



Year One Report

Evaluation of Real Lives Legislation and
Self-Directed Services in Massachusetts

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About the Human Services Research Institute

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

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Executive Summary

The Real Lives legislation, passed by the Massachusetts Legislature in 2014, included a requirement that the Department of Developmental Services commission an independent evaluation of the implementation of the act. The Human Services Research Institute (HSRI) was designated as the organization to carry out the evaluation over three years. The first year of the evaluation focused on the effectiveness of the outreach efforts by the Department of Developmental Services to inform potential participants about the self-direction initiative.

Methodology

HSRI employed a variety of data collection strategies to analyze the effectiveness of outreach. Evaluation activities included observations of training and orientation sessions; focus groups; key informant interviews; surveys of self-direction participants, families, and service coordinators; a review of best practices in self-direction in six states; and an analysis of state aggregate data of characteristics of self-direction participants and the geographic distribution of the program.

Key Findings

Some key findings include:

- People who opt for self-direction are likely to be younger than individuals in conventional services
- The numbers and proportions of people self-directing differ by region
- People who are self-directing are more likely to have a guardian
- Service coordinators believe there are positive benefits to self-direction but most agree that facilitating self-direction is time consuming and complex
- Many families of individuals who are *not* self-directing are unfamiliar with the program
- Self-direction participants have seen positive changes in their lives, but some can use additional help to manage their services
- Many non-participants in self-direction are not familiar with the self-direction option
- A major reason that families and non-participants who know about self-direction choose not to participate is that they are happy with their current services
- Other states make use of family members and self-advocates as trainers and mentors
- Some other states have simplified the menu for services and supports available to self-direct
- There are differences in the characteristics of individuals who choose the Participant-Direction Program and those who choose the Agency with Choice program
- Online outreach is spread across numerous platforms with different information in different places

Recommendations

The major recommendations based on the Year One assessment include:

- Expand outreach and use peers and family mentors to help spread the word
- Build mentoring relationships and structures
- Improve training materials for participants and service coordinators
- Cultivate self-direction experts in every area
- Build additional service coordinator/service broker capacity to support self-direction
- Simplify the process by reconfiguring the service/support menu
- Improve outreach on social media and website
- Introduce self-direction to participants and families prior to transition
- Insure that the implementation of self-direction is consistent across regions and areas

Introduction

In August 2014, Governor Deval Patrick signed HB 980, known as the “Real Lives” bill, into law. Authors of the new law hoped to elevate the concept of self-direction and to expand the numbers of individuals managing their own services and supports in Massachusetts. As defined in the law, self-direction is “an approach to service delivery in which the participant is given control over the decision-making process for . . . supports or services and budget and the participant may tailor the support to meet the participant’s needs.” Provisions of the law included requirements for a fiscal intermediary, individual participant budgets, person-centered plans and plan facilitator, broad public outreach and education, and a statewide advisory committee to monitor progress toward the expansion of self-direction in the state. The law also required that the Department of Developmental Services commission a 3-year evaluation conducted by an independent entity to assess implementation of the law.

The Human Services Research Institute (HSRI) in Cambridge, Massachusetts was awarded the evaluation, which is both formative and summative. The work is divided into three areas of focus, one per year:

1. Year One: Assess the Department’s outreach efforts to enroll potential self-direction participants
2. Year Two: Assess the infrastructure of self-direction, including service coordination, individual planning, and budget development
3. Year Three: Assess the outcomes experienced by participants in self-direction

The following report presents the findings from Year One and is divided into four sections: Methodology, Findings, Recommendations, and Concluding Thoughts.

What is self-direction?

The Department of Developmental Services defines self-determination and self-direction as follows:

Self-Determination is the concept of having more control in one's life and to make decisions about services based on one's vision, path, preferences, beliefs and abilities.

Self-Direction is a process through which an individual/family can design and direct their own services.

Methodology

The HSRI team sought to answer eight research questions with its evaluation:

- What do the data tell us about the **characteristics** of those who opt for self-direction?
- What do the data tell us about **regional differences** in the number of individuals who are self-directing?
- What do the data tell us about the **services and supports** individuals are most likely to include in their individual budgets?
- How had DDS **communicated** the self-direction option? How do stakeholders (families, DDS staff and individuals) receive information about self-direction?
- What do stakeholders (participants, DDS staff and families) see as the **benefits of self-direction**?
- What do stakeholders (participants, DDS staff, and families) see as the **hindrances to self-direction**?
- How do **service coordinators view their roles** in self-direction? What are the positive experiences with self-direction? What are the constraints?
- What are **other states doing to enhance participation** in self-direction?

To answer these eight questions, HSRI carried out several data collection efforts including the following:

Key informant interviews. The HSRI research team interviewed all four DDS Regional Directors; all four regional self-direction managers; service coordinators and/or self-direction point people identified by regional staff in each area across the state (27); and at least one Agency with Choice provider in each DDS region (7 total). Interviews were also conducted with DDS central office staff, fiscal intermediary staff, leaders of advocacy organizations/trade associations, current and former legislators involved in the legislation, and members of the Real Lives Advisory Board. (See Appendix A for the Key Informant Interview Guide.)

Focus groups. Focus groups were held with area directors in each region (4), and with participants in self-direction (Participant-Direction *and* Agency with Choice program participants) in each region.

Observations of educational and training sessions and review of materials. HSRI reviewed the DDS Self Direction Manual; four DDS websites with content relevant to self-direction; and materials used by DDS to address self-direction in its Service Coordinator Academy program. In-person observations were also conducted, including observations of a transition fair, several self-advocate support groups, a family support group, a MASS Annual Meeting, and other educational and outreach activities.

Development of Mail and Online Surveys. To canvass the experiences and attitudes of a range of stakeholders regarding self-direction, HSRI developed five mail and online surveys. Each survey was reviewed by DDS Central Office staff and members of the Self-Direction Advisory Board and field tested with relevant populations before implementation. Based on these reviews, revisions were made for the final distribution. (See Appendices B-F for a description of sampling design, questionnaire design, and dissemination.)

- **Survey of families.** A total of 600 surveys were mailed by DDS to a sample of families, and 176 were completed and returned (26.6% response rate).
- **Survey of Participant-Direction Program (PDP) participants.** Surveys were mailed by Public Private Partnerships to all PDP participants. Of the 528 surveys sent out by PPL, 123 were completed and returned (23.2% response rate).
- **Survey of Agency with Choice (AWC) participants.** Surveys were mailed to all AWC participants. Of the 355 sent out, 86 were completed and returned (23.9% response rate).
- **Survey of non-participants.** A total of 1,450 surveys were mailed by DDS to a sample of individuals who are not currently participating in self-direction; 233 were completed and returned (16% response rate).
- **Survey of service coordinators.** An online survey was made available to all service coordinators statewide. Of a total of 372 service coordinators, 103 completed the survey (27.6% response rate).

A preliminary analysis by HSRI shows that the mail and online survey participants are representative of the larger populations served by DDS.

Review of best practices. HSRI selected six states that have relatively robust self-direction programs—New Jersey, Pennsylvania, Ohio, Idaho, Tennessee, and Connecticut—and conducted interviews with program staff in each state to identify lessons learned and practices and policies that could be translated to Massachusetts (See Appendix H for Interview Guide for States).

Review of DDS data on self-direction. The HSRI team coordinated with DDS to obtain demographic and service utilization data to understand who is (and is not) self-directing, what region they are in, and what services and supports they are most likely to manage. In August 2017, HSRI received data for the 27,808 individuals who received DDS services between July 1, 2016 and July 30, 2017 (FY 2017). The data analysis for the Year One report focused primarily on understanding the following individual characteristics: age, gender, race, preferred language and use of an interpreter, guardianship, and region. In Year One, the analysis involved creating basic bivariate comparisons to understand a) differences between individuals receiving DDS services who are self-directing and individuals who are not self-directing and b) within the self-directing group, differences between PDP and AWC participants. In subsequent years, our analysis will include a more detailed examination of service utilization and other participant characteristics, such as assessed functioning. We will also incorporate additional analytic methods such as multivariate modeling to understand differences between groups, holding individual characteristics constant.

