



Survival Coalition

of Wisconsin Disability Organizations

P.O. Box 7222, Madison, Wisconsin 53707

Department of Health Services
Curtis Cunningham
Assistant Administrator, Long Term Care benefits and programs
Family Care Waiver Renewal Comments
DHS/DMS/BAPP – Room 518
PO Box 309
Madison, WI 53701-0309

Dear Mr. Cunningham:

Thank you for the opportunity to provide ideas to improve the IRIS waiver. We look forward to the Department's continued discussions with advocates throughout the waiver development process.

Survival Coalition supports the Department's IRIS advisory committee as a valuable representation of participants and professionals that provides a continual source of feedback for program improvement. Survival Coalition applauds the Department for its anti-fraud protocols and resulting negligible occurrences of fraud.

Survival Coalition has organized its recommendations by topic.

Everyone can self-direct

The IRIS program is open to all long-term care participants, this is one of the great strengths of the program. This philosophy aligns with the principles of self-determination and presumed competence. Survival Coalition supports the Department's current approach, which does not place any restrictions on who can self-direct.

The current waiver provides for the direction of services by legal representatives or non-legal representatives chosen by the individual; Survival Coalition supports the current policy. Individuals may have a variety of legal arrangements—including rep payees, powers of attorney, limited guardianship, or full guardianships—that may transfer rights to make certain decisions to another person temporarily, circumstantially, or permanently in one or more areas of decision-making. This does not diminish the ability of the IRIS participant to self-direct in areas where they retain their rights, or express their preferences and wishes in areas of their life where their right to make a decision has been transferred to another person. IRIS participants should always be included in discussion and planning regardless if a guardian is making a final decision; the presence of a guardian does not mean that participant can be bypassed.

Even when an individual has been placed under a full guardianship, Wisconsin's guardianship law limits the authority of the guardian

“to exercise only those powers that are necessary to provide for the individual's personal needs, safety, and rights and to exercise the powers in a manner that is appropriate to

the individual and that constitutes the least restrictive form of intervention.” (Wis. Stats. [54.25\(2\)\(d\)1.](#))

Furthermore, all wards retain rights under [54.25\(2\)\(b\)](#), and the law requires guardians to:

*“Place the **least possible restriction** on the individual's personal liberty and exercise of constitutional and statutory rights, and promote the **greatest possible integration** of the individual into his or her community...Make diligent efforts to **identify and honor the individual's preferences** with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation. In making a decision to act contrary to the individual's expressed wishes, the guardian shall take into account the individual's understanding of the nature and consequences of the decision, the level of risk involved, the value of the opportunity for the individual to develop decision-making skills, and the need of the individual for wider experience.” (Wis. Stats. [54.25\(2\)\(d\)3.](#))*

The spirit of Wisconsin's guardianship law, which seeks the least restriction and most autonomy possible, and the limited role of the guardian is compatible and consistent self-direction and the IRIS waiver program.

In addition, Wisconsin's recent recognition of Supported Decision Making (SDM) agreements is an important tool for IRIS participants that desire extra support in gathering information, understanding their options, and communicating their decisions to others. Individuals using formal Supported Decision-Making agreements do not transfer any decision-making rights; the individual makes their own decisions. Survival Coalition recommends that the IRIS program update its policies, practices, and applicable sections of the waiver to correspond with Wisconsin's law that recognizes formal Supported Decision-Making agreements and so Supporters can fulfill their roles as directed by the IRIS participant.

Survival Coalition also recommends:

- The waiver should be required to provide information that supports alternatives to guardianship—including supported decision-making agreements—to ensure that members maintain autonomy and choice in making decisions about their lives and care plan.
- The waiver should be required to provide information that supports independent living services that encourage independence such as money management and budgeting, and limit use of rep payees to where this level of oversight is clearly justified.
- The waiver should add a new robust definition of evidence-based future planning services that includes required training for individuals, IRIS Consultants (ICs), providers, and guardians on alternatives to guardianship, limited guardianship, duties and required responsibilities of guardians under the law and limits of guardian's decision-making authority, and responsibilities of providers to document and confirm identity of the guardian and the scope of the guardian's authority.
- DHS should require IRIS participants, IRIS Consultants, and others the participant has chosen to include on their team, to develop a clear plan to ensure the participant develops the skills to live

and work independently (e.g. in non-congregant settings) and/or continues to live and work independently.

