

The IRIS Report

A Participant-based Appraisal of the IRIS Self-Direction Program

Endorsed by:

InControl Wisconsin

Save IRIS

People First Wisconsin

Wisconsin Board for People with
Developmental Disabilities

Wisconsin Coalition of Independent
Living Centers

EXECUTIVE SUMMARY

IRIS (I Respect, I Self-Direct) has been in existence for 16 years. During that time, there has never been a formal evaluation of the program or an opportunity for participants, families, and advocates to participate in a comprehensive review of the program. This is particularly concerning, because many people feel that IRIS has lost ground in recent years, both in comparison to how the program operated in its first 10 years and also in comparison to exciting developments in self-direction taking place elsewhere.

In November 2023, a number of IRIS participants, families, ICAs, FEAs and advocates convened an IRIS Summit to engage in just such a review. Before the Summit, the invitees were asked to identify the priority aspects of IRIS to focus on in the Summit. Not surprisingly, the responses centered around those aspects of the program where people have the most concerns. The full Report offers recommendations for addressing concerns, with the understanding any implementation cannot be immediate.

We recommend the creation of a broad-based IRIS Task Force with ample participant and family representation to prioritize the problems and recommendations. The objective of the task force would be to develop a multi-year plan to implement a major redirection of the program.

Positive features of IRIS identified at the Summit include:

- Statewide access to a self-directed HCBS Waiver
- IRIS is more participant-friendly than many other parts of the human service system.
- Many IRIS participants are satisfied with their ICs and support they receive.
- Most people who request budget amendments eventually get them.
- Most participants have significant budget flexibility; participants generally get to choose their services and workers.
- Participants have potential access to a wide range of support options, although limited severely by the workforce crisis.
- Many participants participate in the development of their IRIS plans.
- Participants generally appreciate having a choice of ICAs and FEAs
- Most participant-hired workers are paid in a timely and accurate manner.

The major concerns regarding IRIS which are explained in depth in the full Report are:

- IRIS has become increasingly difficult for participants to navigate.
- Confusion and delays surround the IRIS budget-setting and budget amendment process.
- Increasing constraints on participant choice in the areas of budget authority and employer authority
- The absence of a clear definition of self-direction and erosion of the original person-centered values of IRIS
- Concerns regarding the individual planning process in IRIS
- Longstanding concerns about the performance of FEAs
- Concerns regarding DHS's commitment or ability to act on the principles of self-direction and a robust IRIS program.
- Lack of adequate support and training for participants and families to enable them to effectively self-direct.
- Missed opportunities to strengthen the role of ICAs and ICs

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INTRODUCTION

IRIS (I Respect, I Self-Direct) began operations in 2008. In the 16 years since then, there has never been a formal, in-depth external evaluation of the program or any opportunity for participants, families, and other stakeholders to undertake a comprehensive reflection on how well the program is working.

In the early years of IRIS operations, the program grew far faster than DHS expected. Enthusiasm for a non-managed care, fully self-directed program was somewhat expected for the I/DD population. But people with physical disabilities and older adults also embraced it in far greater numbers than anticipated. Early on IRIS was admired by self-direction advocates elsewhere and considered an example to emulate. However, over time several other states started developing self-direction programs and many of them have been actively innovating and improving their programs in recent years (some examples are cited in the Report). Some states commissioned comprehensive external evaluations of their programs conducted by self-direction experts and used the evaluations as a springboard to make major improvements in their programs.

Also, in recent years national and international self-direction networks have grown into formidable clearinghouses for innovative ideas and problem-solving in self-direction. Many states and countries have clearly benefited from their participation in these networks. There is little indication that DHS staff have been engaged in this form of collaboration. A recent example of this is that in 2023, the International Self-Directed Support Network announced a new set of Global Standards for Self-Directed Supports (Appendix I in this Report), developed by a world-wide panel of self-direction leaders. These Standards could provide important guidance and a yardstick for assessing the quality of IRIS. But there has been no indication of DHS interest in exploring their application in Wisconsin.

While many states were evaluating and improving their self-direction programs, DHS was failing to acknowledge problems and negative trends in IRIS and missing opportunities to make improvements suggested by stakeholders or proven effective in other states. The consensus of people paying close attention to IRIS is that the program has become more cumbersome and less participant-friendly in recent years. This report provides details to corroborate this conclusion.

IRIS is the program of choice for approximately a third of the people receiving community based LTC services in Wisconsin. Based on a recent report from AARP, self-direction is the fastest growing sector of the community based LTC system in the U.S. Unfortunately, DHS has not invested the staff resources necessary to give the program the level of quality improvement and innovation attention it deserves.

Due to mounting challenges facing IRIS participants, a number of people who care about IRIS convened an IRIS Summit in November 2023. Attendees included IRIS participants, families of participants, ICAs, FEAs, and self-direction advocates. The purpose of the Summit was to analyze several key aspects of self-direction and how they appear in the experience of people engaged with IRIS in attendance at the Summit.