Findings

Context and Background

Although self-direction has been an option in Massachusetts since the 1990s, when the state received a grant from the Robert Wood Johnson Foundation to conduct a pilot program, the program has grown very slowly since the option became available. There have been some systemic advances in the state related to self-direction including the initiation of the Autism Waiver Program for families with children under 8 years, which is entirely self-directing. Additionally, DDS conducted a pilot study from 2012 to 2013 to better understand the added work involved in supporting self-direction and to gauge the optimal caseload size for service brokers who are supporting individuals who are self-directing. And lastly, DDS offers a program in conjunction with the Department of Elementary and Secondary Education (DESE) that supports families with school-age children with disabilities (ages 9 to 21) to self-direct services, with the goal of keeping children out of more restrictive settings. Besides these efforts, however, self-direction had not made significant inroads into the traditional service system in Massachusetts.

The Real Lives legislation, passed in 2014, was an effort to provide some momentum for self-direction and to spell out the ways in which DDS could facilitate increased enrollment. The law required that DDS create an advisory committee widely representative of stakeholders. The Real Lives Advisory Committee receives updates on progress toward meeting the legislative requirements and aspirations. Some of the requirements in the law include providing all potential and current DDS participants the opportunity to self-direct, taking into consideration the individual's needs and goals; training all state staff; developing individual budgets; outlining requirements for a fiscal intermediary; developing training and orientation materials; providing information on self-direction on DDS websites; as well as other procedural and policy reforms. There were also provisions included to prevent abuse and exploitation and a requirement to conduct a fiscal audit.

To meet the requirements of the law, DDS appointed regional leads for self-direction in the four DDS regions, launched a series of public events around the state to introduce families and individuals to self-direction (including sessions aimed at individuals who are transitioning from school or "turning 22"), and prepared brochures for dissemination at ISP meetings and educational sessions. Moreover, training sessions have been held with state staff, and a self-direction module has been included in the introductory training required for new service coordinators. Additional materials have been placed on state websites describing the self-direction opportunity, and the state has renegotiated its contract with Public Private Partnerships Limited (PPL), the fiscal intermediary.

With this as backdrop, the following section describes HSRI's findings for the Year One evaluation, which address the efficacy of the outreach efforts mounted by DDS.

What Were the Specific Findings?

Findings are presented by group and by region. HSRI promised to maintain anonymity of key informants, so in those cases, findings across the entire group are presented. However, data was gathered to allow for both statewide and regional experiences of self-direction in its various forms to emerge.

What do the data tell us about the characteristics of those who opt for self-direction?

Of the 27,808 individuals who received services through DDS in FY 2016-2017, 1,030 (or 3.7%) were self-directing one or more of their services. Within the self-directing group, 649 (or 63.0%) were enrolled in the Participant-direction program, and the remaining 381 (or 37.0%) were enrolled in Agency with Choice.

On average, self-directing participants were 3.2 years younger than non-participants. In the non-self-directing group, the average age was 36.4 years (standard deviation [SD] 36.2 to 36.6). The average age of self-directing participants was 33.2 years (SD 32.0 to 34.5). This difference of 3.2 years was statistically significant ($p < .001$). For the self-directing group, the PDP and AWC enrollees did not differ significantly by age.

There were no significant differences between the groups with regard to gender. Around 40% of the population receiving DDS services were female, and this proportion did not differ by group (self-directing vs. non-self-directing or PDP vs. AWC).

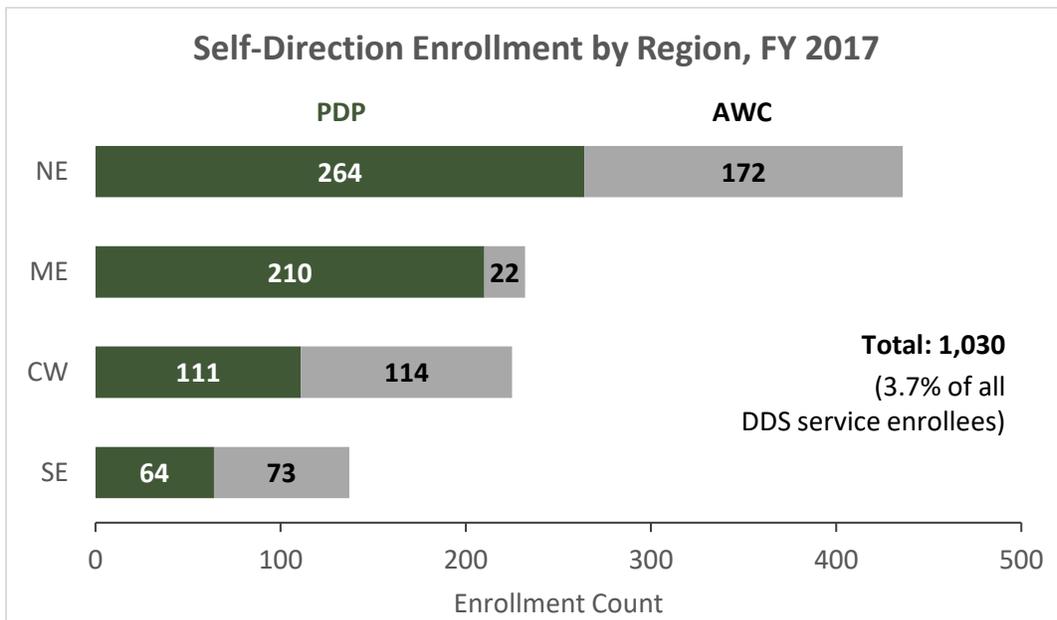
About 20% of self-directing and non-self-directing DDS participants were non-white, but within the self-directing group, PDP enrollees were significantly more likely to be non-white than AWC enrollees. Approximately 25.4% of PDP enrollees were non-white, while only 12.8% of AWC participants were non-white. However, these results should be interpreted with caution because there were a high number of missing values for race; in fact, information about race was unavailable for 57.6% of the total sample. It is also possible that variation in race is related to variation in region (see the subsection on regional differences on the following page). In future years, we will explore these dynamics further.

Self-directing participants were significantly less likely than non-self-directing participants to prefer to use a language other than English, and they were also less likely to use an interpreter during FY 2017. Approximately 12.2% of non-self-directing participants preferred a language other than English, while only 8.3% of self-directing participants preferred a language other than English; this difference was statistically significant ($p < .01$). About 9.2% of the non-self-directing group used an interpreter during FY 2017, while only 5.7% of the self-directing group used an interpreter; this difference was also statistically significant ($p < .01$). There were no statistically significant differences between the PDP and AWC groups. As with the data on race, there were many missing values for these two variables, so these results should be interpreted with caution.

The self-directing group was significantly more likely to be under legal guardianship than the non-self-directing group, and AWC enrollees were more likely to have legal guardians than PDP enrollees. Over half (53.4%) of the self-directing group had a legal guardian, and fewer than half (47.0%) of the non-self-directing group had a guardian ($p < .001$). Within the self-directing group, 60.0% of AWC enrollees had a guardian, and only 49.5% of PDP enrollees had a guardian, and this difference of 10.5 percentage points was statistically significant ($p < .001$).

What do the data tell us about regional differences in the number of individuals who are self-directing?

There was significant regional variation in participation in self-direction as well as AWC vs. PDP enrollment. In the Northeast region, 7.1% of individuals receiving DDS services were self-directing; in the Central West and Southeast regions, the figure was closer to 2%.



What do the data tell us about the services and supports individuals are most likely to include in their individual budgets?

This question will be taken up in subsequent-year reports using several years of data on service utilization for PDP and AWC enrollees. DDS, however, recently submitted a brief report to the Real Lives Advisory Committee highlighting those services most included in the plans of PDP participants:

HCBS Waiver Services

- **Individualized Home Supports (Waiver Code: 5703, 6703):** Support and supervision necessary for the participant to establish, live in and maintain on an ongoing basis a household of their choosing, in a personal home or the family home, to meet their habilitative needs. These supports may include assisting people to develop skills related to personal finance, health,

shopping, use of community resources, community safety, and other skills to live in the community as specified in the plan of care. It may include training and education in self-determination and self-advocacy. This service excludes room and board, or the cost of facility upkeep, and maintenance.

