces the principles of self-direction currently embedded in the IRIS program will attract more of these new consumers.
- ▶ An IHA that develops a reputation for “doing self-direction right” will attract more enrollees entirely new to the system.
- ▶ Because people who self-direct have a closer connection with their provider network (which often includes family and friends) there is less “staff” turnover, better continuity of care, more efficient plan administration and greater consumer satisfaction.

Key Best Practices

- ▶ Fully support the person to have the most control possible over the best possible life. Fully support individuals to set their own goals through a comprehensive person-centered approach.
- ▶ Fully support the person’s decision-making authority over both funding and services; encourage and support the person’s direct responsibility to manage long term care (LTC) services with the assistance of allies chosen by the individual, in order to meet the person’s functional, vocational and social needs.
- ▶ All persons eligible for LTC must have the opportunity to self-direct any or all services and supports.
- ▶ Allow Individuals to utilize Supported Decision-Making tools to maintain and ensure autonomy and choice in making decisions about their lives and care plan.
- ▶ Ensure that managed care is not promoted above self-direction, and that people can make a truly informed choice between managed care and self-direction.



SELF-DIRECTION

- ▶ Ensure that a person can freely choose the self-direction option at any time.
- ▶ Provide training on skills needed to manage budgets, hire and terminate staff, set wage rates and determine what services they need to live a healthy and happy life.
- ▶ Encourage, but not compel, individuals to use family members (paid), natural support or direct care professionals, or any combination of the three.
- ▶ Support and encourage community integrated employment for all.
- ▶ Allow for flexible use of funds to permit individuals to pool resources with other participants for most efficient use of services.
- ▶ Provide conflict-free self-direction support services provided by individuals and organizations with significant training and experience in the practice of self-direction.



COMMUNITY SUPPORTED LIVING

Community Supported Living (CSL) enables people with disabilities to live in their own home with support and services that are flexible to the needs of that individual.¹

CSL can be customized for any level of need, and cost-effectively tailors supports around individuals rather than fitting people into licensed or certified facilities.

Community Supported Living may:

- ▶ Assist in finding a home that meets the individuals' needs;
- ▶ Assist in managing living in one's own home;
- ▶ Help develop community involvement and relationships that promote full citizenship;
- ▶ Coordinate education and assistance related to finances, healthcare, and other needs;
- ▶ Assist with day to day planning and problem solving;
- ▶ Train and support people who assist the individual;
- ▶ Flexibly respond to the needs of an individual, including emergency situations.



How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

- ▶ Community Supported Living is a cost-competitive option for people who would otherwise likely reside in nursing home, Community-Based Residential Facility or Adult Family Home. The cost of supporting individuals in their own home can be 11%-35% less than individuals serving in 5-8 bed CBRFs.²
- ▶ Provider controlled settings often have a one-size fits all approach that results in over-service or unwanted services for many individuals. A customized CSL approach meets person-centered planning goals without excess.
- ▶ Control over one's services is a proven effective quality measure in a Medicaid managed care system. CSL is an option that allows for significant autonomy and self-determination.

Key Best Practices

- ▶ Individuals live in their own home, not owned or controlled by an exclusive service provider/agency. They have their name on the lease or mortgage and exercise choice in regard to location and appearance. CSL practices are in compliance with the Center for Medicare and Medicaid Service's Home and Community Based Services rule, whereas provider owned settings may have to change infrastructure, practices, and be monitored to ensure compliance.



COMMUNITY SUPPORTED LIVING

- ▶ Use of technology such as remote monitoring, medication dispensers, safety alerts etc., can assist individuals when assistance is needed. This cost-effective approach addresses safety, health and security in a way that respects and supports people to live without staff constantly present in their lives.
- ▶ Enable people to choose who is engaged in providing supports within their home; and direct when, where, how and what type of supports are provided.
- ▶ Provide access to support at any time of day as needed and allows for flexibility of supports provided from day to day tailored specifically to the individual. This can be accomplished through a CSL agency, family and/or a working together with individuals to identify needs, solve problems, and strengthen community connections
- ▶ Directs and has access to individualized and integrated community participation



¹ CSL is defined as a partnership between any person needing support to live in their own home and an entity providing individualized assistance. Blueprint: Community Supported Living Within Wisconsin's Long-Term Care System; Wisconsin Board for People with Developmental Disabilities; 2013.

