



# Assessment of Self-Directed Services in Massachusetts

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**About the Human Services Research Institute**

The Human Services Research Institute ([www.hsri.org](http://www.hsri.org)) is a nonprofit, mission-driven organization that works with government agencies and others to improve health and human services and systems, enhance the quality of data to guide policy, and engage stakeholders to effect meaningful systems change.

## Contents

Summary.....	1
Introduction.....	1
What We Did.....	1
What We Found.....	2
What We Recommend.....	2
Background and Approach.....	3
Introduction.....	3
Methods.....	4
Document Review.....	4
Key Informant Interviews.....	5
Focus Groups.....	5
Self-Direction Advisory Board.....	5
Themes.....	6
Introduction.....	6
Recommendations.....	8
Introduction.....	8
Disseminate information.....	9
Develop equitable, transparent, and streamlined policies.....	10
Enhance infrastructure.....	11
Simplify staff recruitment.....	13
Sustainability.....	13
Recent DDS Initiatives.....	14

# Summary



## Introduction

The Massachusetts Department of Developmental Services (DDS) hired the Human Services Research Institute (HSRI) to review the self-direction program. Self-direction is one way that people with disabilities and their families can be in charge of their services and supports and who provides them. This plain language summary describes what we did, what we found, and what we recommend DDS might do to improve self-direction in Massachusetts. The findings are described in more detail in the report that follows.

## What We Did

To complete this review, we did three things:

1. Reviewed documents and materials from DDS
2. Talked with families, self-advocates, providers, and state and regional staff in Massachusetts about self-direction
3. Looked for common themes to form our recommendation

## What We Found

**Learning about self-direction** – DDS shares information about self-direction, but more people need to know about it – especially low income and minority communities.

**Choosing self-direction** – More people used self-direction during the pandemic as day programs closed, but some do not choose self-direction because it is hard to find staff.

**Managing self-direction**– Self-direction can be difficult for both people with disabilities and their families and support brokers/service coordinators.

**Getting help with self-direction** –Many people with disabilities and their families need support to take on all the steps necessary to successfully self-direct.

**Developing the budget** – The budget for self-direction is not clear and is limited to certain services and supports depending on a person's priority level.

**Clarifying what is allowable** – Just as the budget for self-direction is not clear, some noted that it is unclear what services are allowed.

## What We Recommend

Based on what we learned, we would suggest that DDS:

- ✓ Make information more available and accessible
- ✓ Make things simpler and easier to understand
- ✓ Make self-direction easier by providing more support
- ✓ Make it easier to hire staff
- ✓ Make sure the program lasts over time



# Background and Approach



## Introduction

The Massachusetts Department of Development Services (DDS) contracted with the Human Services Research Institute (HSRI) to develop individual budgets for self-direction services consistent with G.L. c. 19B, § 19. Self-Direction gives an individual the ability of chose services and supports that align with their vision, path, preferences, beliefs, and abilities. DDS seeks to advance consistency and transparency in budget setting and to increase the use of self-directed supports by simplifying the Participant Directed Program (PDP) and Agency with Choice (AWC) processes.

Consistent with Massachusetts G.L. c. 19B, § 19, the Department aims to<sup>1</sup>:

- Provide information and education about self-direction, including on the Department's website
- Ensure equal access to self-direction
- Support person-centered planning and use of individual budgets based on assessed needs, and give people information about their budget

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<sup>1</sup> [General Law - Part I, Title II, Chapter 19B, Section 19 \(malegislature.gov\)](#)

- Have individual budgets based on an array of services supported by ample rates, and that are comparable to budgets for traditional services
- Monitor individual budget spending and report on self-direction

As part of this project, we assessed PDP and AWC processes and protocols to look for ways to address transparency and ease of use with the goal of increasing access and interest in self-direction among diverse groups. We also canvassed participants and staff about their experiences with self-direction in Massachusetts (building on the work done for HSRI's 3-year evaluation). Based on this review, we formed recommendations regarding how to make the operation of self-direction more efficient and effective.