- **Individualized Day Supports (Waiver Code: 5704, 6704):** Services and supports tailored to support the acquisition, improvement, and/or retention of skills and abilities to prepare an individual for work and/or community participation and/or meaningful retirement activities. This service can only be participant-directed. A qualified family member or relative, independent contractor or service agency may provide services.
- **Individualized Supported Employment (Waiver Code: 5168, 5180):** Consists of ongoing supports, including job coaching, that enable a participant to perform in a regular integrated work setting. Individual supported employment may include assisting the participants to locate a job or develop a job on behalf of the participant. Individual supported employment is conducted in a variety of settings, particularly typical work sites where persons without disabilities are employed.
- **Adult Companion (Waiver Code: 5707, 6707):** Non-medical care, supervision and socialization provided to an adult. Services may include assistance with meals and basic activities of daily living such as shopping, laundry, meal preparation, routine household care incidental to the support and supervision of the individual.
- **Individual Goods and Services (Waiver Code: 5728):** Services, equipment or supplies that will provide direct benefit and support specific outcomes that are identified in the individual waiver participant's service plan. The Individual Goods and Services promote community integration, or provide resources to expand opportunities for self-advocacy, or decrease the need for other Medicaid services, or reduce the reliance on paid support, or are directly related to the health and safety of the waiver participant in his/her home or community.
- **Transportation (Waiver Code: 5196, 5197, 5198):** Includes travel to and from day programs and travel for participating in community activities. This service may also include the purchase of transit and bus passes for public transportation systems and mileage reimbursement for qualified drivers. This service is offered in addition to medical transportation.

Non-Waiver Services and Supports

- **Community Integration, Skill Development:** Expanded Non-Waiver reimbursable Individualized Goods and Services are available when there is compelling need that exceeds the limit or definition of a Waiver service and/or state plan service. This expansion of goods and services recognizes the individualized and changing circumstances for participants and provides flexibility and accommodation.
- **5300A, C; Adult Education**
 - Benefit: communication/community engagement activity, skill development, learning for new opportunities/options, interest development, career development.
 - Should investigate/utilize scholarships and other possible funding, first.

- 5300F; **Community Activity**
 - Costs associated with community-based activities that enrich a person’s life.

How has DDS communicated the self-direction program? How do stakeholders receive information about self-direction?

The self-direction program is communicated to people who receive services and their families through multiple channels, including:

- Direct reference to self-direction in letters inviting people to participate in to the service planning meeting.
- Print materials about options for self-directing services, presented at the planning meeting.
- Community meetings hosted by DDS staff.
- Presentations at local conferences for self-advocates, families, and service coordinators.
- Web-based dissemination of informational materials and training links.

Dissemination of information and outreach was evaluated through questions in semi-structured interviews with key informants, through questions included in surveys to families, to people who are self-directing, and to those who are not self-directing.

One family noted the importance of regular focus groups:

We attend focus group meetings on a regular basis and have found them very helpful and informative.
 —Survey respondent, Family Survey

Outreach associated with service planning meetings

Survey responses from families and those who are not self-directing demonstrated that people who are receiving services and supports from DDS are not yet fully aware of self-direction options.

Among families who responded to the **family survey**, 58% said they had been informed about self-direction options from their service coordinator or support broker. A smaller group of respondents, 38%, said they had participated in meetings or training sessions about self-direction that had been sponsored by DDS. It is important to note that 53% of the respondents to the family survey included family members of people who were self-directing at least a portion of their supports. Among those whose family members were NOT participating, the most common reason given for not opting to self-direct was “Don’t know about the option” (57%).

The **survey to individuals who are not self-directing** revealed a similar pattern. Of those who responded to the Non-Participant Survey, only 26% said they remember hearing about self-direction at their annual service planning meeting. Another 27% said they “didn’t know” if they remembered.

A follow up survey question provided an image of the cover of the DDS brochure: “*Choosing Which Service Method Is Best For You.*” Respondents were asked directly whether they remembered seeing or receiving the brochure; 21% said they remembered seeing it (59% No; 20% Don’t Know). Only 19%

said they had heard about the option of hiring their own staff or making more choices about services from their DDS worker (54% No; 11% Maybe; 16% Don't Know).

To determine whether people who were more recently enrolled in services were more likely to have heard about self-direction, the HSRI team requested that DDS draw a 400-person oversample in the non-participant survey sample from people who entered services in the past three years. There were only 44 respondents to the survey who indicated they had entered services in the past three years, so comparisons must be made with caution. This group did not show any greater awareness or familiarity with the self-direction materials than those who entered services prior to three years ago.

Additional findings from the surveys of those who are currently self-directing suggest that service coordinators were not always the ones who introduced them to the option. About 70% of those in the PDP program found out about the option from their service coordinator. Others found out about the program at a self-advocacy meeting or from family and friends. For those who were in AWC, provider agency staff assisted with promoting that option: 47% said they had learned about AWC from their service coordinator, 29% had learned from agency staff, and another 24% had heard about it during ISP (service planning) meetings.

Web-based dissemination of informational materials and training links

The HSRI team completed two tasks to review the availability of information regarding the Real Lives Law on the web.

First, we developed a summary of content available that describes self-direction in Massachusetts, and the Real Lives Law. In all, five websites include content relevant to the Real Lives Law. The content and paths to access the information are included in a report that was shared with the Real Lives Advisory Committee. The report is included in Appendix I. The websites that describe Massachusetts self-direction are as follows:

- HHS Self Directed Supports Page: <http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/self-directed-supports.html>
- Self Determination Advisory Board (SDAB): <http://www.mass.gov/eohhs/gov/departments/dds/self-determination.html>
- Real Lives Massachusetts Program Locator Website: www.massreallives.org (This link currently re-directs to this site: <https://familyties.neindex.org/>)
- PCG Public Partnerships MA DDS Website: <http://www.publicpartnerships.com/programs/massachusetts/PDP/index.html>
- DDS Learning Website/Self Determination: <http://www.ddslearning.com/self-determination/>

After delivery of the initial review of web-based content related to Real Lives, the evaluation team learned of a new Facebook community created to help publicize Real Lives and for people to engage in sharing self-directed services info, success stories and problem solving: <https://www.facebook.com/ConnectingRealLives/>. This initiative was developed by The Arc of Massachusetts and M.A.S.S and is being publicized through social media and with a flyer, included as Appendix J.

Second, to evaluate the approach a new user might take in learning about self-direction, the team tasked a summer intern with investigating self-direction as an option for a hypothetical family member. The intern was not knowledgeable about Real Lives or Self Direction, but was familiar with the needs of people with intellectual and developmental disability and able to use the internet for searching. In other words, he was a typical layperson or family member. He was provided with the DDS brochure that describes self-direction, and asked to research self-direction, including the definition of self-direction and why a person or their family or guardian would choose it.

Through his web searching, the intern demonstrated that self-determination in Massachusetts lacks a coherent web presence—at least for those who are unfamiliar with it and attempting to learn about it. Using search terms based on information he gathered from reading the DDS brochure that describes self-direction options, he was able to find the HHS Self Directed Supports Page after several tries; however, he reported frustration at not being able to find the information he thought he needed. Websites from other states, such as New York, were more likely to come up in searches for “What is self-direction?” When focusing the search to include “Massachusetts,” the *Choosing Which Service Method Is Best for You* publication was among the top three results; however, he also was led to the Self Determination Advisory Group’s website, as well as to a presentation on self-directed supports in MLTSS, developed by University of Massachusetts Medical School.

One obstacle he noted was the interchangeable use of the terms “self-determination” and “self-direction” in many documents and on many web pages, resulting in inconsistent web-search results.