Key aspects of Self-Direction Standards:

- Participant-Friendly Processes Throughout the Self-Direction Program
- Transparent, Reliable and Adaptable Individual Budget-Setting,
- Full Budget and Employer Authority
- Clear Self-Direction Definition and Values
- Support for a Participatory Individual Planning Process
- Reliable Fiscal Intermediaries (FEAs)
- DHS Role in Leading and Overseeing IRIS
- Support and Training for Participants and Supporters
- The role of ICAs and ICs

This Report presents the consensus conclusions from the Summit in relation to each of these aspects of IRIS. It includes global, national, and local best practices relevant to discovered concerns.

During the Summit, concerted effort was made to identify positive features of IRIS in relation to each of the aspects of the program which were discussed. These are included in the Report, along with (a much longer list of) concerns. It is not surprising that many concerns were identified, since the invitees chose to focus the Summit on those aspects of IRIS which they believed to be most in need of improvement.

The major participant themes discussed in this report:

- How difficult IRIS has become for participants and families to navigate.
- Confusion and delays surrounding the IRIS budget-setting and budget amendment process.
- Increasing constraints on participant choice in the areas of budget authority and employer authority
- Confusion surrounding the definition of self-direction and erosion of the original values of IRIS (including the growing message that “some people aren’t appropriate for IRIS”)
- Concerns regarding the individual planning process in IRIS

The Report includes a number of recommendations for addressing the current problems in the program. Given the scale of the problems identified (many of which have intensified over several years), we know that even with a serious commitment on the part of DHS and other stakeholders it will take some time to identify necessary changes and implement them.

Consequently, we recommend the creation of a broad-based IRIS Task Force with ample participant and family representation to prioritize the problems and recommendations over a one-year period. The ultimate objective of the task force would be to develop a multi-year plan to implement a major redirection of the program.

Issue One

Participant-Friendly Processes throughout the Self-Direction Program

How hard is it to participate in IRIS?

Relevant Global SDS Standard:

GS 5. Practical administrative processes that minimize participant burden

Best Practice* would include:

- Everything involved in participation in the program is simple, understandable, and timely.
- Red tape is kept to a minimum.
- Avoiding making the self-direction experience too hard for people with cognitive disabilities, which makes IRIS a non-viable option for them.
- Participants and families are expected to take on certain tasks that are specific to self-direction, but the burden of these tasks should not be so great that some people feel it is impossible (even with support) to handle all of them.

Strengths

- IRIS is more participant-friendly than many other parts of the human service system.
- IRIS creates the potential for people to build a “person-centered life.”
- IRIS waiver design envisions “kitchen table” decision making process.
- “IRIS is manageable for me because I know all the hoops.”



* “Best Practice” regarding each issue in this document reflects the consensus of the participants in the IRIS Summit

Overall, Concerns

- Self-direction tasks are too burdensome and the constantly increasing administrative responsibilities placed on IRIS participants overtakes their lives and limits their ability to live full community lives. “There is too much Red Tape.”
- The transaction costs² of IRIS are extremely high; participants and families are forced to complete tasks listed as expectations of IRIS Consultants and Fiscal Employer Agents, in addition to the time spent providing other direct supports due to workforce crisis and system capacity limitations.
- DHS seems overly focused on the possibility of fraud within IRIS, especially on the part of families. There is no evidence of fraud being greater in the IRIS program than any other Medicaid program.
- It is excessively difficult to recruit, hire and retain workers; the onboarding process is complicated and too slow, exacerbating the ongoing workforce shortages.
- Participants do not have access to the education necessary to learn and correctly use the IRIS program and there is not an environment of clear expectations.
- Participants feel that DHS has not provided clear and consistent guidance to ICAs and FEAs on various IRIS processes, and when guidance is provided, it is often not available in public-facing documents for participants to access.
- The Service Authorization Review (required for certain types of services) takes too long.
- Claims and reimbursement process in IRIS is slow, cumbersome, and inconsistent resulting in vendors (e.g., home modifications) refusing to do business with IRIS participants.

Recommendations for Improvement

- Identify IRIS policies that make it overly difficult for IRIS participants to effectively use self-direction. Make changes that will streamline all processes, reduce administrative burden, and keep red tape to a minimum. Make self-direction as easy as possible.
- Ensure all processes are transparent (available in public facing documents) and flexible.
- Review IRIS contracting and reimbursement policies to make it easier for participants to secure needed goods and services (often very specialized) and for contractors to be reimbursed, even if they are not Medicaid vendors.
- Streamline the process of braiding services between IRIS and MAPC to cut red tape and help participants retain and competitively pay staff.
- Deal with situations of potential fraud on a case-by-case basis rather than making policy changes that punish all IRIS participants and make it overly difficult to use IRIS.
- The FEA background check process must be updated to allow for a rehabilitative review process.

² “Transaction costs” refers to all the time, energy and stress associated with dealing with the mechanics of IRIS.