² Community Supported Living Within Family Care: Community Care of Central Wisconsin's Experience; Strenn, Norby and Harkins; October, 2013 paper published by the Wisconsin Board for People with Developmental Disabilities

SUPPORT TO FAMILIES

Supporting families is a cost effective strategy to help control long-term care costs and improve the quality of life for individuals with IDD. Families are the primary source of support for individuals with intellectual and developmental disabilities and serve in many unpaid roles that go far beyond typical familial relationships. The intensity and types of assistance they provide is unique for each family and is provided across the life span. Families play a key role in creating opportunities for full citizenship, community participation, employment and self-direction. In addition, families often provide daily supports including personal care, supervision, service coordination, medical and financial management.



While many families want to stay involved, providing long-term assistance has an impact on family economics and health. Support provided directly to the family mitigates some of the negative impacts of providing support and allows families to stay active and engaged for longer periods of time. Examples of family support include: connecting families to other families for emotional support and resource sharing, funding skilled respite care so that parents can work and have a break, and educating families how to advocate for and use the service system to best meet their needs.

How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

Families provide large amounts of support to individuals with IDD and are also influential in determining appropriate service plans for their family members. As a result supporting families to stay engaged and develop high quality, low-cost supports helps control long-term care costs and improves quality outcomes for individuals with disabilities.

- ▶ When families do not receive appropriate support, they are less able to continue intensive support roles leaving the long-term care system with the full responsibility of supporting individuals.
- ▶ Nationally, families provide more than \$475 billion per year in unpaid direct care for their family members , which would otherwise have to be paid for by IHAs.
- ▶ Families play a significant role coordinating medical and community supports for their family member. Family involvement in health care planning results in improved access to care and reduction in unmet health needs.
- ▶ Families reduce workforce shortages in rural and underserved areas with limited access to qualified service providers.
- ▶ Families promote increased use of community resources, personal resources and unpaid supports, which reduce high cost, long-term care.
- ▶ Families develop innovative approaches to service delivery, which are low cost and high quality.



SUPPORT TO FAMILIES

Key Best Practices

Partner with families to sustain their contributions:

- ▶ Provide a “system navigator” to assist families to navigate across system services (medical, behavioral health, and long term care) as well as community supports. Ensure navigators have small enough case loads to encourage relationship building and person-centered practices.
- ▶ Guarantee rapid access to high quality, family-centered crisis prevention, intervention and response. Families—especially those providing a high level of direct care—worry about what would happen if they suddenly become ill or their family member has increased care needs. Families are more able to continue high levels of support if they trust that assistance is immediately available if circumstances change unexpectedly.
- ▶ Provide flexible respite funding for families as one way to reduce burnout and stress to families.
- ▶ Allow families to be hired as caregivers. When appropriate, this alleviates financial burden experienced by many families as well as mitigates workforce challenges in rural and underserved areas.

Empower families to leverage community resources:

- ▶ Fund education and advocacy services, which support individuals and their families to connect to their community and utilize supports outside of the service system. Access to community resources and networks can be alternatives to high levels of service system funding.
- ▶ Teach and support families to braid traditional services with unpaid supports to meet the unique needs of family members. This will stretch service dollars without sacrificing quality, person-centered outcomes.
- ▶ Provide high quality futures planning that addresses estate planning and transition planning for aging caregivers. A gradual and coordinated transition prevents crisis costs when a family is no longer able to provide support. It also creates opportunities to utilize other unpaid supports rather than transitioning to high cost long-term care services.

Encourage collective and innovative family-led initiatives:

- ▶ Contract with providers to build and maintain peer-to-peer networks, which include parents, guardians, self-advocates, other family members and community members. In addition to providing emotional support, connecting families with similar issues allows them to share resources and develop cost effective solutions for their unique needs.
- ▶ Create integrated support plans that encourage families to pool their service dollars. This is a cost efficient strategy and encourages families to contribute their personal resources.
- ▶ Support an infrastructure to create family cooperatives, family governed groups, micro boards, and informal networks. These reduce use of service dollars and lead to greater community integration. In many Wisconsin counties, collective strategies have increased quality and decreased costs.



COMMUNITY INTEGRATED EMPLOYMENT

Quality integrated employment is a cost effective strategy to lower health care costs, resulting in people with disabilities becoming more independent and contributing more to their own supports.

Integrated employment is a job in the community at minimum wage or higher and in line with industry standards, working alongside co-workers and the public who are primarily not people with disabilities.

The Wisconsin Department of Health Services (DHS) wrote in its December 2013 long-term care sustainability report that community employment is more cost-effective than facility-based employment and that a shift to this type of employment is necessary for long-term fiscal sustainability in state programs. Paid employment is significantly related to better health outcomes and lower per person Medicaid expenditures.²



How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

Research has shown that all individuals—including those with disabilities—who are employed are healthier than those who are not employed. Employment can improve health by increasing social capital, psychological well-being, improving income, and reducing negative health impacts of economic hardship.³

Integrated community employment supports are more cost effective. DHS' 2013 Long-Term Care report cites the cost of integrated employment support at \$8.01 per hour worked, compared with a cost of \$10.45 per hour worked in facility-based employment. And costs for integrated employment supports for individuals decrease over time, as individuals learn real world skills and gain support from co-workers, the need for paid service staff diminishes and may fade away entirely. In contrast, facility-based pre-vocational training services have high overhead and staffing levels, which translates into high fixed constant costs.

