



Applied
Self-Direction

Strengthening Information & Assistance in Self-Direction Programs

*Executive Roundtable Series
White Paper*

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Introduction

As of 2019, more than 1.2 million Americans were enrolled in self-direction personal care programs nationwide with offerings available in every state¹. Subsequently, the COVID-19 pandemic laid bare the profound challenges with institutional care, leading to greater national interest in home and community-based services. While further research is needed, there are consistent anecdotal reports suggesting a rise in self-direction enrollment. And there is great promise for further growth. At least sixteen states plan to utilize the enhanced 10% Federal Medical Assistance Percentage (FMAP) afforded to them by the American Rescue Plan to expand or improve their self-direction offerings².

These opportunities for growth represent a once in a generation opportunity to make self-direction more widely available. This model offers a unique ability to alleviate strain on the professional direct care workforce by allowing people to receive high-quality services from workers they know and trust, including friends and family members.

But will states be ready to meet the demand for self-directed services? In order to effectively scale and maximize their utility for program participants, self-direction programs require robust information and assistance (I&A)³ to support participants.

The Centers for Medicare and Medicaid Services (CMS) define I&A as follows in the 1915(c) waiver technical guide⁴:

Service/function that assists the participant (or the participant's family or representative, as appropriate) in arranging for, directing and managing services. Serving as the agent of the participant or family, the service is available to assist in identifying immediate and long-term needs, developing options to meet those needs and accessing identified supports and services. Practical skills training is offered to enable families and participants to independently direct and manage waiver services. Examples of skills training include providing information on recruiting and hiring personal care workers, managing workers and providing information on effective

¹ <https://www.appliedselfdirection.com/resources/2019-national-inventory-self-direction-programs>

² <https://www.medicaid.gov/medicaid/home-community-based-services/guidance/strengthening-and-investing-home-and-community-based-services-for-medicaid-beneficiaries-american-rescue-plan-act-of-2021-section-9817-spending-plans-and-narratives/index.html>

³ The term I&A in this paper denotes a specific service/function in self-direction programs that is different from the term 'information and referral/assistance' (I&R/A) which refers to the work of supporting people seeking referrals for services.

⁴ 1915(c) waivers are not the only vehicle for self-direction and I&A can look different under different Medicaid authorities, but the majority of self-direction nationwide is currently offered via 1915(c) waivers.

communication and problem solving. The service/function includes providing information to ensure that participants understand the responsibilities involved with directing their services⁵.

States vary widely in their approaches to structure and pay for I&A in self-direction and there are limited resources available on design best practices⁶. Without robust I&A systems, states will struggle to implement self-direction at scale. This is because many people require support to learn how to manage the responsibilities of self-direction. People typically decline participation in self-direction if they feel they have not been given clear or sufficient information about the model, have not received enough time to discuss their questions, or if they believe there will not be enough support available if they choose self-direction. This leaves people to choose between agency services, which are burdened by high demand and insufficient workforce capacity, and institutionalization.

Now more than ever, guidance is needed on how best to design and implement I&A for self-direction to ensure robust uptake. To help meet this need, Applied Self-Direction convened an Executive Roundtable Series in September 2021 to bring together national experts and stakeholders for in-depth discussions on the design and implementation of I&A in self-direction. We hosted two 2-hour virtual sessions attended by a geographically diverse array of thought leaders, I&A professionals actively working in self-direction programs, Financial Management Services (FMS) professionals, and state and managed care organization (MCO) personnel. The following paper summarizes the major themes and recommendations for designing and implementing I&A that came out of these Executive Roundtable discussions. We hope the insights shared by these experts will serve as a valuable reference to states currently seeking to launch or expand self-direction programs.