In summary, the team found that there are multiple online sources of information regarding Self Determination and the Real Lives Law in Massachusetts, including training materials used for DDS staff, an online provider inventory, and forms and materials that individuals or families can use if they are self-directing their services. Yet, the information is housed across many different websites, making it difficult for searchers to find and access the full breadth of available content. At present, people who search for information online are most likely to be successful if they already have knowledge of self-determination and self-direction, and can sort through the material available to find the most relevant content.

What do stakeholders see as the benefits of self-direction?

Responses from the surveys of people participating in PDP and AWC and the surveys of families provide insight from those who are currently self-directing about the perceived benefits of self-direction.

For participants in both the PDP and AWC programs who responded to the surveys, the majority stated that they would continue to self-direct (PDP: 88%; AWC: 90%), and that they would recommend self-direction to others. The most common changes that people reported in their lives after starting to self-direct were: having more independence, making more choices, learning new things, having a job, and having more friends. These findings were echoed in the information gathered through key informant interviews.

Approximately 90% of self-directing participants want to continue self-directing (88% for PDP; 90% for AWC), and most would recommend self-direction to others.

Source: Real Lives Evaluation Surveys

What do stakeholders see as the hindrances to self-direction?

Among people and family members who are not participating in self-direction, there were concerns about the amount of work required to coordinate self-direction, including the effort it would take to hire staff. These concerns were borne out to some degree in the responses among those who are participating in self-direction.

Among PDP program participants, for instance, 42% reported that they had experienced some problems with self-directing *but* that someone had helped with those problems. Only 5% reported having problems and not getting help. The most common difficulties described involved the process being complicated to navigate (48%) and difficulty finding and keeping good staff (37%).

Among AWC program participants, 33% of respondents reported that they have had some problems *but* that someone has helped with those problems. Only 4% reported having problems and not getting help. The most common difficulties described were difficulty finding and keeping good staff (78% of respondents) and the process being complicated (27%).

Key informant interviews supported these survey findings. Several DDS staff identified the complexity of managing the program, the potential confusion over what supports were allowable, and the need to provide detailed support to those handling billing as reasons that some individuals and families refrain from pursuing the self-direction option.

How do service coordinators view their roles in self-direction? What are the positive experiences with self-direction? What are the constraints?

Of the respondents to the service coordinator survey, almost 80% (79.6%) were service coordinators. Of the remainder, 19.4% were support brokers, 10.7% were supervisors, and 11.7% selected the “Other” category (e.g., Trainer, Program Coordinator, Compliance Officer, etc.). Respondents could check more than one option. All of their responses, however, have been included in the following data.

With respect to caseload mix and size, respondents fell roughly into three categories: 1) people whose caseload was predominately composed of individuals in traditional services (50 to 70), with few individuals (less than 7) who were self-directing; 2) people with balanced caseloads (e.g., 24 individuals in PDP and 30 in traditional services; and 3) people with caseloads predominately composed of individuals in the PDP and AwC with very few if any individuals in traditional services. There were no service coordinators/brokers who were serving large numbers of individuals in Agency with Choice (i.e., 2 to 7).

When asked how they introduce self-direction to potential participants and families, the majority (63.4%) of Service Coordinators said they hand out a brochure about self-direction. The next most frequent introduction strategy involved discussing the option at ISP meetings. Service Coordinators also said they discuss self-direction when people enroll in services (32.7%); they let individuals and families know about orientation sessions that are happening in their area (40.6%); and they suggest that families talk to other families who are self-directing (37.6%) and that individuals talk to other self-advocates who are self-directing (19.8%). Only 13.9% said that they discuss self-direction at Individualized Education Program (IEP) meetings.

With respect to outreach, 83% of respondents said that there have been educational sessions or outreach meetings about self-direction in their regions. If they attended any of these sessions, respondents were asked what information was covered; 87% of these respondents said the session covered “who can participate and responsibilities of participants”; 85% said it covered the “responsibilities of family members,” 72.2% said “how to enroll, responsibilities of the service coordinator, and the types of services and supports that can be included in the budget.” Other frequent responses included: the role of PPL (66.7%), responsibilities of the agency in the Agency with Choice Program (68.5%), the family’s role in making choices (66.7%), and where to get more information (66.7%). Other topics included: provisions for backup (42.6%); how the budget is determined (50%); how to recruit workers (40.7%); a step-by-step checklist of the process (35.2%).

When asked what steps could be taken to increase enrollment in self-direction, 85.9% said provide more training to service coordinators/service brokers, 86.5% said to encourage more communication about best practice among service coordinators/service brokers, another 86.5% said use people who are self-directing and family members as mentors and presenters, 86.8% said give participants and

families the opportunity to share experience, 76.8% said simplify the process, and 67% said simplify the service codes. One respondent summarized this issue as follows:

Trainings do not provide . . . adequate information for new service coordinators. Full immersion and support from experienced support brokers is the only way to make the transition from a traditional Service Coordinator to a Service Broker.

—Survey respondent, Service Coordinator Survey

Respondents felt that there were substantial benefits for individuals who are self-directing, including participating in activities (76.4%), being happier (75%), being more empowered to make choices (89.5%), and learning new things (85.5%). Having more friends and close relationships were also mentioned, though not as frequently. As one respondent said,

I see a huge sense of pride from individuals that are self-directing. They feel extremely empowered and know that they are a part of everything we do together, and have a say in their lives.

—Survey respondent, Service Coordinator Survey

There was a fair amount of consensus regarding the complexity of self-direction and an equal consensus regarding the additional time it takes to support individuals in the PDP and AWC programs. Respondents were evenly split (41.9% agree, 45.2% disagree) on whether self-direction is for everyone. Only 50% of respondents said that they have all the information they need to support people who self-direct.

Service coordinators/service brokers who responded were positive about the benefits of self-direction but cited constraints to the process including complexity and the need for more information. In the comments sections, respondents made a number of suggestions they felt would improve enrollment, including the development of a resource center in area offices; ensuring there are service brokers in every area office; doing a better job of introducing the concept to school systems; creating a toolbox for service coordinators/service brokers and participants; creating opportunities for service coordinators/brokers across the state to share ideas; and making sure there is a PDP/AWC specialist in each area office.

Finally, service coordinators were asked what kinds of participants were most likely to choose to self-direct. In order, 73.9% of respondents indicated “people who are unhappy with traditional services,”

60.6% said “people [from]. . . capable families,” 59.4% listed “young people making the transition from school to adult services,” and 47.8% said “people on the autism spectrum.”

What are other states doing to enhance participation in self-direction?

The HSRI team identified six state DD agencies that had significant experience with developing self-direction options. To identify states, HSRI team members reached out to national leaders in the DD field with broad knowledge of state programs. In the selection process, HSRI also wanted to make sure that some of the states selected had service systems that were comparable to Massachusetts. The states selected were Ohio, New Jersey, Tennessee, Pennsylvania, Idaho, and Connecticut. The following discussion summarizes the main factors for enrollment in self-directed options, as expressed by state key informants.

Each state organized and delivered the self-direction option differently; this included variation in the services that could be self-directed, the duties of case managers/service coordinators and service brokers, the configuration of financial management service agencies, and the amount of the typical participant budget. In addition, budgets were configured and paid for in different ways in different states; typical annual budgets ranged from \$23,000 to \$50,000.

From the information shared with HSRI, the percentage of state clients with developmental disabilities self-directing ranged from over 20% in Idaho and New Jersey to roughly 2.5% in Ohio; proportions in Connecticut (13%), Pennsylvania (12%), and Tennessee (7%) were somewhere in between. Strategies employed in high-penetration states varied somewhat from states with more minimal enrollment in self-direction. HSRI paid special attention to variables noted in states with high enrollment.

What approaches have made the biggest difference in expanding access to the self-direction option?

Program Design: To keep the program simple and comprehensible for individuals and families, some states limited the service and support options that individuals could manage and created pre-determined budget amounts based on assessments of need. Although all states offered both Agency with Choice and employer agent models of self-direction, states with higher levels of participant enrollment tended to have made greater progress with the employer agent approach. Some states expressed difficulties in engaging providers in Agency with Choice given the lack of financial incentives; other informants noted that, while Agency with Choice was the more popular option, they were working to persuade potential participants that the employer model was manageable. To reduce participant and family anxiety about self-direction, one state allows the individual to return to traditional services within 180 days if they are dissatisfied with the option.