Issue Two

Budget-Setting, Full Budget and Employer Authority

Does the IRIS Budget Process work? Do participants have actual control over their budgets?
Can they choose the services and hire the people they want.

Relevant Global SDS Standard:

A dedicated budget, individualized and controlled by the person with any support they choose, used flexibly and creatively to promote the person's best life.

Practices that ensure all people have the option to control as much or as little of their support as they choose, based on the presumption of personal capacity.

Best Practice includes:

- Full participant control of individual budget for all allowable costs in the IRIS Waiver.
- No prior authorization requirement for those services.
- Participant freedom to negotiate rates of payments with vendors and workers.
- Participant ability to easily move \$ in their budget between service lines.
- No extra hoops to substitute technology for traditional modes of service.
- Participant choice to receive services from agencies, independent workers, or family members

CMS Guidelines: Budget Authority.

Participants can determine within an individualized budget amount the rate of pay for each of their self-directed providers-participant.

Participants have greater control over their providers' pay rates and may choose to receive fewer hours at a higher rate of pay, or more hours at a lower rate.

(from "Understanding Budget Authority in Self-Directed Home and Community-Based Services," CMS national briefing, May 2024)



Strengths

- Most people who ask for budget amendments eventually get them.
- Most people get their initial IRIS budget allocation early on in the process.
- The Waiver allows for full budget and employer authority; some participants experience it that way.
- People who do not need many budget or service adjustments feel that they have sufficient budget and employer authority.
- Participants have access to a variety of providers, including many small providers who are not available in Family Care.

Concerns

1 The budget-setting process is confusing and lacks transparency.

- IRIS Participants have no access to information on how their IRIS budget is determined and have no options available to appeal a budget determination or to request a new LTFCS (long term care functional screen) (which sets the budget).
- The new budget algorithm has resulted in higher-than-average budget cuts for IRIS participants with IDD in all areas except those with the highest needs (39% in the lowest five tiers are seeing the highest decreases compared to lower levels for older participants and those with physical disabilities).
- Insufficient budgets, due to a flawed budget algorithm, are forcing participants to request more budget amendments.
- IRIS budgets are often inadequate to pay competitive wages and agency rates, and/or to meet the needs of an individual, especially those who need 24/7 support (who are sometimes told they should be in a nursing home).

2 Issues relating to the functional screen and the IRIS budget.

- The functional screen does not adequately capture community integration needs, especially for IRIS participants with IDD; the result is a budget that is not sufficient to achieve community-integration outcomes.
- Participants feel that LTCFS questions do not adequately capture their needs or those being met by unpaid caregivers. Many say they have to learn 'Speak' in order to effectively describe their needs.
- Participants do not automatically receive their report, and many are not even aware that they can request it, making it difficult to identify and correct mistakes and inaccuracies. See #1 above.

3 The Budget Amendment process needs to be streamlined.

- The current process takes too long.
- Participants and ICAs are reporting increased numbers of budget amendment requests, indicating that the current budget algorithm does not meet participants' needs,
- Crisis situations are exacerbated when a rapid approval of a budget amendment is needed but not provided in a timely manner.
- Some ICs discourage people from requesting budget amendments.
- The budget amendment process allows DHS to "manage" too many aspects of people's lives and impedes their ability to self-direct.

4 Concerns with Full Budget and Employer Authority:

- Decision making in IRIS has increasingly become too complex and confusing.
- Kitchen table decision-making has eroded, and final decisions are increasingly determined at DHS.
- Non-transparent “Usual and customary” rates make it too difficult to pay workers competitive wages and are widely inconsistent.
- Certain services/codes are overly scrutinized and limited by DHS making them difficult to utilize and self-direct (support broker, individual directed goods and service...)
- It is nearly impossible to manage budgets because participants don't have real-time access to their budget expenditures. They never get to see, question, or approve billings submitted by vendors and agencies.
- Participants are often being told that they can use ONLY the cheapest option for certain services, regardless of if it is the best option or preferred choice for the participant. Yet the waiver does not require this and indicates that they only need to be less than nursing home care.
- The Supportive Home Care assessment process (from Family Care) is often used by ICAs to limit or reduce access to SHC even when there is money in the person's budget to pay for more hours.
- Applying the RAD process (from Family Care) to IRIS and imposing alternative ways to meet people's needs without involving the participant or the family violates the principles of self-direction.
- Giving SDPC nurses utilization review authority limits self-direction.
- Requiring participants to use all of their SDPC hours (for which the wage is fixed) before they are allowed to access their IRIS SHC hours (where there is flexibility to set a higher wage if necessary for staff recruitment) often results in people getting insufficient SDPC and little or no SHC.