The following describes the methods we used to conduct our assessment and engage with a broad range of stakeholders.

## Methods

Our approach to this assessment was threefold:

1. Complete a document review of materials relevant to PDP and AWC
2. Conduct key informant interviews
3. Categorize information into common themes that could be used to inform recommendations for enhancements to self-direction

## Document Review

We reviewed a range of documents supplied by DDS staff including toolkits, educational materials, and PDP and AWC service and allocation guides, . Examples of specific documents included:

- *Support Broker Toolbox*
- *Agency with Choice Program Service Implementation*
- *Home & Community Based Services, Adult Intellectual Disability Waiver Programs Guide*
- *Participant-Directed Program Allocation Methodology*
- *Community-Based Day Supports Assessment Tool (and supplemental materials)*
- *Appendix J, Participant-Directed Program Non-Waiver Service Description and Guidance for Brokers*
- *Participant Directed Program Fact Sheet*
- *Material and informational videos found at: [DDS Self-Directed Services | Mass.gov](https://www.mass.gov/info-details/dds-self-directed-services)*

These documents provided an understanding of the operation and administration of self-directed services as well as what information is shared about the roles and responsibilities of staff and participants who select the self-directed option.

### *Key Informant Interviews*

To gain an understanding of the experiences of those with first-hand knowledge of the self-direction programs, we interviewed a range of key informants including regional DDS directors, self-direction coordinators, AWC providers, DDS central office staff, support brokers, family members, members of the Self-Directions Advisory Board, self-advocates and area office staff. In all, we spoke with over fifty key informants located across Massachusetts. To facilitate these conversations, we developed interview guides tailored to the specific responsibilities and perspectives of the interviewee(s). During these interviews at least one HSRI staff was assigned as a dedicated notetaker to record their responses.

DDS staff also had a particular interest in learning about how other states were offering services or positions in support of self-direction, therefore, we also interviewed state staff responsible for operating self-directed programs in Connecticut, Wisconsin and Oregon to explore the status of “independent facilitation.”

### *Focus Groups*

In some cases, we interviewed those with similar roles in a focus groups format. We held focus groups with AWC providers, service coordinators/support brokers, families, and area office liaisons. This format was particularly beneficial with these groups because they were able to confer with one another and describe similarities as well as highlight regional differences.

### *Self-Direction Advisory Board*

Leading up to and after the key informant interviews, we provided project updates to members of the Self-Direction Advisory Committee and asked for feedback. Members of the Advisory Committee were invited to participate interviews as well as recommend others who might be well-positioned to offer input.



# Themes



## Introduction

The following overarching themes summarize the content of the key informant interviews conducted by HSRI staff.

**Learning about self-direction** – People find out about self-direction in different ways. Several mentioned the virtual information sessions as a successful avenue to learn about self-direction. Even though there are efforts to share information, some people with IDD and their families still do not know that self-direction is an option. One interviewee talked about how important it is for youth and families to know about self-direction leading up to transition age and that Transition Coordinators are knowledgeable about self-direction. Some noted that developing self-direction materials in other languages would help to recruit racial and ethnic minorities.

**Choosing self-direction** – People often choose self-direction when they are dissatisfied with traditional services, or they are interested in designing supports and services in ways that meet their unique needs. Many reported that the uptake of self-direction increased during the pandemic due to a number of factors such as day programs shutting down and wanting to reduce the number of people the person and their family were interacting with. Working families without support networks may be at a disadvantage in terms of choosing to manage self-direction so may be channeled into traditional services.

**Managing self-direction** – Some interviewees reported that PDP has become more complex due to changes with PPL, multiple service codes, and more rules around background checks. Several people said that the process to onboard a personal support worker can take several weeks to months. Some workers cannot wait this long. Some also said that getting status updates during the process of approving the hire was challenging. Support brokers and service coordinators noted that the service matrix was confusing and complicated.