State staff have worked hard to make the budget process understandable by creating a simplified structure and developing written materials that are accessible to potential participants; they also

noted that they'd put the self-direction manual online. To maximize the availability of staff support with expertise in self-direction, one state created three levels of intake—intake worker, service coordinator, and state self-direction lead; the state self-direction lead joins the conversation for the more detailed discussion. The use of specialized staff with familiarity in self-direction was also mentioned in other states.

Personnel and Roles. The clear definition of roles, and the tasks assigned to those roles, appears critical in making self-direction efficient. It is important to note that the states that have the highest penetration of self-direction make the greatest use of specialized support, build in opportunities for peer mentoring, and include mechanisms to help those people who do not have ready-made networks of family and friends experience the opportunity to self-direct. In another state, the fiscal intermediary is taking over some of the service coordinator functions by helping participants with the application process.

In some states, there is a clear distinction between service coordinator and service broker. The former assists participants to develop and implement a service plan, and the latter assists individuals who are self-directing. Depending on the state, support brokers may be paid by the state directly, by the fiscal intermediary, or their services may be purchased by individuals through their individual budget. States have found other ways to support participants in self-direction using self-advocate peers and family mentors. In one state, a new waiver service called “peer-to-peer” can support people through the planning process.

Outreach Strategies. States used a variety of methods to inform potential participants regarding the self-direction option. One state held monthly meetings around the state, reached out to individuals on the waiting list for residential services, and stressed the option at intake and at successive planning meetings. Putting a “human face” on the program through materials and presentations was also seen as an effective technique. This included producing a DVD of success stories that could be shown at planning meetings. Another state linked potential participants with support brokers and individuals who were successfully self-directing.

The service coordinator is a critical piece of outreach. As one interviewee noted, “The more comfortable the service coordinator is with self-direction models, the more they talk about it. Once service coordinators realize the process is going faster and smoother, they are more comfortable.”

Potential Participants. Individuals attracted to self-direction across the states fell into similar patterns. Adults with autism and families with children on the autism spectrum were noted as more likely to self-direct. Individuals and families who were dissatisfied with their traditional services or who were struggling were also more likely candidates. Individuals who wanted to leave their group homes, and young people who were transitioning out of school were also more interested in self-direction. Finally, some interviewees noted that families in rural areas where services were sparse and families on waiting lists were likely to choose the self-direction option.

Several problems with the implementation of self-direction were noted. Many interviewees noted problems with staff recruitment in some parts of the state, and an uneven availability of providers—particularly in rural areas. Concerns were also raised regarding the aging of family members, the increasing frailty of older participants, and the challenges in supporting individuals with behavioral health needs. With respect to implementing Agency with Choice, one interviewee noted that many traditional agencies find it difficult to give up control and retain an institutional mindset.

What training approaches have been successful?

In one state, support brokers hired by participants are required to meet state qualifications and to participate in state-sanctioned training. In another state, support brokers are requalified every two years. In a third state, there are basic two-day training modules for paid and unpaid support brokers and the training must be retaken yearly. For participants and families, one state sponsored a required class on “Guide to Self-Directed Care.”

With respect to workers hired by participants, two states mandate that they take training through the College of Direct Support. One state noted that staff are required to train on emergency preparedness and another requires medication training if workers are administering meds. In another state, before a worker can be employed, they must go through a 30-day certification. One final state does not require specific training on the assumption that all training should be based on individual and family needs.

All interviewees in each of the six states expressed a belief that self-direction is an important option. Each of these states has specific plans to continue to grow self-direction. Some of the lessons that can be drawn from the experiences in these states include:

- The program needs to be clear and simple with a modest number of self-direction options;
- Clear and organized policies and procedures make the self-direction option more accessible;
- States that had self-direction specialists who became proficient in helping people decide on self-direction and then operationalize their plans were more successful;
- Support from peer mentors and experienced family members is an important ingredient;
- Special supports are needed for participants who do not have a large involved network of family and friends.

Finally, in another best practice vein, Massachusetts may want to listen closely to some of the lessons the Veterans Health Administration (VHA) is sharing after eight years of experience with Veterans-Directed HCBS. The message from the VHA is that the program, and the way it is explained, must be SIMPLIFIED, and standard protocols should be developed so that options are offered to clients in a consistent manner and not left to the discretion of individual service coordinators. People could start with a question on whether they wish to self-direct, and end with the question on whether they need an institutional setting—following the time-honored principle of offering support in the least restrictive environment.

Recommendations

Based on findings from the various data collection strategies used by HSRI, nine recommendations emerged that could offer DDS opportunities to promote and support self-direction more effectively.

1. Expand outreach and encourage peers and family members to share their experiences

The most involved and enthusiastic recruiters for the PDP and AWC programs are family members and participants. In some areas participants and families have a role in telling others about self-direction, though in other areas DDS staff are the ones giving out information. Finding a way to encourage conversations among individuals and families who are self-directing and those who might potentially self-direct would give some real-life information, an opportunity to explore their own questions with peers, and perhaps build connections among peers and families for the future. This was also a best practice identified in HSRI's scan of self-direction processes in six other states.

We didn't know self-direction existed until we read about it online in September 2016. It was like a secret. We need training workshops to inform us about what exists.

—Survey respondent, Family Survey

2. Build mentoring relationships and structures

Families, participants, and providers are more likely to listen to what their peers say about self-direction. Opportunities to create peer mentoring abound within the model: service brokers could be part of a statewide or regionwide network of support brokers, with meetings—or at least a web presence—where questions could be shared, successes celebrated, and frustrations aired; participants and families could be connected to one another as they start to be involved in self-direction for support and assistance, and over time for support and sharing; providers would benefit from support from other providers as they develop their own capacities in offering self-direction through Agency with Choice. Developing ways for interested support brokers, participants, families, and providers to serve as mentors would address a number of suggestions made by stakeholders in the interviews and surveys conducted for this evaluation. Using the New England INDEX model for Support Conference would allow DDS to roll out a web based support network in a very short time.

Service coordinators should be offered the opportunity to be mentored by experienced support brokers. Mentors should be offered an incentive (monetary or otherwise) to provide mentorship.

—Survey respondent, Service Coordinator Survey

3. Improve training materials for participants and service coordinators

Throughout the evaluation, participants and service coordinators/service brokers expressed the need for better training to ensure that accurate information is available, to improve skills, and to understand the types of supports required to self-direct. While orientation meetings and the current self-direction manual do convey basic information, respondents favored the opportunity to work with peers with more experience, to have mentors who could offer advice, and to have a way to collaboratively problem solve. This kind of collaboration would be a means to more confident participation and more accurate paperwork. To facilitate this form of learning, DDS should consider developing web-based, interactive training materials that could support hands-on training to provide accurate information and build skills.

Offer computer training to families considering the model to enhance their ability to negotiate the portal. Ensure the PPL staff are troubleshooting and facilitating problem solving rather than [just] identifying [problems] and not working toward resolution.

—Survey respondent, Service Coordinator Survey

In addition, the self-direction manual for service coordinators and service brokers should be more accessible, readable, and laid out in a step-by-step fashion.

4. Cultivate self-direction experts in every area of the state

Regional self-direction support was widely praised across the state. Identifying and supporting at least one expert in each area would enable local service coordinators/brokers to get the support they need when they need it. It would also enable the Department to better insure that information and dissemination about self-direction is more consistent across the state.

Develop a toolbox for everyone to use. It would be easy to understand and provide information guides, resources. . .