Recommendations to Improve the IRIS Budget Process and Full Budget and Employer Authority:

1 Improve the Budget-Setting Process to be more Transparent and Fairer

- Comply with 2024 CMS Guidelines by providing a clear explanation of how budgets are developed, and the connection between the functional screen and the budget.
- Review the budget-setting process and the LTCFS, that feeds the budget algorithm, to ensure budgets remain stable from year to year and that community living goals have the same priority as medical/behavioral needs. Extend the “hold harmless period” until this can be resolved.
- Determine budgets based on acuity to reflect a person’s actual needs and not be reduced if they utilize unpaid care. Current practice puts them at risk if/when that care is no longer available.
- Ensure budget calculations account for updated competitive wages, agency rates, and budget amendment history to ensure participants can maintain their level of care.
- Allow participants to appeal their budget if it decreases.
- Return to the previous practice which allowed people to know their IRIS budget before they have to decide between IRIS and Family Care; people should also be informed of the budget amendment process if they believe their initial IRIS budget is too low to meet their needs.

Stakeholders say:

“I don’t really have budget or employer authority because I haven’t had the opportunity to utilize my full budget.”

“ICAs view IRIS budgets as upper limits on what people can spend - - they pressure us to choose the cheapest services, even when there is room in our budget to choose higher-quality providers.”

“I feel like I’m in an ongoing battle to do life, because I need to update my budget and get new authorization so often - -it wears me down.”

“It feels like we have to fight for everything beyond custodial care, including support for achieving the goal of community integration.”

“DHS imposes too many budgets and wage limits.”

“Full budget and employer authority would mean ‘participant authorization’ of all allowable services - - we do not have that.”

2 Ensure that the Budgeting Process Reflects the Principles of Self-Direction and provides for Full Employer and Budget Authority.

- Empower IRIS participants by embracing “full budget and employer authority” and the “kitchen table” decision making process that embraces the belief that “people know best what they need” and allows participants, with the help of their ICs (rather than someone at DHS, who doesn’t know them), to make all plan decisions.
- Provide clear, written information on “usual and customary” rate parameters and clarify when exceptions can be made to make it easier to recruit, hire and retain workers.
- Increase budget authority to shift funding between services quickly and easily without the need for an IC.
- Allow participants access to WISITS or a user portal similar to online banking where they can view expenditures and adjust their budgets and make plan authorizations and changes in real time.
- The “Budget Year” and “Plan Year” should always be the same. It is confusing and hard to develop a plan that is only partially funded based on the budget year.
- Reduce unnecessary barriers to innovation that promotes self-direction and increases positive community outcomes (support broker, IDGS...)
- Technology assessments should be readily available to help people understand how they can better utilize technology to meet LTC needs.
- Ensure that the SHC (supportive home care) tool is not the sole determinant of how many hours of SHC a person can put in their budget.
- DHS should allow a “staff shortage” exception to the rule which requires participants to use all of their SDPC hours before using IRIS SHC hours.
- The Criminal Background Check Policy should be changed to make it consistent with the policy in Family Care. It should not be more restrictive.

3 Improve and Streamline the Budget Amendment Process.

- Conduct a systematic review to determine the reason for the high number of BAs and ways to reduce the need for them. Initial budgets should be adequate to meet participants' needs. Participants, ICAs and DHS should not be dedicating so many resources to this issue.
- Require that 90% of BA requests are completed within 30 days and that 100% all BA requests are completed within 60 days.
- Apply “Rapid Approval” (within 5 business days or less) for:
 - Crisis situations
 - Wage increases necessary to retain workers.
 - Job supports and transportation for increases in CIE.
 - Non-crisis situations where unpaid support is no longer available.

Issue Three

Support for a Participatory Individual Planning Process

Does the IRIS individual planning process really enable participants and families to self-direct?

Relevant Global SDS Standard:

GS 6. Person-centered planning - a process of identifying what is important to a person with strategies to support what is important - that demonstrates a commitment to people's capacity and value.

Best Practice includes:

- Ample time and support for participants and families to focus on what the participant wants.
- Commitment to enable the participant/family to make informed choices.
- Participant is in the driver's seat for decision-making and plan development.
- Opportunities for all participants to participate in the planning process to the degree they are able (including people with guardians).

Positives:

- In the ICA contract, ICs are required to involve and support people in the planning process; most ICs adhere to these requirements.
- True participatory, person-centered planning is more possible in IRIS than in Family Care.
- Some local advocacy organizations provide education and resources for people to help them in the planning process.
- Most participants and families do have opportunities to participate in creating their plans and have their say.

Stakeholders say:

"My IC is friendly and directs questions to my son and shows interest in his goals and hobbies."

Concerns:

Overall Concerns:

- For many participants, there is not enough time and space in the planning discussion to brainstorm options and possibilities.
- Many ADRCs do not provide accurate information before the planning process starts and there is a lack of clear, plain language resources regarding this process and people's rights in plan development.
- Many participants do not know what services are allowed or how to find providers for those services and are generally not provided a list of enrolled IRIS vendors and providers.
- There is confusion in the planning process regarding the role of guardians.
- Participants with guardians are sometimes completely excluded from the planning process, even when they have preferences that should be factored into the plan.
- The IRIS plan document is unwieldy and hard for many participants and families to understand.