I&A Structure

I&A Structure: Overview

States are afforded wide latitude by CMS in the various approaches they may take to structure I&A within self-direction programs⁷. The 1915(c) waiver technical guide presents three ways to underwrite I&A:

⁵ https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/instructions_technicalguide_v3.6_12.pdf

⁶ <https://generations.asaging.org/care-management-and-self-direction-compatible>

⁷ https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/instructions_technicalguide_v3.6_12.pdf

1. **Case Management Activity:** I&A support is provided by the case manager, in addition to their other duties which typically include evaluating the person's level of care, assessing the need for waiver services, coordinating multiple services, and more.
2. **Waiver Service Coverage:** I&A support is provided via one or more distinct waiver services. States using this model often establish a 'support broker' role to provide the I&A as distinct from the case manager. As a waiver service, the person self-directing may choose from a pool of qualified support brokers and control the extent to which they avail themselves of the I&A support. The state must allow for the enrollment of any qualified support broker. Under this model, states have the option to receive the cost of this service at the state's FMAP rate. It is possible for an FMS entity to provide I&A under this model, when the appropriate requirements are met.
3. **Administrative Activity:** I&A support is provided by Medicaid agency staff, or more commonly, by one or more contracted entities. These entities are typically organizations that provide support brokerage services.

States may opt for a combination of the above options, allowing for numerous permutations in approach. The scope of I&A should be proportionate to the scale of the self-direction programs - if you are in a more complex program, you will need more support to be successful.

I&A Structure: Major Themes from Executive Roundtable Discussions

Our roundtable participants had a wide range of experiences with various approaches to structuring I&A in self-direction. Across our conversations, the following themes emerged:

1. **The majority of experts expressed concerns about case managers absorbing the responsibility of providing I&A support.**

For many reasons, most of our roundtable participants felt this approach was inadvisable. For one, case managers may have limited bandwidth to take on the additional (and extensive) responsibilities of providing I&A. Sufficient time is rarely granted for case managers to dedicate themselves to I&A or receive adequate training and support on this aspect of their work. Case managers, especially those that oversee a mixed caseload of traditional and self-directed services, are often not fully on board with the self-direction philosophy and approach. Whoever is providing I&A needs to believe that self-direction is effective and not be guided by a bias against the model. Many experts noted that traditional case management takes a more hierarchical approach whereas self-direction I&A requires an entirely different mind-set where the person providing I&A serves as more of a coach and

guide. Adding the responsibilities of providing I&A on top of case managers' many other responsibilities is not effective for increasing interest and enthusiasm for self-direction. When I&A is provided by case managers, the model is at higher risk of being diluted such that the person self-directing is not empowered to the fullest extent. Additionally, the skills required to provide I&A are distinct from those required to be a case manager. As one expert noted, coordinating services is very different from coaching someone to essentially run and manage a business. Case managers can be more effective in this role when they have a dedicated self-direction caseload and are able to immerse themselves fully in the philosophy and technical challenges specific to self-direction. Most roundtable participants agreed that when case managers have only a few people who self-direct across their caseload, prioritizing I&A frequently goes by the wayside.

2. When I&A is offered as a service, people who self-direct should be strongly encouraged to utilize a support broker.

While CMS requires that all people who self-direct have access to I&A, as per the 1915(c) waiver technical guide, "in general, participants may elect whether to avail themselves of these supports and may determine the extent of the support that they require (within any limits established by the state)."⁸ Many of our experts observed that when people who self-direct have to choose whether to utilize funding in their budget for support brokerage services, they tend to prioritize their care needs and forgo or limit I&A. As one Executive Roundtable attendee noted, when you have a limited budget and need someone to get you out of bed in the morning, cost is a significant barrier to opting to hire a support broker. Under such circumstances, it does help to provide participants with more context about how a support broker can help them - as one expert said, "this isn't just something that's nice to do, it's essential." Many people who self-direct may not initially understand what a support broker does or how much guidance they will need to benefit fully from self-direction. One suggestion was that during the initial on-boarding to self-direction, case managers should strongly encourage the person to engage with a support broker for the first 30 days in the program and to help the person self-directing to determine how much support they may need into the future. While such suggestions can make a difference, we ultimately heard from many experts that ideally states should structure their programs so participants aren't faced with the dilemma of whether to prioritize services over support brokerage. People should have easy access to care and the necessary support to manage their care. Multiple experts

⁸ https://www.hhs.gov/guidance/sites/default/files/hhs-guidance-documents/instructions_technicalguide_v3.6_12.pdf (see p.218)

noted that better funding for self-directed programs would greatly ease this tension and free up participants to pay for both care and I&A.