People working in integrated community employment earn higher wages, resulting in more financial independence and the ability to be less reliant on Medicaid funded services. In Dane County, which has a 75% integrated employment rate for those in long-term care of working age, more than \$3.6 million in earnings are generated and pumped back into the local economy. The cost of supporting these individuals is almost fully offset by their wages. According to DHS data, people in integrated employment earn more than three times more per hour than their facility based counterparts (\$8.28 per hour versus \$2.43 per hour). Greater earnings can lead to more self-direction and participants contributing to their own supports.

Key Best Practices

- ▶ Presume all people are able and expected to work, regardless of disability, in integrated jobs where non-disabled people are working for commensurate pay.
- ▶ Include person-centered, participant-driven job development based on the individual's personal interests and potential in service plan development. This leads to better job fits and less reliance on job coaching/direct supports.
- ▶ Include other services that people need to obtain and maintain employment in employment goals and job development service plans (personal care at home and on the job site, transportation).

COMMUNITY INTEGRATED EMPLOYMENT

- Provide payment rewards to providers who have higher integrated employment rates and more hours per participant working.
- IHA's should invest in providing training to providers so they shift toward supporting long-term care participants in community jobs at prevailing wages.
- Invest in provider network: ensure adequate rates that prioritize paid employment.
- Invest in innovative new models that show cost-effectiveness and improved outcomes (paying businesses to support co-workers as job coaches, participating in youth training programs, etc.) Develop expertise in specific skills known to successfully support workers with the most significant disabilities.
- Develop and regularly review (at least annually) meaningful job goals in each long-term care participant's care plan that lead to job advancement and growth over time.



¹<https://www.dhs.wisconsin.gov/publications/p0/p00590.pdf>

²Hall, J.P., Noelle, K.K., & Hunt, S.L. (2013). Employment as a health determinant for working-age, dually-eligible people with disabilities. *Disability and Health Journal*, 6, 100-106.

³A LEAD Center policy brief from November 2015 concludes, "an added benefit of investing in the employment of people with disabilities... would be to lower public expenditures on health care." http://www.leadcenter.org/system/files/resource/downloadable_version/impact_of_employment_health_status_health_care_costs_0.pdf

COMMUNITY INTEGRATED DAY SUPPORTS

The goal of the long-term care system should be to work with the individual to understand how he/she wants to spend his/her day, what is most important to him/her, the community resources that can be tapped into, the natural supports that can be used, and lastly, the formal, paid supports that the individual needs to achieve goals and maintain or improve their independence, involvement in the community and health.

Community Integrated Day Supports are those supports that wrap around a person's competitive integrated employment to create a meaningful day and week. Current data indicates that when individuals with disabilities, even those with complex disabilities, are working in community integrated employment their health outcomes are better and their healthcare utilization is lower, with verified lower per person per month Medicaid expenditures.¹

However, a person with a disability may not always work a typical 40-hour week. In addition to building a set of meaningful activities, community integrated day supports can be used to build natural support connections and enhance employment skills – leading to increased hours worked, new employment opportunities and higher wages. Data from the Council on Quality Leadership indicates that in managed care systems individuals in more integrated community settings and engaged in integrated community employment reach their person-centered goals and achieve improved outcomes.



How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

- ▶ Supports that connect a person to the community and increase their healthy living (including a person's mental status) correlate with important social determinants of health.
- ▶ A focus on community integrated employment and community integrated supports that help to build relationships (natural supports) in a person's life can reduce the reliance on publicly-funded services.
- ▶ Targeted community integrated day supports that build upon interests and skills can lead to increased employment opportunities and earnings.
- ▶ Research indicates that having friendships throughout the lifespan is critical for everyone, including people with disabilities (who are often socially isolated) and relate significantly to increased quality of life.
- ▶ The Wisconsin managed care organization with the strongest emphasis on community building and community connecting has found this approach contributes to a greater use of natural supports and associated savings.



¹ Hall, J.P., Kurth, N.K., & Hunt, S.L. (2013). Employment as a health determinant for working-age, dually-eligible people with disabilities. *Disability and Health Journal*, 6, 100-106; <http://www.ncbi.nlm.nih.gov/pubmed/23507160>

² Best practices supported and informed by Wisconsin's federally funded Partnerships in Employment Let's Get to Work grant.