**Getting support to navigate self-direction** – Many said that for self-direction to be a successful option, individuals and their primary caregivers need support with things like recruiting, hiring, onboarding, training and, if necessary, firing staff. These tasks are often the responsibility of the primary caregiver/parent/guardian. Some reported that their service coordinator/support broker really put the effort in to help them get set up to be successful with self-direction. One family member said, “If everyone had a support broker like ..., things would get more traction.”

Finding personal support workers is challenging – Interviewees often said that finding personal support workers took a lot of time and effort and those that had the most success had established networks and social connections. Some people have approval for services but cannot find a personal support worker to provide the support.

**Developing the budget** – The budget development process considers individual needs as well as the overall regional budget allocation. Most people receive an allocation comparable to a day program. For most people, this meets their needs. However, interviewees told us that they cannot use that allocation to hire staff to provide support in an individual’s residence. Some reported that the process to arrive at the budget was not clear, and they would like to have a way to know how much money will be available to them to help inform if self-direction is a workable option for them.

**Clarifying what is allowable** – Several people reported that it would be helpful to have more information and guidelines about what was allowable for them to purchase under self-direction. Several examples were provided of an individual requesting a particular service or support that was denied but they were unclear as to why that decision was made. One family member mentioned that rules and regulations about the self-directed program were hard to find online or elsewhere.

Self-direction appears to be working well for people with autism spectrum disorder who are seeking supports that are not part of the tradition IDD system. Many may not be interested in a traditional day program and prefer the flexibility offered through PDP. Adults with ASD get access the PDP program via state funds only and have a \$25,000 cap

# Recommendations



## Introduction

The following specific recommendations should be understood as entailments of a larger recommendation: that the self-direction program in Massachusetts should be reconceptualized as a discrete programmatic option with its own identity, processes, service coordination, funding, and priorities. Self-direction in Massachusetts has basically been built on the existing traditional service system using the same assessments, service categories, funding levels, and planning protocols. The Real Lives legislation was an attempt to make self-direction a more distinct entity but there are a variety of institutional obstacles and policies that have made it difficult to create self-direction as a distinct and dynamic person-centered opportunity.

Further, there is no one self-direction program in the state but rather silos of self-direction including self-direction as part of the autism waiver, self-direction as part of the DESE program, Agency with Choice, Person Directed Program, the adult autism program, funding from Turning 22, and to some extent, the MassHealth PCA program, the family support program. It will be important overtime to harmonize these efforts to allow families and people with disabilities to avail themselves of self-direction in a seamless way over the life course.

With respect to the adult self-direction program, there is no dedicated budget line to support the program. Funding at the regional level – in addition to Turning 22

funding – comes in large part from residual unexpended funds from traditional contracts. This means that regional budgets vary from year to year depending on contract vacancies. Further, budget amounts derive from limits on traditional services such as day programs. While regulations are currently being developed, the AWC manual has still not been released. Though there have been stricter guidelines regarding the conduct of the program developed since the early days of the Robert Wood Johnson program, there is still a sense among stakeholders and staff that some decisions are still being made in an ad hoc fashion. These perceptions lead to complaints of a lack of transparency and a sense that decisions are not being made in an equitable fashion.

There are many improvements that have been made to self-direction in Massachusetts including expanding the number of support brokers, developing outreach to families and people with ID/DD, improving the availability of materials and guidance to service coordinators/support brokers, developing videos of people self-directing and establishing a speaker's bureau for self-advocates. Taken together, the recommendations that follow add up to taking a holistic look at the operation of the self-direction program with an eye toward reinventing parts of the program to make it more reflective of the unique features of self-direction -- individual choice and empowerment. This reinvention should also result in increased transparency and equity in the management of the program across the state.

Finally, it should be noted that the changes recommended in the self-direction program – including building support budgets based on needs – may eventually prove to be disruptive to the traditional provider-based service system. As self-direction becomes a more equitable, person-centered, and transparent program, there will inevitably be ripple effects in the larger system.