—Survey respondent, Service Coordinator Survey

5. Build Additional Service Coordinator/Service Broker Capacity to Support Self-Direction

Almost everyone contacted at the area and regional offices addressed the need to rethink the way caseload size is determined. The DDS pilot study conducted in 2013 indicated that the optimal caseload size for service brokers working with individuals who are self-directing is 30. Expanding the number of service brokers with expertise in self-direction would be optimal. However, given resource limitations, the number of service brokers statewide remains small. To relieve the pressure

on service coordinators working with people who are self-directing, a weighted caseload scheme was developed that reduced the conventional caseload by a percentage based on how many of their clients were beginning to self-direct. Based on feedback from our interviews and surveys, service coordinators with conventional caseloads are still struggling to find enough time for self-direction. There are only a few options left to DDS: hire more service brokers, reduce caseloads for service coordinators, encourage participants to hire their own coordinator, or all of the above. Although these recommendations have resource implications, it is hard to imagine a significant expansion of self-direction under current circumstances

It will be important in the next year of the evaluation to explore the time demands on coordinators/brokers once people have been self-directing for some length of time. We will investigate to see if time demands and support requirements decline over time.

6. Simplify the process by reconfiguring the service/support menu

The complex nature of the current service and support menu came up in almost every conversation about self-direction, and it was identified through the survey process as well. DDS needs to find a way to strike a balance between what it will pay for and what people need. As noted in the review of best practices, many states have simplified the menu of services and supports that individuals can self-direct to a few broad and readily understandable categories—such as job supports, community supports, etc. DDS should explore ways of keeping the complexity of the service codes in the background while making service descriptions outlined for participants more intuitive for individuals to grasp. This is currently the way the autism and DESE programs operate. Learning from the experience of those two initiatives could inform streamlining of PDP and AWC. These ideas were captured in the following quotes:

We have been considering this option for a while and if we could be sure of the funding, simplification of the process, and the ability to revert back if it doesn't work, we could definitely try it.

—Survey respondent, Family Survey

SIMPLIFY THE PROCESS!! Service Coordinators cannot explain how it works so they don't explain it to families and individuals at all.

—Survey respondent, Service Coordinator Survey

7. Improve outreach using social media and a web-based presence

Social media provides an excellent way for service brokers as well as participants in PDP and AWC and their families to share their stories and lessons learned. Access to this kind of material would supplement printed materials and manuals. Videos allow those who are not readers an opportunity

to “hear” from those involved directly. Videos could be the beginning of a core of stories that could be used across the state as part of a recruiting package.

To minimize confusion for participants trying to learn about Real Lives and self-direction, DDS should ideally establish one unified source of information about DDS Self-Direction options. This source should include contacts, training materials, and links to the provider inventory. This content should be organized by target audience: individual/family/guardian; service coordinator/service broker; provider of self-directed supports.

I wish there were ways to connect with other people in my area. It would help if everything did not have to go through the support broker.

—Survey respondent, AWC Participant Survey

I've encouraged one of the families to build a Facebook page where families can share their thoughts.

—Service Coordinator interviewee

8. Introduce self-direction to participants and families prior to transition

In many of the service coordinator interviews, interviewees said that they wished that families had a longer time to consider self-direction and learn about the mechanics before they are faced with making the choice. Families and participants also suggested that more information and time to consider the model would be welcome. Ideally, the conversation should begin before young people make the transition out of school. DDS should consider collaborating with Parent/Teacher organizations to offer regular presentations on the model, with guest speakers who are using the model, while youth are in grades 7 to 9. Self-advocacy organizations could be encouraged to reach out to younger audiences to do the same. This might result in greater interest when transition-planning time comes, and it would certainly result in more opportunities for accurate information to be shared in a robust and interactive way.

Partner with school systems and connect with local SEPAC and Special Education Directors, offer training, and attend collaborative events – all this would help.

—Survey respondent, Service Coordinator Survey

9. Insure that implementation of self-direction is consistent across regions and areas

Any statewide program will have some regional variation, based on history, culture, and resources. However, variations in what is, or is not, paid for; who is, or is not, encouraged to participate; and the scope of what providers do, and do not, provide should not exist.

Services and options here are different than in most of the state.

—Survey respondent, Participant Survey

I believe there are huge gains in the past few years, but I'm still amazed at the differences in people's awareness from region to region.

—Survey respondent, Service Coordinator Survey

Supporting regional and area experts in self-direction should support greater consistency across the state. Working with provider organizations/trade associations should also enable the kind of information sharing and best practice efforts that would result in greater consistency of implementation. More robust publication of stories and practices will encourage replication, which in turn will establish more concretely what is and isn't possible.

Concluding Thoughts

During the next year of the evaluation, HSRI will probe for issues arising from the infrastructure that DDS has put into place to support self-direction. Some infrastructure issues have already arisen during Year One of the evaluation which we will address in Year Two, including service coordinator/ broker caseload size, the availability of funding for self-direction at the regional and area office level, the development of standardized protocols for self-direction, reasons for regional differences in the uptake of self-direction, and the ways in which budgets are developed.

The chart below is a graphic representation of the project goals and tasks over the 3-year period of the evaluation.

Goal	Evaluation Approach	Y1	Y2	Y3	
Goal 1: Training	Examine Existing Training - Print materials - Observe trainings	X			
	Assess Reach - Demographic Analysis - Non-SD-User Survey	X			
	National Scan of SD Best Practices - Training - Systems and Infrastructure	X	X		
	Service Coordinator Survey (training, implementation and administration of SD)	X	X	X	
	Review Policy, Regulation, and Existing Data	X	X		
	Key Informant Interviews - DDS Staff - Potential and Current Mentors		X X		
	Focus Groups (Family, SD participants)		X		
	Goal 2: Systems & Infrastructure	SD Participant Satisfaction (satisfaction with training, access to information, outcomes) - Mail surveys to all SD participants - Face-to-face interviews - Compare NCI national and MA survey results	X	X X	X X
Goal 3: Satisfaction					

Appendices

Appendix A: Key Informant Interview Protocol

Key Informant Interviews Guide

Please use some or all of this guide – depending on the applicability of the questions – for interviews with DDS managers, service coordinators/service brokers, providers, and advocates

1. To what extent are service participants, their families, providers and other stakeholders aware of the self-direction option? What outreach activities are you familiar with? If you are familiar with the DDS self-direction training and outreach activities, what aspects of the trainings have been successful in encouraging enrollment, not successful?
2. Social media is one way that DDS can provide information on self-direction. In what ways has DDS used social media to promote self-determination? What is working? What can be improved?
3. With respect to the numbers of people enrolled in self-direction in MA, should the numbers be higher? About what you expected? Lower? What do think are the factors that contribute to an individual deciding for and against self-direction?
4. Are there individuals (age group, level of disability, etc.) who are more likely to be attracted to the self-direction option? More likely to adopt PDP? Agency with choice?
5. Does service coordinator/broker training provide an adequate orientation to SD? Person-centered planning? What's best about the training? How could the training be improved?
6. Are there people receiving traditional services who would/ might be interested in SD? What is the best way to introduce these individuals to self-direction? (e.g., IHP, self-advocate meetings, family trainings)
7. Are there specific reasons that might deter individuals from enrolling in self-direction? What are the constraints to the enrollment of people in self-direction? (e.g., inadequate number of service brokers, complexity of the process, level of funding, etc.).
8. What do you see as strengths and challenges to self-direction option?
9. Do you think that self-direction will become a significant component of the ID/DD system in MA? Is yes, why? If no, why?

10. Has the state budget allocation afforded sufficient resources to ensure continued growth of SD? If not, what areas need additional resources?

11. Are the numbers of service brokers keeping pace with the demand for self-directed supports?

12. Do you have any anecdotal information about the impact of self-direction on participants and families? services? Do you have any anecdotal stories? Either positive or negative.

Appendix B-F Survey Tools

Mail out surveys were developed based on the evaluation goals and research questions. Each survey was piloted tested with users either by taking the survey or participating in a focus group. Based on feedback from the pilot testing and focus groups, the team revised the survey questions and content to ensure that they were clear and used language that was understood by people who were receiving services and their families.

The questions for each survey are presented in the summary survey reports.