COMMUNITY INTEGRATED DAY SUPPORTS

Key Best Practices²

- ▶ The typical day and life of an adult with a disability should mirror that of someone without a disability —centering around a work or school schedule and supplemented by hobbies, home chores, volunteering, shopping, exercise, faith groups, and other personal interests and activities.
- ▶ People need support to envision and define their preferred lifestyle. Planning a “meaningful week” or preferred lifestyle for an individual with a disability begins first by considering typical activities his/her peers without disabilities are involved in (including integrated employment), how these fit with individual goals and preferences and then determining the types of services and supports the individual needs to engage in these activities.
- ▶ A combination of different types of supports (include paid and unpaid supports) can be used to meet each individual’s goals. Supports (such as transportation) must be available during evenings and weekends to support a full life.
- ▶ Cultivate community partnerships to engage non-traditional community partners and increase involvement and options. These partnerships result in cost-sharing, increased service flexibility and respond to needs in areas where there is a provider shortage.
- ▶ Developing natural supports (supports that develop through relationships and that supplement paid services) requires an upfront dedication to staff supports and should be made part of the business model. Development of natural supports should be an expected outcome of the services delivered (along with other expected outcomes).
- ▶ Currently Family Care/IRIS benefit services can be combined creatively to develop a meaningful “integrated day” for someone with a disability. IHAs should continue to use this strategy, and allow creative combinations of long-term care benefits such as: Individual Supported Employment; Small Group Supported Employment; Community-Based Pre-Vocational Services; Daily Living Skills Training; Supportive Home Care, and Community-based Day Services .



DISABILITY INFORMED ACUTE AND PRIMARY HEALTH CARE

Adults with intellectual and developmental disabilities (IDD) experience poorer health than adults in the general population for a variety of reasons. Broadly speaking poor health status can be related to a variety of health disorders that co-occur with IDD, limited access to primary, acute and specialist health care, less emphasis on preventive primary care, and a host of social factors that can negatively impact health status. Taken together, these factors decrease life expectancy, increase morbidity, and increase risk for chronic health conditions (such as obesity, diabetes, heart disease, osteoporosis, and constipation).

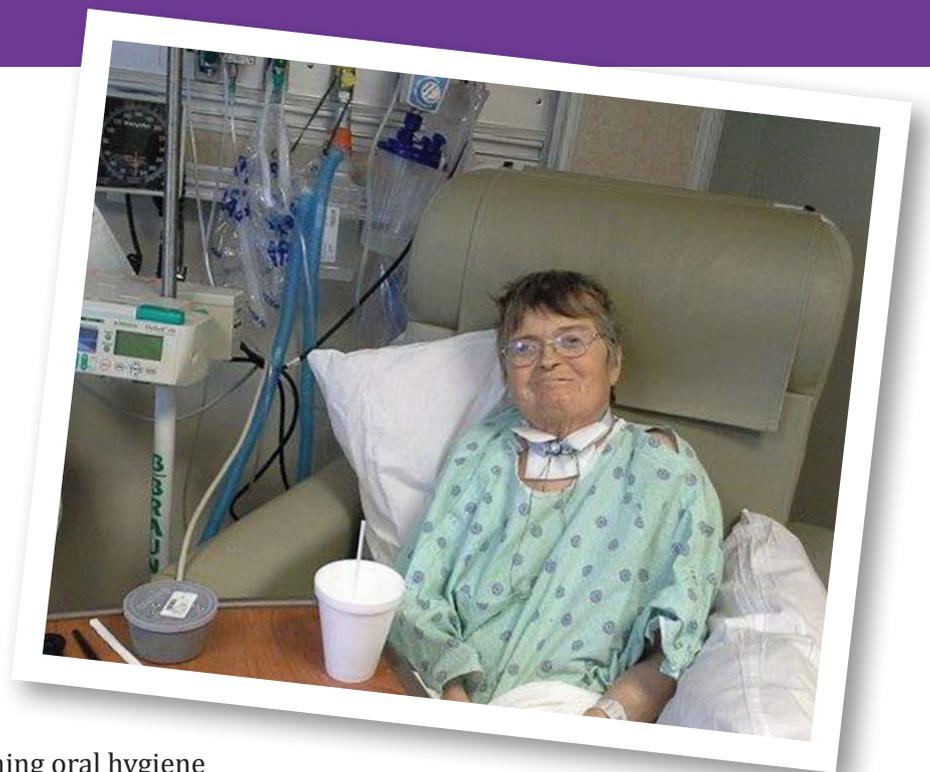
How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

- ▶ Regular access to disability informed acute and primary health care services reduces hospital admissions for treatment of ambulatory care-sensitive conditions (e.g., asthma, constipation, dental conditions, diabetes, and otitis media) that can be managed in the outpatient setting.¹
- ▶ Care coordination through a primary care medical home is associated with greater access to comprehensive, community-based and culturally-competent care, higher ratings of health status and greater satisfaction with specialty care.²
- ▶ Continuity and coordination of primary and specialty health care was associated with a 28% reduction in emergency room usage by persons with IDD.³
- ▶ As in the general population, access to health screening increases early detection and the potential to reduce costs by preventing life-threatening chronic illnesses.

