Wisconsin BPDD
WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

April 28, 2019

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.

The Wisconsin Board for People with Developmental Disabilities (BPDD) supports Survival Coalition's IRIS waiver ideas and has these additional ideas and recommendations for DHS to consider.

Everyone can self-direct

BPDD wishes to reiterate Survival Coalition's comments that every individual may self-direct regardless of any 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.

For IRIS participants who do have a limited or full guardian, BPDD recommends that DHS require the letter of guardianship be submitted to the Department, and that this document be provided to IRIS consultants and providers so that the parameters of the guardians' decision-making authority are understood. BPDD has heard from individuals with disabilities that providers and others assume that whomever says they are a guardian is, without confirming whether that is true or if that person has any authority to make their decisions. It should be standard practice to require documentation that identifies the guardian and the limits of their authority.

Many providers have described guardians who they believe are overstepping their statutory authority, or are not acting in the spirit of the law to place the "least possible restriction," "promote the greatest possible integration" or "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" of their ward (Wis. Stats. 54.25(2)(d)3.). This has led to providers deferring to or seeking out the guardian to make decisions they may not have authority to make and it contributes to the false notion that if an individual is subject to guardianship, they are not allowed to have self-direction or determination.

BPDD recommends IRIS consultants and providers receive training on:

- Limits of guardians' decision-making authority and statutory requirements for guardians to place the least possible restriction, promote the greatest possible integration, and identify and honor the ward's preferences.
- Understanding what rights have been retained if an individual is under limited guardianship and how to read the letter of guardianship.
- Rights always retained by the ward under state statute.
- Best practices for guardians to solicit and understand the wishes and preferences of the ward, involving the ward in decision-making, and taking ward's wishes/preferences into account in decisions made by the guardian.
- How to identify when a guardian may be overstepping or exceeding their authority, and strategies to help the guardian understand the ward's wishes and make decisions that result in the least restrictive and most integrated supports and services possible.

BPDD recommends a feedback loop for providers to document areas where they feel the IRIS participant is capable or could learn life skills to become capable of supports and services that are more integrated and less restrictive. BPDD has heard frustration from providers who feel individuals are artificially being kept in congregate or restrictive settings because of the guardian's preference or administrative ease for the guardian. This information is helpful to contribute to important conversations about future planning, and drive progress towards HCBS compliance and better community based outcomes.

BPDD recognizes guardians need the same training recommended above. BPDD further recommends self-advocacy training for IRIS participants that include strategies for clearly expressing their wishes and preferences to guardians and IRIS consultants, and how to assert themselves with their guardian when they feel the guardian is overstepping their authority or acting contrary to their best interests or wishes.

With the passage of Wisconsin's Supported Decision-Making law, BPDD recommends the Department examine its IRIS policies and procedures to ensure that Supporters may fulfill their role—assistance with gathering of information, assistance with understanding information and options/choices, and/or communication of decisions to others—as the IRIS participant has defined within their supported decision-making agreement. Just like IRIS, complying with Supported Decision-Making agreements is not intended to be administratively burdensome. Understanding Supported Decision-Making agreements, the role of the Supporter, and incorporating Supporters as they fulfill their roles assigned by the IRIS participants should be routine for IRIS Consultants, Providers, and the FEAs.

BPDD emphasizes that self-direction means that IRIS participants drive what is in their own care plans, choose the services and the providers, and have the authority to move funding within their budget if they decide they wish to spend their budgets differently. We are aware of instances where an IRIS Consultant or IRIS Consulting Agency actively discourages a participant from putting a service in their plan or that DHS staff is telling participants to take items out (and specifying budget items to take out) in order to add new services.

The care plan should accurately reflect the participant's goals and outcomes and the services and supports they need to achieve them; if not the plan should be revised and services/supports adjusted accordingly. Additionally, individual care plans should contain goals that align with the community

integrated outcomes that the program is intended to facilitate. BPDD has been consistently concerned that many care plans do not contain goals in important sectors of people's lives, including community integrated employment for working-age participants, community integrated day activities, and more independent living options. BPDD also recommends more emphasis on and education about potential technologies that could increase independence and individual control, including smart devide apps and remote technologies for home and work. Outcome improvements start by ensuring that plans are focused on community integrated goals and then establishing performance measures that demonstrate that the supports and services to meet those goals are delivering results.

Simplifying administrative requirements and processes

IRIS participants need a participant portal 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. Including participant plans within the portal may enable DHS to collect better data on plan goals and outcomes across the program.

This portal should enable IRIS participants to directly access plain language instructions, trainings, or mini-webinars on IRIS rules, policies, and program changes. In the past, DHS has communicated changes to policies with ICAs and FEAs, which have in turn created their own trainings, policies, and instructions for their staff and participants. Unfortunately, this has led to inconsistent and sometimes incorrect information that sometimes conflicts with the Department and with other ICA/FEAs. BPDD recommends that the Department work to produce streamlined and participant-friendly communications. This would address continuity across ICAs and participants getting the same information regardless of which ICA they are with. Moreover, it enables the Department to easily update and notify participants of new information and be responsive (through FAQs etc.) to common participant questions.