Survey sampling is as follows:

Survey	Sample
Real Lives Participant-Direction Program Survey	<p>All participants in the PDP program, including those who are participating in PDP only, PDP and AWC, PDP plus Traditional Services, PDP plus AWC plus Traditional Services.</p> <p>A total of 528 surveys were sent (123 valid surveys returned)</p>
Real Lives Agency with Choice Survey	<p>All participants in the AWC program, including those participating in AWC plus Traditional Services.</p> <p>A total of 355 surveys were sent (86 valid surveys returned)</p>
Real Lives Family Survey	<p>Individuals who have a family member identified as a contact (either guardian or in family demographics)</p> <p>A sample of 300 family members from all individuals age 18+ Self-Directing or AWC</p> <p>A sample of 300 family members from all individuals age 18+ receiving a DDS community service without any SD/AWC</p> <p>A total of 600 surveys were mailed (176 valid surveys returned)</p>
Real Lives Non-Participant Survey	<p>People who were not participating in any self-direction program (AWC or PDP). The surveys were mailed to support recipients, with a letter stating that people could have help to complete the survey.</p> <p>A total of 1450 surveys were sent (233 valid surveys were returned).</p>

Consent to participate and privacy in survey design and dissemination:

Prior to sending out the surveys, DDS sent a letter to the guardians of people who were under guardianship, informing them about the survey, and giving the guardians the option to request that the survey not be sent to the person for whom they are a guardian. Only a few guardians responded and DDS removed those individuals from the mailing labels of surveys. For the PDP program, the surveys were mailed by PPL, the fiscal intermediary. For all other surveys, the surveys were mailed by DDS. HSRI did not receive any individually identifiable information in either the mailing or returned addresses. Results from the paper survey were entered by HSRI staff and contractors into an online data collection tool (Survey Monkey). Summary reports were prepared for each survey, with highlights included in this final report. A preliminary analysis of age and region characteristics shows very similar compositions between survey participants and the overall DDS service recipients in all groups (PDP, AWC, or nonparticipants).

Real Lives Evaluation

Self-Direction Family Survey

You are receiving this confidential survey because you are a family member and/or guardian of an individual who is receiving services from the Massachusetts Department of Developmental Services (DDS). The purpose of the survey is to understand family attitudes about self-direction.

Self-direction allows families and individuals with intellectual and developmental disabilities to decide how to use some or all of the resources in their budgets. With self-direction, families and their family members can also choose the providers they want to hire and the agencies they want to work with. Self-direction is an approach to services that was described in the Real Lives Law that passed in 2014. For a copy of the legislation, go to: <https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>.

The survey results will be used as part of an evaluation of self-direction conducted by the Human Services Research Institute and funded by DDS. Thank you in advance for being part of this important study!

If you would prefer to complete this survey online, please go to:
<https://www.surveymonkey.com/r/RLFAMILY>

- 1. What is your zip code? _____**
- 2. Are you a**
 - Parent
 - Sibling
 - Spouse
 - Relative
 - Other (specify) _____
- 3. Are you the legal guardian for your family member?**
 - Yes
 - No
- 4. How old is your family member?**
(If you have more than one adult family member who receives services from DDS, please answer for the youngest family member)
 - 18 – 23
 - 24 – 40
 - 41 – 65
 - Over 65

5. **How long has your family member been receiving services from DDS (including services as a child and as an adult)?**
- 1 to 3 years
 - 4 to 6 years
 - 7 to 11 years
 - More than 12 years
6. **Does your family member have a diagnosis of an Autism Spectrum Disorder?**
- Yes
 - No
7. **Has your support broker/service coordinator informed you about the self-direction option?**
- Yes
 - No
8. **Have you participated in any meetings or training sessions sponsored by DDS regarding self-direction?**
- Yes
 - No
9. **Is your family member currently participating in one of the following self-directed options (definitions are provided in the footnote below)?¹**
- Person Directed Program
 - Agency with Choice
 - No, not participating in either
 - Yes, participating in both PDP and Agency with Choice

If they're *not* participating in self-direction, please answer Questions 10, 11, and 22.

If they *are* participating in self-direction, please skip to Question 12 to complete the survey.

¹ **Person Directed Program (PDP)**

The person or family self-directing is responsible for recruiting, hiring and managing their own staff, and determines how their DDS funding is spent for supports, goods and services (within DDS guidelines). Public Partnerships LLC (PPL) acts as the fiscal intermediary.

Agency-with-Choice

The Agency with Choice model allows individuals and families to choose and supervise their staff and to purchase goods and services through an agency. An agency manages regulatory, accounting, legal and technical duties associated with being an employer and purchaser.

10. If your family member is *not* participating in self-direction, why not? (check all that apply):

- Don't know about the option
- Educational session on self-direction didn't provide enough information for us to decide
- I didn't learn enough at the meetings I attended
- Written materials didn't give me enough information
- Too much paperwork (staff recruitment, etc.)
- Don't want to lose current providers if it doesn't work out
- Family member likes his/her current providers
- Don't know anyone who has tried it
- We tried it and it didn't work for us
- Not sure I can manage it
- Other (please specify) _____

11. What would help you feel more comfortable about participating in self-direction? (Check all that apply)

- More information about the benefits of participating
- Stories from families that are participating and opportunities to ask them questions
- Encouragement from our support broker/service coordinator
- Assistance from a currently participating family
- Increased interest by our family member
- Assurances that we could come back to current providers and services if it doesn't work out
- Assurances that the support broker will help me through the process
- Simplification of the process
- If I knew exactly how much funding I would receive
- Other (please specify):

If your family member *is* participating in self-direction, please answer the remaining questions

12. Why did you and your family member choose to participate? (Please check all that apply)

- Family member wanted to be more in charge of his/her choices
- We were dissatisfied with current provider(s) or provider choices
- Our support broker/service coordinator encouraged us to participate
- Another family recommended it
- We wanted more flexibility in our services
- We wanted to make our own choices about staff

- Other (please specify)

13. How or from whom did you hear about the self-direction option? (Please check all that apply)

- It was described in the eligibility letter we got from DDS
- At our annual ISP meeting
- Another family that is considering it
- Another family that is participating in it
- Our support broker/service coordinator
- Received brochure
- Transition coordinator
- Family support specialist
- Family support center training/information session
- From an advocacy organization sponsored event (e.g., the Arc, Self-advocacy group etc.)
- At a training given by DDS
- At a conference for families
- Other (please specify):

14. Once you decided to self-direct services, did you receive enough training and orientation to the process

- Yes
- No
- Not sure

15. Who provided the orientation and training? (check all that apply)

- DDS staff other than the support broker/service coordinator
- Support broker/service coordinator
- Other _____

16. What did you learn from the training? (check all that apply)

- Description of the self-direction option
- Who can participate
- Description of the fiscal role of Public Private Partnerships (PPL) if enrolled in PDP
- Responsibilities of the participant (e.g., hiring staff, etc.)
- Responsibilities of the support broker/service coordinator
- Responsibilities of the agency if participating in Agency with Choice

- Types of services and supports that can be included in the budget
- Provisions for backup
- Where to get more information if needed
- The family's role in making choices/monitoring, etc.

17. How much do you agree with each statement about your family member since he/she started using self-direction?

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
My family member is making more choices in their own life	<input type="radio"/>				
My family member is happier	<input type="radio"/>				
My family member's self-confidence has improved	<input type="radio"/>				
My family member has more friends	<input type="radio"/>				
My family member has a boyfriend or girlfriend	<input type="radio"/>				
My family member's health has improved	<input type="radio"/>				
My family member is learning new things	<input type="radio"/>				
My family member is more included in the community	<input type="radio"/>				
My family member has a job	<input type="radio"/>				
My family member is less lonely	<input type="radio"/>				
My family member is involved in more activities of his/her choosing	<input type="radio"/>				

18. How much do you agree with these statements about self-direction?

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
The fiscal intermediary does a lot of the bookkeeping for us	<input type="radio"/>				
Our support broker/service coordinator has been very supportive	<input type="radio"/>				
The services are much more individualized and flexible	<input type="radio"/>				
The process is very complicated	<input type="radio"/>				
It takes a lot of time	<input type="radio"/>				

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
It has been difficult to recruit staff	<input type="radio"/>				
The resources available are not sufficient	<input type="radio"/>				
We didn't have enough information at the beginning	<input type="radio"/>				
There has been confusion about roles and responsibilities	<input type="radio"/>				
We've found it hard to get answers to our questions	<input type="radio"/>				
There have been problems with the fiscal intermediary	<input type="radio"/>				

19. Has participation in self-direction made you and your family feel more positive about the future for your family member?