Key Best Practices

The following best practices are considered essential in providing disability informed acute and primary health care.

- ▶ Regular access to acute and primary health care services that adhere to professional standards of care designed for adults with IDD (e.g. Canadian Guidelines for Primary Care of Adults with Developmental Disabilities) can minimize disparities and improve quality of health care for people with IDD.
- ▶ Dental disease is among the most common health problems in adults with IDD because of difficulties maintaining oral hygiene routines and accessing dental care. Regular access to dental professionals knowledgeable about people with IDD is essential to minimize this risk.



DISABILITY INFORMED ACUTE AND PRIMARY HEALTH CARE

- ▶ Interdisciplinary health care is effective in addressing the complex needs of adults with IDD but requires coordination of multiple health professionals to maintain continuity of care.
- ▶ People with IDD often have difficulty communicating their health concerns (pain, distress) to health care providers that may delay receipt of appropriate treatment. Nonspecific changes in behavior may be the only indicator of medical illness or injury. Toolkits designed for primary care providers can maximize communication effectiveness in health care encounters.
- ▶ A focus on social determinants of health can enhance people's health outcomes. An acute and primary care system that incorporates and helps to coordinate supports related to social determinants (housing, education, transportation, community membership, etc.) will see health improvement for participants.

¹Balogh, R.S., Ouellette-Kuntz, H., Brownell, M., & Colantonio, A. (2013). Factors associated with hospitalizations for ambulatory care-sensitive conditions among persons with an intellectual disability – a publicly insured population perspective. *Journal of Intellectual Disability Research*, 57(3), 226-239.

²Farmer, J.E., Clark, M.J., Drewel, E.H., Swenson, T.M., & Ge, B. (2011). Consultative care coordination through the medical home for CSHCN: A randomized controlled trial. *Maternal Child Health Journal*, 15, 1110-1118.

³Wood, D., Hall, A., Hou, T., Wludyka, P., & Zhang, J. (2007). Continuity of care to prevent emergency room use among persons with intellectual and developmental disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 4(4), 219-228.

BEHAVIORAL SUPPORTS AND BEHAVIORAL HEALTH SERVICES

About half of current Family Care program participants have identified mental health and/or substance use needs. Many participants in long term care have a dual diagnosis (intellectual disabilities and co-occurring mental health needs) and may require specialized supports. Some of these individuals may exhibit challenging behaviors and may be at risk of costly involuntary hospitalizations.

Investing in integrated behavioral health services and behavioral supports can address the enhanced and complex needs of individuals with co-occurring IDD and mental illness, reduce and accommodate challenging behaviors, and prevent costly involuntary hospitalizations.

How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

- ▶ The 2014/2015 daily rates for individuals with co-occurring conditions and complex behavior health needs staying at Wisconsin's Mental Health Institutes range from \$ 1275 to \$ 1630. These rates do not include costs for law enforcement or county agencies involved in the emergency detention process. Comprehensive behavioral support and behavioral health services addressing the needs of individuals with co-occurring conditions have proven to prevent and shorten costly stays at Wisconsin's Mental Health Institutes and other institutional settings.
- ▶ Behavior support and health practices as described above add community capacity for supporting individuals with challenging behaviors. When a crisis occurs they provide a proven alternative to moving individuals to more restrictive settings, thereby allowing for continuity in community support. Continued community living is a prerequisite for promoting meaningful relationships and meaningful activities, which are key quality of life indicators.²
- ▶ Best practice behavioral health services allow for supports to be added when needed, but only as much as is required. They create an opportunity to foster natural supports and to adjust supports over time to promote independence while assuring safety.