1 The planning process works for some people, but not others.

- ICs have too many responsibilities and too many people to support; they do not have enough time to help people create truly inclusive and individualized plans or to provide the support needed to implement and manage them.
- Many ICs lack knowledge about what services are available in the locales where their participants live.
- Due to high turnover and despite training, there are many ICs who have significant gaps in their knowledge of the program. There should be better accountability to ascertain whether ICs have mastered the content and are prepared to work with participants.
- DHS does not always adequately hold all ICAs accountable for their consistent contract compliance regarding IC caseload ratios, enrollment timelines, IC choice and availability.

2 There are not enough helpful resources available for the planning process.

- The participant education materials do not provide clear, plain language explanations.
- Participants need more support and training in the planning process to understand which services are allowable and how to access them.

Stakeholders say:

“Because so much of what’s possible in the plan is based on the individual budget (which is often inadequate), it doesn’t feel like we have much say about what will be in the plan, i.e. it feels more like rationing than planning.”

The individual planning process no longer provides an opportunity for ‘kitchen table’ discussions and decisions.”

“When I ask questions of my IC in the planning process, they are often not answered; when I have concerns, they are often downplayed.”

Recommendations:

- Provide clear guidance requiring that the participant’s preferences and goals are at the core of the planning, regardless of the participant’s disability or legal status.
- Provide the ability to make most plan changes without getting IC approval.
- DHS should review and implement aspects of the CLTS planning process that would create more opportunities for people to be creative and to streamline the transition to IRIS.
- Take a holistic view of the person rather than focusing on the issues that require HCBS funding for services.
- Redesign the IRIS plan document in plain language so participants and families can understand it.
- Develop and implement ready access to mentors and/or peer support to assist in all facets of the IRIS process (e.g., ADRC meeting, functional interview, planning, SDPC personal care assessment, and finding workers and providers).



Issue Four

Clear Self-Direction Definition and Values

Is it clear what “self-direction” means in the IRIS program, and what the guiding values are in IRIS?

Best Practice includes:

- ☑ A clear definition of self-direction in statute, policy, regulations, and program materials.
- ☑ A clear recognition that the “self” in “self-direction” refers to the person with a disability in combination with their chosen supporters.
- ☑ Clearly stated positive values related to self-direction, e.g., community integration, a sense of belonging in the community, opportunity to participate in paid work, etc.
- ☑ Effective mechanisms to educate and ensure that these values guide the practices of DHS staff, ICAs, FEAs, and ADRCs

CMS Definition: What Are Self-Directed Services?

“Self-directed Medicaid services means that participants, or their representatives if applicable, have decision-making authority over certain services and take direct responsibility to manage their services with the assistance of a system of available supports.”

(from “Understanding Budget Authority in Self-Directed Home and Community-Based Services,” CMS national briefing, May 2024)

Positives:

- The IRIS Waiver places very few limits on self-direction, other than itemizing allowable costs.
- Generally, service definitions allow access to the service if the service will maintain a person’s capacity (or slow the deterioration) or improve the person’s life.

Concerns:

- The values of self-direction in IRIS have eroded over time. This may be due to the perception that IRIS is “too expensive,” the fear of public/political backlash, concern for fraud and/ or that DHS staff does not have a clear set of self-direction values that drives policy and operations.
- DHS often compares IRIS practices with Family Care practices, with a clear implication that “IRIS should be more like managed care” - - that is a major distortion of self-direction.
- There is an implied “capability requirement” to be in IRIS and it is increasingly not seen by DHS nor the ADRCs as a program for people with the highest needs or those who lack unpaid support to self-direct.

- DHS assumes that IRIS participants or their families must perform ALL of the functions of self-direction. DHS official recently: “If a person needs a long-term support broker service, they are in the wrong program” and some ADRCs tell people that IRIS will be too hard for them and that Family Care is better for them. This shows a lack of understanding of the right to receive support to fully and successfully self-direct. Self-Direction is different from self-implementation.
- The lack of robust employment initiatives in IRIS often result in minimal/no effort to encourage/support people to get jobs (this does not fit Employment First values).

Recommendations:

1 Clarify DHS Policy and Values regarding Self Direction and IRIS

- A definition must provide:
 - Clarity of IRIS Core Values
 - Clear definition of Self-Direction consistent with 2024 CMS Guidelines, which specify that “participants or their representatives if applicable, have decision-making authority over certain services.”
 - Opportunity for input from stakeholders as part of the recommended task force.
- This definition should be codified in the IRIS Waiver, and included throughout IRIS program communications, and provider contracts (ICA, FEA)
- Participants should have the ability to enforce definition and values.