Caregiver Crisis

Wisconsin has a documented shortage of home and community-based (HCBS) workers—including direct-care workers, home health workers, job coaches, person hired workers etc.—that are critical to meeting the daily needs of IRIS participants and are essential to ensuring they can live and remain as independent in the community as possible.

Survival Coalition is concerned that the shortage of home and community-based workers—especially when coupled with aging family caregivers and smaller family sizes—is limiting the options to self-direct, is putting them at greater risk of institutionalization, and is putting the state in danger of Olmstead violations.

Survival Coalition proposes the following changes to the IRIS waiver to stabilize the workforce and ensure that participant care needs are adequately reflected:

- Establish a tiered rate structure—as the Children’s Long-Term Supports and Services waiver does—that includes criterion that enables IRIS participants to provide enhanced wages for workers. Criterion that makes workers eligible for an enhanced rate should include (but not be limited to):
 - IRIS participant has a higher level of health care and support needs. Participants who need consistent and continual daily supports from workers should be assured that they can offer competitive pay to recruit enough workers as an individual participant needs or requires.
 - IRIS participant needs more specialized services, or services that require advanced knowledge or training. IRIS participants should be able to compensate workers who have more training, certification, and service delivery experience.
 - IRIS participant lives within an area with a workforce shortage.
 - IRIS participant lives in a location where workers have to invest significant time and distance to commute to the participant’s home. Currently, there is no mechanism to compensate workers for the time they spend getting to or from their participant’s residence or other site of service¹, which puts rural IRIS participants at a disadvantage when recruiting staff.
- Establish a mechanism to allow IRIS participants to be able to pass on increased wages/bonuses to direct care workers and personal care workers, so there is parity between the IRIS and Family Care waiver programs. Survival recommends increasing the wage range, and changing the

¹ The nature of providing individualized services often within the participant’s home means that workers are traveling between multiple job sites and the costs of doing so are not reimbursed to the worker resulting in high travel costs coming out of worker’s already low salaries. These costs are increased as the time/distance between decentralized work sites increases.

budget calculation methodology to fund the same amount and hours of services at a more realistic and competitive wage. Survival suggests DHS explore using labor data and other information to ensure that direct care and personal care wages reflect the average wages for comparable roles in a given area.

- Establish a Medicaid reimbursement rate for transportation costs associated with direct care workers commuting to and from participant homes. These costs should at minimum include gas, millage, and public transit system fares².
- The waiver should include mechanisms that incentivize provider agencies—through an enhanced rate—to provide their HCBS workers with fleet vehicles. The waiver could include reimbursement to provider agencies for the depreciation, mileage, gas, and maintenance of fleet vehicles.³
- The waiver should include a mechanism within the rate setting formula to adjust direct care worker pay rates upward in counties adjacent to borders of other states (Iowa, Minnesota, Illinois, Michigan) so Wisconsin direct care worker rates are competitive with the rates in adjacent states.
- Modify background check requirements to ensure qualified workers are not being excluded from the workforce based on minor infractions, and that requirements for IRIS are not more stringent than they are for workers in Family Care/PACE/Partnership. Survival Coalition recommends that DHS develop criteria for the IRIS participant to waive background check requirements under certain conditions. This should be an individualized exceptions process that recognizes special circumstances.
- Establish a statewide contract with a proven interface⁴ that IRIS participants can use to match their needs with available workers, schedule support, and track hours⁵.

Development of additional provider capacity

Survival Coalition has consistently raised concerns about a shortage of quality providers for many waiver services across the state, with provider shortages significantly more pronounced in some geographic

² Currently, the workforce is only reimbursed for travel time and not mileage. Travel time reimbursement often does not cover the cost of gas, wear and tear on a personal vehicle, or public transportation fares. Many occupations include commuter benefits (parking costs, public transportation costs) and travel reimbursement for employees to cover the costs incurred when employees must travel in the course of their job duties.

³ For low income workers, the costs of maintaining a vehicle, repairing a vehicle, or saving enough to acquire a vehicle may be difficult or insurmountable. The lack of reliable transportation is a factor in the caregiver crisis. The ability for workers to have access to a employer's fleet vehicle would remove commuter costs from the worker entirely as well as the instability caused by an unreliable vehicle.