BEHAVIORAL SUPPORTS AND BEHAVIORAL HEALTH SERVICES

Key Best Practices

- ▶ Individualized outreach behavioral consultation: Behavior consultants work directly with individuals and their support team, establish/model therapeutic relationships and provide situational counseling. Consultants work collaboratively with families and support teams to develop Behavior Support Plans and provide individualized trainings and consultations in the community on how to safely respond to challenging behaviors when they occur.
- ▶ Trauma informed services that support choice. There is a high prevalence of trauma in this population, often related to experiences of abuse or involuntary and coercive treatment. All staff, including front line staff, must be trained on how to provide a trauma informed environment that fosters resilience and choice. Coercive treatment is never appropriate, except when there is a direct threat or a significant risk of substantial harm to health and safety. Even then, listening to members and respecting their choices is essential to designing service plans that succeed.
- ▶ Training to address the unique support needs of individuals with co-occurring conditions in community settings: Effective training activities focus on the multiple, day-to-day support challenges experienced by individuals with IDD and their care givers in community settings. Trainings strive to enable care givers to become knowledgeable in both preventive (behavior) health support strategies (e.g. teaching self-regulation strategies to individuals with complex sensory differences, trauma-informed approaches), but also in intervention (i.e. crisis management) strategies.
- ▶ Home and work place adaptations and modifications: Expertise in creating individualized living environments - safe for individuals who experience intense behavioral challenges and their care givers - is needed to ensure the person's continued participation in community life.
- ▶ IDD-informed community nursing: community nurses work closely with individuals and their community support teams focusing on restoring, maintaining and promoting maximal health and independence. Individuals with IDD often present complex health care needs, but live in non-medical, community settings. If unaddressed these needs are often expressed through challenging behaviors and can lead to inappropriate and costly hospitalizations. Community nurses can prevent and mitigate health and behaviors so people can stay living independently in the community.
- ▶ Community based, IDD-informed psychiatry and psychotherapy: Accessing psychiatric care remains a major challenge for many individuals with IDD. Effective community psychiatry needs to be knowledgeable of the unique challenges experienced by individuals with IDD and the options to approach those challenges in community settings. Psychotherapy provided by a clinician who is experienced serving persons with IDD and behavioral health needs should be considered, especially when there is a history of trauma. Psychotherapy can be key to development of greater resilience and related skills.
- ▶ Coordination with County Mental Health services: In Wisconsin, counties play a key role in the delivery of mental health and substance use services. Some Medicaid behavioral health benefits such as Comprehensive Community Services (CCS) and Community Support Program (CSP) can only be accessed through counties. These evidence based services should be available to eligible individuals in long term care - when appropriate and with the consumer's consent. This will require passing the mental health screen administered by counties.
- ▶ Community- based, IDD specific crisis response: Effective Crisis Response requires advance crisis planning and coordination with law enforcement, community mental health practitioners, and counties who have statutorily defined responsibilities for providing crisis care. Specialized Crisis Response services for individuals with IDD should allow care givers to access additional supports in the community. This should include crisis consultation and coordination, additional staff support or temporary out of home placement in safe houses/crisis homes for individuals with IDD. Such a response assures continued participation or a quick return to community life.

TRANSPORTATION

Transportation is consistently identified as the number one challenge impacting employment options and independent living by people with disabilities.¹

Successfully supporting people with disabilities and older adults to live independently in their homes, obtain and maintain employment, access community businesses and accomplish daily living tasks, be meaningfully integrated and engaged in the community, and maintain health is dependent on transportation.

How Adoption of Best Practices Can Increase Cost-effectiveness or Provide a Competitive Advantage to an IHA

If rides don't come or are late, it can cause other disruptions in an individual's life, and causes a ripple effect that touches families, employers, in-home care providers, and medical professionals, which in turn can result in increased costs.

When people can't get where they need to go on their schedule, the ability to live independently, obtain and maintain employment, access community businesses and accomplish daily living tasks, be meaningfully integrated and engaged in the community, and maintain health is diminished. The ability to use one mode of transportation for multiple destinations and purposes adds great value for the individual and IHA. From a business model perspective, a reliable consistent scheduled transportation network gets more clients more connected to the community and at lower costs. Transportation is a critical component of long term care that helps IHAs meet performance goals and outcomes, increased integrated employment, improved health outcomes, etc.—are dependent on the ability to access places and services that are outside a participant's home.

Key Best Practices

1. Coordinate transportation so individuals can accomplish multiple needs with one ride. Transportation coordination strategies include:

- ▶ Contract with County Coordination Councils and County Mobility Managers to maximize and leverage dormant transportation equipment owned by a variety of entities—schools, one stops, hospitals, community transportation, volunteer driver programs—share transportation coverage areas, and conjoin service delivery for LTC participants.
- ▶ Work with local governments to address jurisdictional issues that prevent access to public transportation across county or other municipal boundaries. Creative service contracting can increase access to transportation and expand integrated employment options.
- ▶ Build creative transportation arrangements through use of braided funding sources in collaboration with local non-profits and other community organizations to expand transportation options and increase access to the community.