## Disseminate information

- **Guide for Individuals and Families**—In order to provide an introduction for each potential participant of the self-direction program, some support brokers suggested that DDS prepare standardized materials that can be shared with families and people with disabilities. Such materials could include written material as well as videos. Materials should be in plain language and translated into Spanish. The materials should also spell out the reasons for specific procedures, such as the assessment.
- **Accessible venue for self-direction materials** – Some parents noted that it would be helpful if there was a central place where families could go to explore self-direction, what supports and services were available, and who was eligible. DDS should review their current media options to see whether there is a way of making them more accessible, more informative, and easily accessed. Families also noted that it would be helpful to have a platform where families and people with disabilities could communicate with one another.



- **Partnership with family support centers and autism support centers** – Conversations with regional and area staff suggested that there were varying levels of coordination and cooperation with family support and autism support centers. Given that these groups have similar missions, it would make sense to encourage further information sharing and harmonization of policies and procedures.
- **Support broker guide** – While materials are available to service coordinators and support brokers regarding the self-direction program requirements, some staff reported that even more explicit information would be helpful – especially for service coordinators who have only one or two people self-directing on their caseload. DDS might consider bringing together a group of service coordinators/support brokers to give input on the types of information that would be the most useful.
- **Transition age coordination** – The transition from school to adulthood is an important moment to introduce self-direction with people with disabilities and families. The self-direction coordinators are already presenting at transition events which is positive. DDS may also want to consider preparing materials for educators as well as videos and webinars to ensure that self-direction is presented in a realistic and engaging fashion.
- **Outreach to minority participants** – Self-direction has the possibility of being uniquely culturally appropriate given the ability of individuals to hire support staff from their own communities. But in order to attract those individuals it will be important to ensure that materials are in a range of languages and at least in Spanish, that those making the introduction to self-direction are native speakers, and that participant and family mentors are available.

### Develop equitable, transparent, and streamlined policies

- **Consolidation of service codes** – Self direction began as a highly flexible program during the early days of the Robert Wood Johnson grant. As the program grew, guidelines regarding what services and supports became more complex and previous groups of services were “unbundled” to ensure waiver coverage. Based on feedback from interviews, the resulting set of service codes is very complex and confusing. The program would be greatly improved if service codes could be simplified and consolidated. To revise the codes, DDS might consider bring together service coordinators and support brokers to suggest simplifications. This process should also include a review of flexible funding guidelines to see whether simplification is possible there as well.
- **A la carte menu** – Most participants are receiving supports linked to day services allocations. Families have reported that they are unable to use these hours to receive in-home supports. In some cases PCAs from MassHealth are used for that purpose. The introduction of a budget allocation construct



should allow people to mix and match supports at home, on the job, or in the community. For example, in Minnesota, DHS offers a self-directed program called Consumer-Directed Community Supports (CDCS). There are four categories of services under CDCS including personal assistance, treatment and training, environmental modifications and provisions, and self-direction support activities.<sup>2</sup> While there are some per service limits, participants are free to select the type and amount of services from these categories to meet their needs within their budget amount.

- **Budget transparency** – Currently, participants and family members are unaware of the budget amount during planning and are not afforded an accounting of how the funds are dispersed. Some support brokers suggested that this puts less assertive families at a disadvantage since they are hesitant to demand services whereas more assertive participants will push strongly for the broadest array of supports possible. If all participants knew what their allocation was, they would be able to advocate for services within the cap. Not knowing the budget allocation also feeds the feeling that decisions are not being made in an objective fashion and that people are treated differently leading to a sense of inequity. In addition to budget transparency, many interviewees felt that the planning process would be greatly enhanced if potential participants were told what services and supports they were eligible for even if only through descriptions of the categories of services.
- **Menu transparency** – Interview participants expressed that it would be helpful to know what services were allowable under the PDP and AWC programs. A few interviewees described that a particular service might be available under PDP but not under AWC.