⁴ My Support (<http://www.mysupport.com/>) is an example of a platform currently operating in California, New Jersey, and preparing to launch in January in Iowa.

⁵ Applications have been developed that match participants and workers by via profile information (care needed, geography, availability), enable participants to self-direct and hire workers that fit their needs and personality, enable personal care agencies and workers to track hours to prevent incurring overtime expenses, and enable provider agencies and managed care organizations to reduce administrative overhead while tracking workflow and billable Medicaid expenses. Adequate rates would allow for providers to invest in technology to more efficiently schedule workers, provide visit verification to prevent and detect fraud, and automate billing and payroll functions that would create a timesheet to be easier for personal care workers to complete and reportable to the state.

areas. Provider shortages are resulting in limits and delays in accessing many services and few or no options for specific services depending on the area of the state.

While IRIS participants can exercise their full employment authority flexibly, if there are no workers or providers to hire the authorized services and care plan hours cannot be filled.

- Include a mechanism for IRIS participants to report and document services authorized in the individual's care plan that have not been rendered because the participant has been unable to hire a provider or worker. Survival Coalition is concerned that authorized hours that are unused in care plans are assumed to be unnecessary when in fact it is a reflection of a lack of capacity and may be resulting in care needs that are going unmet.
- Include a mechanism for IRIS participants to document services that family caregivers and others that provide unpaid supports.. Sometimes these individuals may be providing IRIS participants with supports and services that should be reflected in the care plan or they may be filling in on an emergency basis when paid support staff is late or misses shifts.
- When individual care plans identify natural supports, the waiver should include a cyclical re-examination of the capacity, capability, and continued willingness of individuals to provide natural supports. As family caregivers age or their life situations change, there may be a need for IRIS participants to rebalance the amount of natural and paid supports identified in their plans. This should be considered a component of the robust evidence-based futures planning service definition that Survival Coalition recommended in an earlier section.
- Include requirements for cyclical review of data by the IRIS Advisory Committee of participant reporting of services delivered late or not rendered, complaints made to the IRIS Ombudsman and advocates to identify gaps, and opportunities to develop innovative approaches to improve provider capacity and outcomes. Require a consistent reporting form for both agencies serving as an Ombudsman for IRIS participants.
- Include a mechanism to develop and implement plans to increase quality provider capacity in geographic areas and service categories where a lack of capacity is identified. Plans should identify any specialty supports, services, or formulary prescriptions where the number of qualified specialists or providers is limited statewide. Implementation of plans should be outcome focused and require tracking of increases in the number of quality providers, hours of service provided, timely delivery of services, and number of participants receiving services.

Improving ease of participant administration and IRIS plans

Survival Coalition members have heard from IRIS participants that IRIS Consultants spend the majority of time completing paperwork rather than assisting participants with developing a plan, advising on ways participants can maximize their budgets to achieve their goals, and helping participants develop strategies to achieve their plan goals.

A proliferation of paperwork and forms has created a layer of bureaucracy that is confusing for participants and can interfere with timely service delivery and payment. Survival Coalition finds that the

Department has created an administrative burden that exceeds what is required to be collected by CMS or state statute. Survival Coalition recommends DHS consolidate forms and streamline processes to reduce the administrative overhead and improve program clarity for participants.

Further, IRIS participants need a participant portal—a bank website is an appropriate model—that allows them to access their IRIS budgets in real time, and see what services are included, their budget ranges and how they can move funds within their budget, see their IRIS plan, make budget adjustments, access the rate adjustment process, access the appeals process, access the necessary paperwork to hire a new employee, update their contact information, and other routine business. This functionality would enable IRIS participants to solve many of their own problems and would reduce the amount of time and FEA/IC staff it takes to get information or resolve relatively minor questions. This capability would also add value for the Department, as it would provide valuable data to identify burdensome administrative processes, unnecessarily time intensive processes, and overall quality assurance.

Similarly, participant-driven applications have been developed that can match participants with direct care workers via profile information (care needed, geography, availability, and other factors). This kind of application could offer IRIS participants an easy way to find and schedule workers, provide visit verification to prevent and detect fraud, and automate billing and payroll functions while creating a timesheet that is easier for personal care workers to complete and reportable to the state. Survival Coalition recommends DHS establish a statewide contract with a proven interface⁶ that can be used by both provider agencies and IRIS participants to match their needs with available workers, schedule support, and track hours⁷.