¹Lack of transportation directly impacts the ability of people with disabilities to participate in the workforce. Even people with disabilities living within major metropolitan areas and employment centers may have restricted or no access to places relatively close to their front doors because flexible and reliable transportation options do not exist. In suburban and rural areas, reliably getting from one town to another and/or crossing county lines can be an insurmountable barrier for those who do not drive.

TRANSPORTATION

2. Build transportation into individual's service plans as a needed element to facilitate community integrated employment and self-determination.

- ▶ Consideration of transportation options and access is an important factor for residential placements, the ability to become and maintain employment, employment options, and access to the community. People who have more transportation options they can access themselves—public transit, rideshare programs, natural supports—may independently address their needs rather than relying on service providers.
- ▶ Full reflection of transportation access and options in relation to the goals outlined in a person centered plan may result in more access to the community and less reliance on disability specific transportation services.

3. Use existing multi-model transportation infrastructure to meet transportation needs.

- ▶ Public transit systems are generally a lower-cost alternative than other Medicaid funded single-ride/single-purpose programs. For individuals with access to accessible public transportation, fare cards may offer individuals the ability to determine and stick to their own schedule.

4. Use innovative practices to build transportation networks that can serve rural places and underserved communities.

- ▶ Uber/Lyft and other shared ride drivers, or costs associated with volunteer drivers (gas, mileage) could be Medicaid reimbursable services that can be utilized by LTC participants. Uber has launched two programs called uberASSIST and uberWAV that are specifically for travelers with disabilities.
- ▶ Innovative uses of technologies and apps—that can track rides and eliminate or predict wait and arrival times—improve quality of transportation services to all individuals.

5. Use Pay for Performance billing to guarantee that rides show up and get riders to their destination on time.



SPEAKER DIRECTORY

1. SELF DIRECTION

Shanna Jensen, TMG- IRIS: Shanna.Jensen@tmg-wis.com 608-210-3961

Tara Treglowne, LSS-Connections tara.treglowne@lsswis.org, 715-456-5675

Monica Bear, Dane County Department of Human Services, bear@countyofdane.com 608-242-6438

Kathryn and Julie Burish, IRIS Participant and Guardian of IRIS participant, respectively, jaburish29@gmail.com, 262-347-8652

Mitch Hagopian, attorney, Disability Rights Wisconsin, 131 W. Wilson St., Suite 700, Madison, WI 53703, mitchh@drwi.org, 608-267-0214

2. COMMUNITY SUPPORTED LIVING

Julie Strenn, LinkEd, LLC, julie.strenn@my-linked.com, 715- 741-0215

Kate Norby, LinkEd, LLC, kate.norby@my-linked.com, 715- 340-7870

Julie Nichols-Younes, jnichols@optionsmadison.com, 608-249-3372 (Options in Community Living)

Duane Tempel, duane@nosllc.com, Chris Patterson, chris@nosllc.com, 1-877-559-1642 (Night Owl Support Systems, LLC)

Fil Clissa, Wisconsin Board for People with Developmental Disabilities, 101 E. Wilson St., Madison, WI 53701, fil.clissa@wisconsin.gov, 608-266-5395

3. SUPPORT TO FAMILIES

Patti Becker, Community Partnerships and Outreach Specialist, TMG, pbecker@tmgwisconsin.com 608-210-3704

Elizabeth Hecht, Specialist for Public Policy, UW-Waisman Center UCEDD, Community Outreach Wisconsin, 1500 Highland Ave., Madison, WI 53706, hecht@waisman.wisc.edu, 608-263-7148

Amanda Bell, Outreach Specialist-Living Our Visions, UW-Waisman Center UCEDD, Community Outreach Wisconsin, 122 E. Olin Ave, Suite 100, Madison WI 53713, bell@waisman.wisc.edu, 608-516-4285

Harriet Redman, Executive Director, WisconSibs, Inc., 211 E Franklin St Appleton, WI 54911, info@wisconsibs.org, 608-968-1742

4. EMPLOYMENT

Doug Hunt, Community Program Specialist, Dane County Department of Human Services, 1202 Northport Drive, Madison, WI 53704, 608-242-6358, Hunt.douglas@countyofdane.com

Shannon Huff, Consultant, InControl Wisconsin, Inc., 136 Dewey St. , Sun Prairie, WI 53590, shannon@incontrolwisconsin.org, 608-318-0700

Adam Notstad, Owner of AdamCan Recycling, Deb Notstad, Business Manager, Legal Guardian, and Mother of Adam Notstad , 916 Bristol Court, Stoughton, WI 53589, 608-513-5050; Deb.notstad@promega.com; adamcanrecycling@gmail.com