2 Implementing and Promoting a Clear IRIS Definition and Values

- The core values of self-direction must drive all DHS policy and operation decisions.
- IRIS participants should receive orientation and ongoing training on utilizing self-direction and the values that IRIS is based on.
- All DHS materials regarding IRIS should be reviewed, by a variety of stakeholders, to ensure that the values of self-direction are consistently messaged.
- Community Integrated Employment (CIE) must be truly promoted first and valued in IRIS
- Administrative Law Judges need to be educated on the values and definition of self-direction.

Stakeholders say:

“IRIS is starting to feel more like a managed care program than a self-direction program.”

“Rather than supporting those of us who have family members with complex needs, DHS says we should switch to Family Care.”

Issue Five

The Role of ICAs and ICs

Are ICAs fulfilling the role envisioned for them?

Relevant Global SDS Standard:

GS 7. No-cost assistance with technical aspects of self-directed services and supports, including help meeting program requirements and assistance with locating, hiring, and managing staff.

Best Practice includes:

- Adequate reimbursement for ICAs to enable ICAs and ICs to carry out the full array of responsibilities specified in the DHS-ICA contract.
- A manageable scope of responsibility for ICs in their job description in order to make it possible for them to fulfill all of those responsibilities.
- A manageable caseload size for ICs in light of their scope of responsibility and the predictable proportion of participants on their caseloads who are in medical, behavioral, family or housing crisis at any point in time.
- Safeguards to ensure that all ICs are properly trained in self-direction values and IRIS best practices and have sufficient knowledge of the services available to participants in the geographical area they serve

Stakeholders say:

“ICs need to do a better job of meeting us where we’re at, i.e. at our level of understanding of how the budgeting process works.”

Positives:

- Many ICs are well trained and get positive reviews from participants and families.
- Participants have a choice of ICAs and can change ICAs at any time if they are not satisfied with the support they are receiving from the ICA.

Concerns:

- IC caseloads are too high - ICs cannot carry out all of the duties identified in the contract and in their job descriptions for all the participants on their caseloads.
- The lengthy list of IC duties creates the misleading impression that participants are actually receiving all of the support included on that list.
- Some IC duties would be more appropriately performed by support brokers, particularly for duties IC role does not have capacity to provide.
- Many participants think ICs are the final decision-makers on plan development, whether to request a budget amendment, etc.; they don’t realize that as participants they are supposed to be the decision-makers and that it’s OK to disagree with ICs and challenge their advice.

Recommendations for improving ICAs:

- First year IRIS participants are given choice of an experienced IC.
- Require and ensure new ICs are adequately trained before they work with participants.
- Establish an IC skills and comprehension test to ensure competency before IC is available for being chosen by participants.
- Give new ICs lower caseloads for the first year.
- Require ICAs and their staff to support and embrace the importance of empowering participants to question and challenge bureaucratic decisions to limit participant choices.
- Make sure that caseload size allows ICs adequate time to work with people in the individual planning process and enable them to be creative in meeting their LTC needs and goals.
- Develop one consistent job description for ICs in all ICAs; otherwise, a participant who moves from one ICA to another will face a difficult transition.
- Offload some IC duties to support brokers.
- Review ICA per member per month rates in light of current caseloads, number of cases requiring high levels of support and the current list of responsibilities of ICs and decide whether rate adjustments are needed.
- Develop clear guidelines for ICs on how to effectively and truly include participants in the planning process when they are under guardianship.



Issue Six

Reliable Fiscal Intermediaries

Are IRIS FEAs meeting the expectations of DHS and participants?

Since IRIS began operations in 2008. Fiscal Employment Agencies (FEA) have been a perennial concern. They continue to be the most common focus of complaints from IRIS participants, and participant hired workers. DHS has made efforts in the past to address FEA performance, but unfortunately this continues to be one of the weakest parts of the IRIS program.

Relevant Global SDS Standard:

GS 5. Practical administrative processes that minimize participant burden

Best Practice would include:

- Making accurate, timely payments to agencies and workers and generating easy-to-understand spending reports.
- Easily accessible customer service function.
- Fair, accurate and timely onboarding of participant- hired workers.
- Accurate and real time access to current IRIS plan and billing submissions and payments.

IRIS Positives:

- It is good that participants have choices of FEAs.
- Most workers get paid in a timely and accurate manner.

Concerns regarding IRIS FEA Performance

Overall Concerns:

IRIS participants report that issues with FEAs continue to be their biggest problem.

1 The procedures are cumbersome, too slow, and often result in errors.

- Pay schedules cannot be altered or changed to pay workers more quickly/often.
- Ongoing delays and inaccuracies in onboarding and payments to workers results in lapses of needed care and workers often quitting. This results in participants not receiving needed care as planned.
- Customer service issues with FEAs is a perennial problem for IRIS participants (long wait times, incorrect information, no call-backs)
- Lack of real-time information from FEAs regarding expenditures and budget balances.

2 Other concerns

- DHS does not effectively hold FEAs accountable for quality. Customer satisfaction has been historically low.
- Participants find it difficult to efficiently utilize budget authority and maintain and/or complete payment for needed services.
- Monthly statements are often incomprehensible or unclear and do not provide real-time information.