## Enhance infrastructure

- **Support for people self-directing** – There are still not enough Support Brokers to provide the necessary assistance that some participants and families need to be successful at self-direction. As a consequence, the program is a real challenge for single parent, minority and low-income families who may not have the resources and time to master the various parts of the process. The previous personal agent service was time limited and rarely used. DDS is currently considering the possibility of revamping the personal agent as a waiver service that would be continuing and not time limited. It is interesting to note that the Real Lives legislation included mention of an “independent facilitator” as a key component of self-direction.
- **Focus on natural supports** – The creation of a plan for a self-directing participant should include a canvas of natural supports similar to the Charting the LifeCourse approach. While some regional and area office staff said that

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<sup>2</sup> Consumer Directed Community Supports Consumer Handbook: [DHS-4317 10-15-13-gjf \(state.mn.us\)](https://dhs-4317-10-15-13-gjf.state.mn.us)

they are working with participants to identify community and natural resources, others were not sure that this was happening systematically. DDS may want to consider doing some webinars with state staff on LifeCourse planning if that is not currently part of ongoing training.

- **Support brokers versus service coordinators** – Interviews suggest that there is some confusion about the relative roles of service coordinators and support brokers. Though time in motion pilot that conducted several years ago recommended a ratio of 2:1 for support brokers, there is no uniform state standard for support broker caseloads. If a service coordinator takes on a person who is self-directing then their caseload can be reduced by a few cases. It seems that it is the luck of the draw depending on what Area Office you are in whether you are assigned to a support broker or a service coordinator. Now that more support brokers have been hired, some suggested that it was time to standardize the roles and responsibilities of these two staff classifications.
- **Bridge between DESE and adult self-direction** – Families in the DESE program are supported to be self-directing. The movement into the adult system should be seamless. However, the two programs operate with different regulations, funding streams, and paid assistance. One interviewee mentioned that as people make the transition they cannot keep their current staff. These families, as one interviewee said, are the future of the system and their move into adult services should not be met with barriers and discontinuities.
- **Increase waiver reimbursement**– Funding for self-direction includes significant amounts of state only funding. While this increases the flexibility and range of possible supports, this level of funding may be unsustainable as the program grows over the next few years. Taking time to review those supports currently encompassed in flexible funding to determine whether there are some that can be waiver eligible could reduce that burden on state funding.
- **Dedicated funding stream** – DDS should consider making the argument to the administration and the legislature that full implementation of the Real Lives legislation necessitates dedicated funding to ensure equal access to self-direction across the state and to support addition utilization.
- **Agency with Choice Issues** – A number of issues surfaced with respect to AWC. First, it is clear that the value of AWC weighs heavily on the competence of the navigators. To ensure that AWC navigators have the requisite skills, DDS should consider some training videos and the creation of a community of practice. Second, there seemed to be some difference of opinion in terms of how involved the participant is in hiring staff. In some cases, interviewees noted that participants are encouraged to hire agency staff rather than finding their own staff. Further, choices of staff were in some cases dependent on whether the potential support staff already had hours covered by other participants. Third, some of those interviewed suggested that

there was a need to spell out to participants the ways in which AWCs can contribute. Finally, many interviewees noted that the AWC Manual has still not been issued. These guidelines have now been in the works for several years. It may be necessary to ensure that they reflect the current service system context and should definitely be reviewed by stakeholders including people using AWC services.