IRIS participants are diverse. Many adult learners learn visually, and benefit from infographics and simple language. Short video segments, demonstrations, or ways for people to practice interacting with an interface can be effective strategies. There is a significant number of IRIS participants (especially in the I/DD population) who may not be readers. The participant portal can be an important resource that can be consulted at any time or place convenient to participants.

In addition to inconsistency between ICAs/FEAs on training and other programmatic changes, individual IRIS consultant staff are often uninformed of the many policies in place or do not remember them. For many IRIS participants this results in confusion and an inability to resolve problems until they find the right person to help them.

BPDD consistently hears about the volume of forms, paperwork, and redundant information required to accomplish tasks. BPDD recommends the IRIS Advisory Committee be charged with completing a critical review of all non-CMS required forms and coming up with recommendations to reduce and streamline forms and other administrative paperwork and processes. Many required fields on forms are the same (name, address, birthdate, Social Security number), requiring a participant to fill out basic information once and then enabling them to auto-populate across forms is an easy way to save tremendous amounts of time.

DHS should ensure that both DRW and BALTC Ombudsman are reporting data in a consistent way.

BPDD recommends that FEAs work directly with the participant to complete the hiring process.

We applaud DHS for their swift response to concerns of fraud. The safeguards/protocols in place not only have identified the low incidence of fraud but also ensures incidents of fraud remain low.

Provider capacity

BPDD agrees with all of Survival Coalition's recommendations to address the caregiver crisis and develop additional provider capacity.

BPDD recommends DHS facilitate the ability for IRIS participants to connect and network with each other for purposes of braiding funding or banding together as a unit to demonstrate to providers that there is a volume of work that is worthwhile. BPDD piloted three family-led groups that generated significant cost savings and innovation in independent living, community employment, and transportation.

The Waukesha pilot was specific to IRIS participants and focused on transportation. Nine families assessed they collectively needed more than 1500 rides per year for employment and community activities; by carpooling they reduced the number of Medicaid rides by 150 resulting in IRIS program savings. And their ability to demonstrate the collective demand for 1350 rides per year enabled them to negotiate transportation services with a vendor who had previously not considered the volume of rides needed by each individual IRIS participant sufficient to accept their business.

BPDD believes that that facilitation of these connections between participants is a role that Support Brokers can play and that these services should be accessible throughout the state. Establishing platforms that enable IRIS participants to recruit and retain direct support staff, applications that enable on-demand transportation services, and allowing greater use of assistive technologies and individualized home monitoring/response services are all strategies that BPDD identifies as helping maximize autonomy of participants and increase service capacity through efficiency.

The Customized Goods and Services code is unique to IRIS and essential to self-direction. This category is an important part of how IRIS participants have driven innovation and identify the supports and services they need to meet their goals and outcomes. IRIS participants have found new approaches to meet their individualized needs. Customized goods and services are also cost-effective. Sometimes simple products that are readily available and are better alternatives for what people need as opposed to costly medical suppliers. In many cases applications, technology, and products can reduce or even eliminate the need for staff time.

To the extent that patterns have emerged within the code—like remote monitoring and other technology enabled services—that are occurring routinely enough that they warrant their own code, BPDD supports the Department to create new codes. However, the Customized Goods and Services category should remain to cover services and supports that do not neatly fit into other existing categories.

Improving community outcomes

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

Participants with community 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.

BPDD recommends that DHS develop a code for community supported living. Community living is the best practice and uses family and community resources to bypass more expensive and restrictive Medicaid funded residential services. BPDD believes a shift to community supportive living will help the state meet HCBS rule requirements, better reflect the autonomy many IRIS participants would like to achieve, and has demonstrable cost savings for the Medicaid budget.

In one of BPDD's family led pilot projects in Dane county, families focused on moving loved ones into community supported living and achieved the following results:

- 20 individuals now live independently for 70% lower than if they were in an adult family home placement[1].
- Medicaid is saving 30% annually because five families are sharing responsibility for hiring, training and scheduling shared staff and thus avoiding the overhead costs of a residential agency. [2]
- Medicaid will save an estimated $27 million over the course of 9 individuals' lifespan because 9 families developed a clear succession plan to ensure their children can live in the community and avoid potentially decades of high cost, restrictive residential placement.[3]

We look forward to the Department's continued discussions with advocates throughout the waiver development process.

Thank you for your consideration,

Beth Swedeen, Executive Director

[1] If these 20 individuals were placed in Adult Family Homes the cost of supporting them would be $480,000 to $1,340,000 per year. $24,000/year per person rate in 1-2 person certified AFH ($480,000/year); $67,000/year per person rate in contracted 3-4 person licensed AHF ($1,340,000 per year).

[2] $23/hour if using residential agency and $16/hour using no agency—Dane County estimate

[3] $75,000/year for CBRF x 40 years=3,000,000 per person; 3,000,000/person x 9 people=27,000,000

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