Survival Coalition recommends:

1. Increasing pay ranges for direct care workers to maximize participant budget authority.
2. More flexibility and less paperwork.
3. Limiting the requirements for prior approval and shortening delay and wait times.
4. The Department should seek out opportunities to make the program more flexible to better reflect the real lives of participants. This includes reexamining and reducing prior authorization requirements.

Survival Coalition members continually hear multiple issues with regard to FEAs. Each FEA has their own way of operating, and the inconsistency between how FEAs are administering has led to concern over quality and lack of oversight. Participants consistently report problems with FEAs, and ICAs have little control or ability to resolve issues. Survival Coalition recommends DHS direct resources—including consulting with the IRIS Advisory Committee—towards developing a set of consistent statewide best practices for FEAs and then incorporate those best practices as a FEA contract requirement.

IRIS participants need support to develop robust plans to be as independent as possible. Participants should be trained and have resources on the elements of self-determination and self-directing, creating

⁶ My Support (<http://www.mysupport.com/>) is an example of a platform currently operating in California, New Jersey, and preparing to launch in January in Iowa.

⁷ Applications have been developed that match participants and workers by via profile information (care needed, geography, availability), enable participants to self-direct and hire workers that fit their needs and personality, enable personal care agencies and workers to track hours to prevent incurring overtime expenses, and enable provider agencies and managed care organizations to reduce administrative overhead while tracking workflow and billable Medicaid expenses. Adequate rates would allow for providers to invest in technology to more efficiently schedule workers, provide visit verification to prevent and detect fraud, and automate billing and payroll functions that would create a timesheet to be easier for personal care workers to complete and reportable to the state.

the best self-directed plan, how to use and leverage IRIS budgets the most efficiently and effectively, and other topics that lead to better community integrated outcomes.

Survival Coalition strongly supports the current service definition of support brokers in the waiver, and believes support broker capacity should be expanded so IRIS participants throughout the state are able to access this service.

Survival Coalition finds that Support Brokers could play a valuable role to train participants, conduct comprehensive motivational interviewing, self-directed planning process to ensure person's goals are known and progress can be made, and develop tangible goal-driven plans. Support brokers provide a distinct direct service that does well beyond what ICs can do and add significant value by helping to identify services to help people live independently.

Survival Coalition recommends adding a transportation coordination service and allowing support brokers to help IRIS participants identify and coordinate their own transportation. IRIS participants have transportation needs, but as individuals, the volume of rides needed may not be significant enough for a transportation provider to accept their business. Family led networks where IRIS participants living geographically close can band together as a unit to assess their need for rides as a collective, and then used that information to demonstrate sufficient volume for providers. Support brokers could assist IRIS participants to identify other IRIS participants and their transportation needs in an area as well as assisting IRIS participants with ride coordination to maximize the use of their IRIS budgets.

Integrated community outcomes and quality assurance

IRIS budgets should incentivize services and supports that result in the greatest integration in the community in the least restrictive environments—including competitive integrated employment, integrated day services, community supported living, and the associated transportation needed to achieve these goals. Survival Coalition recommends the following to improve community integrated outcomes:

- Participants with competitive integrated employment, community supported living, and integrated day service goals, must have more flexible budget ranges that ensure the budget is sufficient to meet those outcomes. Provider capacity may limit the number of quality providers accessible to the participant that may be best suited to achieve plan outcomes. The IRIS participant care plan should establish outcomes and establish performance measures to assess progress or achievement of those outcomes over a specific time period.
- Similar to the existing bundled services payment option within Family Care, DHS should develop a methodology/criteria that allow IRIS participants to pay a daily rate to one agency that coordinates multiple services-- residential, transportation, personal care/supportive home care etc.—that are currently billed separately. Billing strategies like this increase flexibility for IRIS participants to move funds within their budget, better matching how people really live their lives.
- Include specific required outcome measures that can be tied to quality assurance requirements. Appendix A in the current waiver includes metrics that can be used as indicators that negatively impact the self-directed services model, including: number of prior authorizations, amount of

paperwork required, amount of mistakes, volume of administrative work compared to services delivered, plan hours authorized versus services provided, and other indicators used in the Family Care program that indicate provider inadequacies.