Kim Kessler, Vocational Consultant, 608 335-3896, kwk@chorus.net

Beth Swedeon, Executive Director, Wisconsin Board for People with Developmental Disabilities, 101 E. Wilson St., Madison, WI 53701, beth.swedeon@wisconsin.gov, 608-266-1166

SPEAKER DIRECTORY

5. COMMUNITY INTEGRATED DAY SUPPORTS

Shannon Huff, Co-President Wisconsin APSE; Associate InControl Wisconsin; Madison-area, WI. shannon@incontrolwisconsin.org; 608.284.8980

Amanda Bell, Outreach Specialist-Living Our Visions, UW-Waisman Center UCEDD, Community Outreach Wisconsin, 122 E. Olin Ave, Suite 100, Madison WI 53713, bell@waisman.wisc.edu, 608-516-4285

Peg Gagnon, BRIDGE For Community Life, Inc. Executive Director: Hudson, WI. 715-381-8230; peg@bridgeywd.org

Mary Beth Popchock, Executive Director, Lakeside Curative Services; Racine, WI. Phone: 262-598-0098 Ext. 104 popchockm@lakesidecurative.com www.lakesidecurative.com

Lisa Mills, Disability Employment Systems Change Consultant; Moving To a Different Drum, LLC; Madison, WI. 608 225 4326 LisaMills@mtdd.onmicrosoft.com or LisaMillsMTDD@gmail.com

Stefanie Primm, Outreach Specialist-Living Our Visions, UW-Waisman Center UCEDD, Community Outreach Wisconsin, 122 E. Olin Ave, Suite 100, Madison WI 53713, primm@waisman.wisc.edu, 608-263-5557

6. PRIMARY AND ACUTE HEALTH

Marcia Stickel, RN, Director, Wellness Inclusion Nursing, Waisman Center, 122 E. Olin Avenue, Ste. 100, Madison, WI 53713, (608) 890-2843, Stickel@wisc.edu

William E. Schwab, MD, Vice Chair of Education, Department of Family Medicine and Community Health, University of Wisconsin School of Medicine and Public Health, William.schwab@fammed.wisc.edu, (608) 241-9020

Greg Nycz, Director of Health Policy for the Marshfield Clinic, Executive Director, Family Health Center of Marshfield, Inc., 1000 North Oak Avenue, Marshfield, WI 54449, Nycz.greg@marshfieldclinic.org, (715) 387-9137

Jessica Nell, Green Bay, WI, Jessica.nell@sbcglobal.net, (920) 360-2169

William E. MacLean, Jr., PhD, Director, University Center for Excellence in Developmental Disabilities, Waisman Center, University of Wisconsin-Madison, 1500 Highland Avenue, Madison, WI, 53705, maclean@waisman.wisc.edu, 608-263-5254

7. BEHAVIORAL HEALTH

Axel Junker, M.S. Special Education, UW-Waisman Center, Community Outreach Wisconsin, <http://cow.waisman.wisc.edu/>, junker@waisman.wisc.edu, (608) 265-9428

Deb Hall, Parent and Advocate, 1501 Longview St., Madison, WI 53704, Deb.david.hall@gmail.com, 608-215-0401

Gary Stark, Ph.D. , Clinical Program Director, Community Consultation Team, Milwaukee County Behavior Health Division, <http://www.mkebhd.com/cct/> , Gary.Stark@milwaukeecountywi.gov, 414- 257-4543

Axel Junker, Program Manager, UW-Waisman Center UCEDD, Community Outreach Wisconsin, 122 E. Olin Ave, Suite 100, Madison WI 53713, http://cow.waisman.wisc.edu, junker@waisman.wisc.edu, 608-265-9428

Kathi Cauley, Director, Jefferson County Human Services Department, 1541 Annex Road, Jefferson, WI 53549, 920-674-8111

Barbara Beckert, Milwaukee Office Director, Disability Rights Wisconsin, 6737 W. Washington St., Suite 3230, Milwaukee, WI, 53214, Barbara.beckert@drwi.org, 414-773-4646, Ext. 15

SPEAKER DIRECTORY

8. TRANSPORTATION

Bob Olsgard, North Country Independent Living, Transportation Coordinator, bob@northcountryil.org
218-390-6451 (cell), 1-800-924-1220 v/tty (office) Extension 20

Joe Krebsbach, Door County Human Services Director, Jkrebach@co.door.wi.us, 920-746-2337

Joe Entwisle, Health and Disability Advocates, Senior Health Policy Analyst, jentwisle@hdadvocates.org,
312-223-9600 ext. 9086

Tami Jackson, Wisconsin Board for People with Developmental Disabilities,
101 E. Wilson St., Madison, WI, 53701, tamara.jackson@wisconsin.gov, 608-266-0979