Recommendations to Improve FEA Performance:

- Standardize and streamline the FEA process.
- Conduct a review of all FEA onboarding procedures. Enhance and standardize technology capabilities to ensure all participants can access an employee onboarding process that allows for rapid onboarding (within the pay period of submission) of new workers and vendors.
- All onboarding of new workers should be done by the FEA; participants should not have to go through the ICA first.
- There should be protocols and time frames for:
 - Sending out notifications of errors on onboarding documents (or using online formats which immediately identify errors in real time)
 - Proactive follow-up by the FEA to get the corrected information.
 - FEA errors related to worker underpayments should be corrected within 48 hours.
- Implement customer service requirements that vastly improve call times, accuracy, and response times.
- Participants should have access to multiple formats of the monthly budget report, including an accessible, easy to use portal where they can view the status of new hires, background checks and have real-time access to all billings and payments as well as their current and past monthly statements.
- FEAs should use identical or similar easily understandable monthly reports. Refer to the recommendations from the DHS sanctioned IRIS workgroup (2019 Budget Statement Workgroup)
- Increase flexibility and reduce complexity to change FEAs.
- The FEA background check process must be updated to allow for a rehabilitative review process.

Increase FEA accountability for performance.

- DHS should hold FEAs accountable for accuracy and customer service standards of 95%, with a pay for performance model.
- DHS should utilize corrective action plans (CAP) more often for FEAs and monitor adherence to those plans.

Stakeholders say:

“I have lost many workers due to errors by the FEA.”

Issue Seven

Support and Training for Participants and Supporters

Are participants and supporters getting the help they need to successfully self-direct?

Relevant Global SDS Standard:

Outreach and education on self-directed boards, beginning in early childhood.

#4 -Clear and simple information on self-directed support, widely available in the mainstream, tailored for cultural responsiveness and relevance, and fully accessible.

#7 -No-cost assistance with technical aspects of self-directed support, including help meeting program requirements and assistance with locating, hiring, and managing staff.

#8 - Information and resources for families, friends, and other allies to support the person.

#10 - Peer support - mutual aid for well-being and navigating the system - bolsters participation, promotes equitable access, and drives innovation.

Best Practice includes:

Participant and family access to a variety of support as needed to successfully navigate all aspects of IRIS.

Participant and family access to free initial orientation and high-quality ongoing training

IRIS Positives:

- The cost of support from ICs is not charged to an individual's IRIS budget.

Concerns regarding IRIS Support and Training for Participants and Families:

- There is no initial in-depth orientation or adequate ongoing training available to participants and families
- High turnover of ICs undermines consistency and timeliness of support.
- There is no peer support model available in IRIS.
- Participants who lack support from family/friends believe they receive fewer services in IRIS than those who have that support. Despite the desire to self-direct, some move to Family Care, or remain in IRIS but with inadequate services.
- There is an overreliance on unpaid support from families for both coordination/case management and direct support.
- DHS applies an excessive level of scrutiny over the support broker model, especially for participants who need long-term and ongoing support broker services to use IRIS/self-direction ("If you need extra support beyond an IC, you should be in Family Care").
- Inadequate individualized support available for participants to train their workers.

Recommendations to Improve Support and Training for Participants and Families:

- Ensure a consistent level of orientation, training and support for all participants, and extra support as needed for participants who do not have support from families (Note: The New Jersey Division of Developmental Disabilities has an Office of Education of Self-Directed Supports. All of the staff are deployed to engage in a variety of ongoing educational activities for participants and families in their state.)
- Review model education practices and self-direction principles experienced with WI Children's Long-Term Support (CLTS) related to effective self-direction methods that creatively utilize a limited budget to meet goals and increase community integration.
- Provide comprehensive and readily available planning tools for participants and families in self-direction, goal setting and life planning, (e.g., PATH planning, Care mapping, "Deciding Together")
- Provide readily available, accessible, free orientation and ongoing training for participants and supporters on the planning process and how it serves the self-direction definition and values.
- Look at payment rates and variable IC caseload ratio requirements to fairly reflect a portion of participants with complex support needs, rather than strictly on a per capita basis.
- Create an accessible, easy to use self-direction toolkit to help participants and families understand self-direction and effectively implement it in their lives.
- Explore the possibility of using a peer support model in IRIS (Note: New Jersey regularly convenes peer-to-peer networking sessions for participants across the state.)
- Implement a robust initiative to educate and support participants on Community Integrated Employment (CIE). Without additional support, it is unlikely that CIE numbers in IRIS will grow.
- Provide free, accessible, and understandable training for participants and families on how to be an employer, including a tip sheet that explains the entire onboarding process for workers and training supports or resources.

Stakeholders say:

"We get no support or training on how to be an employer."

"We don't get enough support to navigate this program."



Issue Eight

DHS Role in Leading and Overseeing IRIS

Is DHS helping to improve IRIS?