3. When I&A is offered as a waiver service, which allows for open enrollment of any qualified support broker, this affords more flexibility for participants but states should plan carefully to avoid quality problems.

Offering I&A as a waiver service gives people who self-direct access to a large pool of potential qualified support brokers. One expert noted that some participants prefer to only use independent support brokers because they know the payments are going directly to the person they chose with no overhead costs. However, several experts noted that the quality of services provided by support brokers can vary greatly, especially in states with loose requirements to qualify. For instance, one state was described as providing no oversight for independent support brokers. There was a supposed minimum training requirement, but it was not monitored, and there were no recertification requirements. Experts also noted that overseeing quality in states with hundreds upon hundreds of qualified providers is a daunting task. Such a structure permits incompetence to go unchecked. Experts pointed to an overall need to professionalize support brokerage as a service by undertaking measures such as tightening qualification requirements, verifying qualifications, providing some degree of oversight, and offering ongoing training opportunities.

4. Most experts felt that providing I&A as an administrative activity offered many upsides, despite costing more.

By and large, the roundtable experts felt providing I&A as an administrative activity was an excellent approach. This approach allows the state more oversight including the ability to specify their responsibilities, evaluate their performance, and monitor ongoing activity. Some suggested this model allowed greater ease for monitoring and preventing fraud and abuse. One expert attendee had experience working with an Area Agency on Aging (AAA) contracted to provide I&A. In this scenario, it worked well that the AAA was knowledgeable about both traditional and self-directed services - affording some flexibility to refer to various services as needed. As a best practice, this AAA ensured that the case managers providing I&A worked only with people in self-direction programs. This allowed the I&A providers to develop expertise in self-direction and they were required to have more experience and higher qualifications with the necessary skills to coach, engage in motivational interviewing, and support family dynamics. In addition to AAAs, experts noted that Centers for Independent Living (CILs) can serve as excellent I&A providers.

5. While FMS entities can be uniquely well-suited to provide I&A, strong systems are needed to avoid conflict of interest.

Some experts felt that FMS entities are in many ways ideal to provide I&A since they deeply understand self-direction and, regardless of whether they are formally

contracted to do so, provide I&A to some degree as part of the provision of FMS. One FMS expert felt this approach afforded the person self-directing with the most seamless experience. Under this model, the participant has fewer contacts to manage and the contracted entity is highly knowledgeable about the program details. However, if the same entity is contracted to provide FMS and I&A, a firewall is needed within the organization to avoid conflict of interest. For instance, if a participant has a complaint about the FMS entity, there need to be adequate systems in place to ensure their I&A provider is able to act as a supportive ally. One expert felt that I&A and FMS should not be provided by the same entity arguing that separation allows for the necessary checks and balances.

6. MCOs are sometimes contracted to provide I&A, but their contracts often require I&A to be delivered via case management.

In many states that contract with their MCOs to provide I&A, the MCO is required to deliver I&A as a case management activity. As mentioned above, most experts agreed this approach risks diluting self-direction. According to one MCO expert, ideally contracts would enable the MCO to delegate I&A to a separate entity.