## Simplify staff recruitment

- **Families need a network** – It seems clear that families that come to self-direction with a potential network of people to draw from to provide support are more likely to be prime candidates for self-direction. Anecdotally, some interviewees suggested that people without networks are encouraged to move into traditional services. To ensure that all participants have equal access to self-direction, it will be necessary to provide more hands-on support to those without networks to draw upon to help them recruit staff.
- **PPL list of staff** – Many of those interviewed mentioned that it would be very helpful if PPL could identify staff on their books who may have hours available to support people self-directing. This may be something that should be included in the next PPL contract.
- **On-line employment packages** – Many of those interviewed noted that onboarding staff can be a very time-consuming process. One suggestion was that PPL put the necessary forms online with fillable fields. Others suggested that the forms be translated into Spanish. A final suggestion was that PPL hire someone to oversee and manage the onboarding process.
- **Paying parents** – During the pandemic DDS agreed to pay families in some cases, which were assessed and determined based on individual circumstances. It is not clear whether that policy will persist in the future. One concern is whether families are committed to the type of support anticipated in the CMS Settings rule including helping the individual to secure employment, making choices about daily routines, and having privacy and the ability to entertain friends. Further, in contrast to parents, support by a DSP may broaden the individual's social network and introduce new experiences.

## Sustainability

- **Aging caregivers** – Some of the families interviewed expressed concern about what would happen when they are no longer able to assist their family member to self-direct. They recognize the amount of work involved and are fearful that there is no one else in the family who is willing to take on the responsibility. It will be important to work with these older family members to help to strategize what future supports will be necessary. Charting the LifeCourse would be useful and should be used years before these families are unable to continue.

- **Learning Communities** – The possibility of setting up a learning community for AWC navigators was mentioned above. As DDS begins to bring on personal agents, it might be useful to include these individuals as well given that their responsibilities are similar.
- **Consultation with participants** – In order to support continued reform and improvement in the self-direction program in Massachusetts, it will be important to find ways to hear the voices of those who are self-directing. These voices should assist DDS to carry on a continuous quality improvement of the program. One of the recommendations in the Year 3 evaluation that HSRI conducted earlier, it was suggested the DDS – perhaps with other advocates – sponsor a conference highlighting self-direction and showcasing experiences of individuals, families, support brokers and support staff.

## Recent DDS Initiatives

While this assessment was underway, the Department of Developmental Services addressed some of the recommendations above including: :

- Drafting a guide for individuals and families on what they can expect if they opt for the PCP and AWC programs
- Expanding support broker training opportunities
- Consolidating service codes
- Identifying, through the PPL system, staff who may have availability to work for self-directing participants
- Contracting to provide *Rewarding Work* as a resource to help individuals and families find staff

Table 1: Summary of Recommendations

<b>Disseminate Information</b>	<ul style="list-style-type: none"> <li>■ Provide guides for individuals and families</li> <li>■ Create an accessible venue for self-direction materials</li> <li>■ Create partnerships with family support centers and autism support centers</li> <li>■ Provide additional guides for support brokers</li> <li>■ Increase coordination with transition personnel</li> <li>■ Outreach to minority participants</li> </ul>
<b>Develop equitable, transparent, and streamlined policies</b>	<ul style="list-style-type: none"> <li>■ Consolidate service codes</li> <li>■ Develop an a la carte menu of services and supports</li> <li>■ Increase budget transparency</li> <li>■ Increase service menu transparency</li> </ul>
<b>Enhance infrastructure</b>	<ul style="list-style-type: none"> <li>■ Provide more support for people self-directing</li> <li>■ Focus on natural supports</li> <li>■ Clarify the roles of support brokers versus service coordinators</li> <li>■ Build a bridge between DESE and adult self-direction</li> <li>■ Increase waiver reimbursement</li> <li>■ Seek a dedicated funding stream</li> <li>■ Address Agency with Choice issues</li> </ul>
<b>Enhance and simplify staff recruitment</b>	<ul style="list-style-type: none"> <li>■ Assist families to identify staff</li> <li>■ Encourage PPL to develop a list of available staff</li> <li>■ Put employment packages online</li> <li>■ Review paying parents</li> </ul>
<b>Sustainability</b>	<ul style="list-style-type: none"> <li>■ Work with aging caregivers</li> <li>■ Create Learning Communities</li> <li>■ Consult with participants</li> </ul>