- Broaden the existing service definitions to encourage use of applications and other strategies that allow more autonomy and require less staff, and ensure that assistive technologies and individualized home monitoring/response services are available to IRIS participants, and incentivized as a mechanism to decrease reliance on congregant settings.
- Require at least one non-disability specific integrated residential, day, and employment setting, and service delivery option is always available in all areas of the state without wait lists.

Competitive integrated employment for working-age IRIS participants

- Wisconsin is an employment first state. Presume competitive integrated work and expect it. IRIS participant plans should contain specific language requiring all working-age IRIS participants to have a competitive integrated employment goal within their care plan,
- IRIS as a whole program should have integrated employment outcome targets, performance metrics for employment services, specific data collection⁸ and reporting requirements, and tie employment outcomes to performance incentives
- For IRIS participants utilizing time-limited pre-vocational services, participants should be provided with targeted information to facilitate individuals making progress towards competitive integrated employment goals.
- The competitive integrated employment/supported employment service definition should be expanded to provide employment services for all IRIS participants who are eligible at the non-nursing home level of care.
- Require all care plans to include the full array of transportation services needed to support community integration, community integrated employment, and all care plan goals.
- Add service definition to provide training for IRIS participants on establishing boundaries, employer/employee expectations, interpersonal communication skills, conflict-management skills, and maintaining positive relationships with HCBS service workers.

⁸ Required data elements should include: number/percentage of working-age members (16-60) with disabilities working in Competitive Integrated Employment (CIE) at least 15 hours per week; For participants working in competitive integrated employment, average gross wages adjusted for length of time on job, number/percentage with some level of health care coverage through employer, number/percentage with paid time off, number/percentage who advanced in career during prior year (defined as achieving increased hours; additional part-time job; promotion with higher pay); Among working-age members (16-60) not engaged in CIE, the number/percentage with a goal in their Plan of Care/ISP to obtain CIE for at least 15 hours a week; Among working-age members (16-60) not engaged in CIE, the number/percentage receiving services to obtain CIE of at least 15 hours a week through the IHA or another recognized funding source; Number of participants receiving pre-vocational services, total length of time receiving pre-vocational services, number of hours per week of pre-vocational services received, and average gross wages adjusted for length of time on job delineable by individual and pre-vocational service provider.

Other

- Survival recommends more emphasis on and education for participants about potential technologies that could increase independence and individual control, including smart device apps and remote technologies for home and work.
- Add a service definition for accessibility assessments. Services include assessment of the need for, arranging for and providing modifications and/or products that would provide for improvements to a participant's living quarters and/or increased independence, community inclusion, or safety. These Accessibility Assessments will provide recommendations for the safest and most cost-effective ways to address the disability-related barriers. The Assessments may include the following components: Adaptive Aids, Assistive Technology/Communications Aids, Home Modifications, Environmental Accessibility Adaptions. Vehicle Modifications⁹.
- Include access to the Adaptive Aids program housed within Central Wisconsin Center to all IRIS participants.
- Add a service definition to provide caregiver training for unpaid caregivers. Training services should reflect evidence-based practices to meet main caregiver needs and to reduce burnout.¹⁰
- The requirement for contractor bids should be changed from three to two due to the delay in the process and inability to find contractors throughout the state.

Survival Co-Chairs:

Beth Swedeen, beth.swedeen@wisconsin.gov; (608) 266-1166;

Kristin M. Kerschensteiner, kitk@drwi.org; (608) 267-0214;

Lisa Pugh, pugh@thearc.org; (608) 422-4250

⁹ Accessibility Assessments are the provision of services to assess the need for, arrange for and provide modifications and or products that would provide for improvements to a member's living quarters and/or increased independence, community inclusion, or safety. The completed assessment provides written recommendations, alternatives, and a comprehensive description of the safest and most cost-effective approaches considered relative to the identified barriers/requested modification or adaptations. A qualified assessor must complete an accessibility assessment. A qualified assessor must be knowledgeable, be independent of all contractors and should not be a potential provider of any material part of the proposed project. The cost of this assessment is funded by the IRIS program and is not considered a cost to the participant's budget.

¹⁰ Family Support Promising Practices (University of Illinois-Chicago; National Council on Aging): <http://fsrtc.ahslabs.uic.edu/wp-content/uploads/sites/9/2017/11/Family-Support-Promising-Practices-Report-Final-11.30.17.pdf>)