Relevant Global SDS Standard:

- GS 15. Quality practices and outcomes measurement that support continuous learning and improvement in whole systems accountable to the principles of self-directed support.
- GS 17. People with disabilities and those with chronic illnesses are fundamentally trusted and have principal roles in the oversight, governance, and administration of support systems.

Best Practice includes:

- DHS staff who are knowledgeable about self-direction, believe in its values and recognize how it is different from managed care.
- DHS has an active ongoing dialogue with IRIS participants and families, which includes seeking feedback from them and making improvements in IRIS as needed.
- DHS has an effective plan for educating relevant players in the LTC system and the general public regarding self-direction and its guiding values.

Concerns:

1 Distorting Self Direction by exerting excessive control over participant' choice making.

- Erosion of the principles of self-direction in IRIS and increased scrutiny and interference in decision-making by DHS makes IRIS too “managed” and too like Family Care
- The desire by DHS to standardize services and cut costs in IRIS, which at times undermines individual choice and service quality.

2 Limiting Citizen Participation in Policymaking.

- Participants, families, and advocates feel they have little or no say in setting IRIS policy and are discouraged from providing individual feedback related to their lived experiences with the program and possible improvements.
- IRIS policy changes are often made without adequate notice or opportunity for public input.
- Over the past five years, DHS has diminished the charge of the IRIS Advisory Committee (IAC) by eliminating officers, member control over the agenda, and the ability to form subcommittees and/or workgroups. This has led to the committee no longer being an effective voice for IRIS participants on IRIS policy, procedures, or quality improvement.
- DHS does not have effective methods for obtaining input from a variety of IRIS participants and families on an ongoing basis to help inform quality improvements in the program.

Stakeholders say:

“DHS doesn’t know us but makes decisions that determine how we live our lives.”

3 Other concerns

- DHS has not embraced or promoted the importance of participant and family-led initiatives and innovative collaborative efforts involving participants, families, and the community. Creative arrangements that do not fit neatly into the current service codes are not allowed or viewed as potentially fraudulent.
- The respective roles of ICAs and FEAs are not clear to participants and seem to change often; causing confusion and delays that make it hard to use IRIS.
- DHS does not provide clear and consistent guidance to ICAs on various IRIS processes or the expectations for transition, usual and customary rate determination, and appropriate supported living settings.

Recommendations to improve the role of DHS:

- DHS needs to draw a clear line between IRIS and managed care, discontinue and roll back efforts to apply managed care mechanisms to IRIS, and embrace IRIS’s potential to allow people real choice in LTC.
- DHS should develop more effective ways to obtain input from the IRIS Advisory Committee, IRIS participants and families (including people of color and people in rural parts of the state) before important policy and program decisions are made.
- DHS should empower the IRIS Advisory Committee so that its voice will carry more weight within DHS
 - Re-establish a Committee Chair
 - Ensure that all eligible populations are well represented on the committee,
 - Provide members more say in setting the committee agenda,
 - Provide the Committee with detailed information about policy review and potential policy changes as well as ample time to discuss these matters, and allow the committee to form workgroups and subcommittees as needed.
- All DHS decisions should prioritize the real-life impact on participants with the goal of making it easier (not harder) to utilize IRIS. The entirety of this paper is focused on specific and detailed ways to do this.
- DHS should ensure that the DHS staff who are involved in setting policy, making program changes, and overseeing IRIS, are knowledgeable about and committed to self-direction and its values.
- DHS should clarify whether it accepts any responsibility for educating key players in the LTC system and/or the general public, to include communication of how it intends to fulfill that responsibility.
- DHS should more energetically fulfill the charge inherent in the Employment First legislation in relation to IRIS, while respecting participant choice
- DHS should adopt a more accepting and supportive posture in relation to participant and family-led initiatives and innovation that supports community inclusion.

Final Note:

Several of the problems identified in IRIS are similar to pervasive problems in self-direction identified by Applied Self-Direction (ASD), the leading organization in the U.S. advancing quality in self-direction. In the October 2023 report titled “Bridging the Gap: Strengthening the Self-Directed Workforce,” ASD identified the following problems in several states:

- Fifty percent of participant representatives surveyed reported that participants sometimes lack care due to absence of workers.
- Low wages are contributing to workforce shortages.
- Lack of benefits ... Inefficient hiring processes also contribute to workforce shortages.
- Recruiting and retaining workers is extremely challenging for participants; 75% of participants surveyed report that this is difficult.
- Participants need training on how to be employers.
- Support brokers and peer mentoring provide useful assistance but remain underutilized and difficult to access.
- Many participants and families feel overwhelmed by administrative responsibilities ... and believe the administrative aspects of self-direction could be streamlined.

Appendix

global-standards-for-selfdirected-support-easy-read.pdf (citizen-network.org)

<https://citizen-network.org/uploads/attachment/851/global-standards-for-selfdirected-support-easy-read.pdf>

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