I&A Payment

I&A Payment: Overview

States typically utilize one of the following approaches to reimburse for I&A provided as either a waiver service or an administrative activity via:

- A set rate per time unit (15 minutes, 1 hour, etc.)
- A 'Per Member Per Month' (PMPM) flat fee

I&A Payment: Major Themes from Executive Roundtable Discussions

Roundtable experts were split regarding which payment option is most ideal:

1. Experts with experience as I&A practitioners tended to emphasize the advantages of unit-based payment methods.

Those experts with experience providing I&A argued that unit-based payment (a set rate per time unit) allows for the most individualization. Since people's needs for support brokerage may fluctuate over time, the unit-based approach allows for adjustment as needed. For instance, one expert who works as an independent support broker noted that some people need a high number of hours when getting started with self-direction, some have extensive ongoing needs, and others only need a small number of hours per year. A unit-based approach accommodates the variation of needs across participants over time. One expert noted that a PMPM fee is more of an administrative convenience, but is a less person-centered approach

and does not accommodate the unpredictability of life. Many experts noted that a PMPM flat fee may be cost prohibitive for participants who pay for I&A from their individual budget.

2. Experts with national program design experience tended to emphasize the advantages of a PMPM flat fee.

Roundtable experts representing an administrative and payer perspective were largely in favor of a PMPM fee. One advantage of this approach is that program costs are more predictable and simpler to execute. Some experts argued that in a unit-based payment structure, participants might have a harder time understanding how much support they have available or might be hesitant to reach out to a support broker due to the expense. With a PMPM fee, the cost of the support broker is covered for the month and there is no disincentive to pick up the phone to contact your support broker with a question. It was noted that support brokers may be able to save time in a PMPM structure because there are fewer cumbersome documentation requirements.

I&A Professionals

I&A Professionals: Overview

Across the country, the skills requirements to provide I&A support varies widely. Some states require minimal training with little or no ongoing training while others require professional credentials.

I&A Professionals: Major Themes from Executive Roundtable Discussions

All roundtable experts agreed that I&A providers should have a wide-ranging skill set and adequate training is needed to ensure high quality services. Major themes from their discussion include:

1. Experts identified numerous skills that I&A providers should ideally possess.

The work of a support broker requires a diverse array of skills and talents.

Numerous experts emphasized the importance of being a good teacher capable of instructing others on the skills to be a successful employer, including how to hire, manage, train, and fire workers. A skillful I&A provider will be able to distill complex information, including Medicaid or tax and labor rules and regulations, in a simple manner that is easily comprehended by a lay audience. I&A providers should also have a deep understanding of community resources and be able to refer participants to various supports that best meet their needs. Experts also emphasized that I&A providers must embody the values and principles that underpin self-direction. This means being committed to empowering participants to make their own choices and honoring the dignity of risk. It also requires the support broker to presume

competence and to believe that with the right support self-direction is possible for anyone who wants to participate. One expert described a need for I&A providers to be fearless, meaning that these professionals need to be committed to creativity and able to operate flexibly within the program rules without being hampered by compliance anxiety. Many experts also emphasized the importance of cultural competence and an understanding of how to help navigate family dynamics. While not required, people who have lived experience self-directing their own services bring an especially valuable perspective to the support broker role.

2. Many experts felt training and oversight for I&A professionals is often inadequate. Some argued that more work is needed to ‘professionalize’ this key role in self-direction.

Throughout our roundtable discussions, experts noted that I&A providers often do not receive enough training and support to fulfill their responsibilities effectively. Many states utilize one-time training, but experts urged for more systematic, ongoing training approaches including adequate oversight to reinforce training and monitor for quality. Multiple experts urged for the development of national competency requirements and standards to better professionalize this role.

Conclusion

The Executive Roundtable Series represented an important first step towards a strengthened national dialogue on best practices for providing I&A in self-direction programs. Feedback from experts highlighted the wide variety of approaches taken to providing I&A in self-direction across the country. The lack of consistency and understanding around I&A may contribute to uneven quality in the support provided to people who self-direct. States should consider using new funding opportunities, such as the American Rescue Plan, to invest in improvements to their I&A systems for self-direction.

Applied Self-Direction is grateful to all of the experts who participated in these discussions and to Centene for sponsoring this initiative. In a forthcoming publication, we will present core standards for designing and implementing I&A that will be further informed by a diverse cross section of stakeholders. To get involved and share your feedback about I&A, please contact us at info@appliedselfdirection.com.