- Very much
- Somewhat
- Not really
- Not sure

20. If self-direction has not been positive for you and your family member, what would improve the experience? (Please describe):

21. How do you think the process could be improved for other families? (check all that apply)

- More contact with other families who have had experience
- Materials that spell out the process step by step
- More help from support broker/service coordinator
- Quicker response to my questions
- Streamlined process that reduces the paperwork
- More support to get answers to questions
- Support groups of individuals who are self-directing
- Support groups of families of individuals who are self-directing
- Other, please specify:

22. Anything else you would like to say about self-direction?

Thank you so much for participating!!



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Real Lives Evaluation

Self-Direction Participant Survey

(for Individuals Enrolled in the Participant-Direction Program)

You are receiving this confidential survey because you get services funded by the Massachusetts Department of Developmental Services (DDS) and you are enrolled in the Participant Directed Program (PDP). The purpose of the survey is to find out about your experience with **self-direction**.

Self-direction as part of the PDP, allows people to decide how to use some or all of the money in their DDS budgets. People can also choose the support providers they want and the agencies they want to work with. Participants in the PDP also use Public Partnerships (PPL) to pay their support workers and handle the paperwork. Self-direction was part of a recent state law called the Real Lives law. For a copy of the legislation, go to:

<https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>

Your answers will be used as part of an evaluation of self-direction conducted by the Human Services Research Institute and funded by DDS. Thank you for answering these questions!

If you would prefer to complete this survey online, please go to:

<https://www.surveymonkey.com/r/MAPDP>

1. What is your zip code? _____

2. How old are you?

- 18 – 23
- 24 – 40
- 41 – 65
- Over 65

3. Where do you live?

- With my family
- In my own home or apartment
- In a group home with other self-advocates
- With a foster family or in shared living
- Other _____

4. How long have you made choices about your services and staff that help you?

(Self-directing as part of the Participant Directed Program)

- Just started (less than a year)
- A little while (1 to 3 years) just started
- A long time (4 to 6 years)
- A very long time (More than 6 years)
- Not sure

5. How did you find out about self-direction/making choices for your own supports? You can check more than one.

- Staff person from DDS
- Staff person from my agency
- A friend
- Meeting at my school
- At my ISP (service planning) meeting
- A family member
- At a self-advocacy meeting or conference
- Other _____

6. Tell us about the information you got about self-direction/making your own choices for your services and supports.

- I got all the information I needed when I was starting
- I got some information, but could have used more
- I still have questions that I need answered

6a. If you need more information do you know who to ask?

- Yes
- No

N/A I have all the information I need

7. Do the people you hired do what you ask them to do? (For example, do the people you hire come on time? When you need help, do your staff help you the way you want them to?)

- Yes
- No
- Not sure

8. Now that you're self-directing/making choices about your services and staff, what's better in your life? You can check more than one.

- I am making more choices in my life
- I hire my own staff
- I can go shopping when I want to
- I can help myself more when I'm alone
- I'm more independent
- I belong to some clubs in my community
- I have a job
- I have a girlfriend or a boyfriend
- I have more friends
- I feel better about myself
- My health is better
- I am learning new things
- Nothing has changed in my life
- Other _____

9. Are there things in your life that haven't changed or that you still want? Please explain. _____

10. Have you had any problems since you've been self-directing/making choices about your own support?

- No, everything is going well
- Yes, I've had problems but someone helped me with them
- Yes, I have had problems that no one has helped me with

11. If you have had problems, what are they? You can check more than one.

- It's hard to find and keep good staff
- The process is complicated
- It takes a long time to make a change in my services
- I'm having problems with the agency I'm working with
- I still have questions about the process
- It is hard being the boss
- Other _____

12. Do you think you will continue to self-direct/make your own choices about your services and staff in the future?

- Yes
- No
- Not sure

13. Would you recommend or encourage others to self-direct the way you do?

- Yes
- No
- Not sure

The next questions ask about what it's like to work with your DDS support staff (Support Broker).

14. Do you know who your DDS Support staff (Support Broker/Service Coordinator) is?

- Yes
- No (If no, skip questions 16-18)

15. Is it easy to get in contact with your DDS support staff (Support Broker) when you need to?

- Yes
- No

16. Which statement is true about the help you get from your DDS support staff (Support Broker) about self-direction? (Choose One)

- I get all the help I need from my DDS support staff (Support Broker)
- I get some help
- I could use more help

- Not sure
- If you answered yes, what additional help could you use?

Comment: _____

17. Overall, have you had a good experience working with your DDS support staff (Support Broker)?

- Yes
- No

The next questions ask about what it's like to work with **Public Partnerships (PPL)**. – These are the people who handle the money part.

18. Does PPL process your employee's timesheets correctly and on time?

- Always
- Very Often
- Sometimes
- Not very often
- I don't know

19. Does PPL pay your employees accurately and on time?

- Always
- Very Often
- Sometimes
- Not very often
- I don't know

20. If your employee's timesheet is denied, delayed or pending payment, does PPL tell you right away?

- Always
- Very Often
- Sometimes
- Not very often
- I do not talk to PPL – the support worker I hired does this

21. Do you feel comfortable calling PPL if you have a complaint or concern about their services?

- Always
- Very Often

- Sometimes
- Not very often
- I do not talk to PPL – the support worker I hired does this

22. Do PPL staff respond to your questions and concerns in a timely and professional manner?

- Always
- Very Often
- Sometimes
- Not very often
- I do not talk to PPL – the support worker I hired does this

23. Do you find PPL's instructions for completing enrollment paperwork helpful?

- Always
- Very Often
- Sometimes
- Not very often
- The support worker I hired deals with this

24. Is the information you receive from PPL staff helpful and correct?

- Always
- Very Often
- Sometimes
- Not very often
- I don't know – the support worker I hired does this

25. Did anyone help you to answer these questions?

- Yes, my family
- Yes, my DDS Support worker
- Yes, the support worker I hired
- Yes, someone else
- No, no one helped me
- Other: _____

Is there anything else you would like to tell us?

Thank you for your help!!



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Real Lives Evaluation

Self-Direction Participant Survey (for Individuals Enrolled in Agency with Choice)

You are receiving this confidential survey because you get services funded by the Massachusetts Department of Developmental Services (DDS) and you are enrolled in the Agency with Choice program. The purpose of the survey is to find out about your experience with **self-direction**.

Self-direction through **Agency with Choice** allows individuals to supervise staff and buy goods with the help of an agency, and without the paperwork. Self-direction was part of a recent state law called the Real Lives Law. For a copy of the legislation, go to:

<https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>

Your answers will be used as part of an evaluation of self-direction conducted by the Human Services Research Institute and funded by DDS. Thank you for answering these questions!

If you would prefer to complete this survey online, please go to:

<https://www.surveymonkey.com/r/RLAWC>

1. What is your zip code? _____

2. How old are you?

- 18 – 23
- 24 – 40
- 41 – 65
- Over 65

3. Where do you live?

- With my family
- In my own home or apartment
- In a group home with other self-advocates
- With a foster family or in shared living
- Other _____

- 4. How long have you made choices about your services and staff that help you?**
- Just started (less than a year)
 - A little while (1 to 3 years)
 - A long time (4 to 6 years)
 - A very long time (More than 6 years)
 - Not sure
- 5. How did you find out about self-direction/making choices for your own supports? You can check more than one.**
- Staff person from DDS
 - Staff person from my agency
 - A friend
 - Meeting at my school
 - At my ISP (service planning) meeting
 - A family member
 - At a self-advocacy meeting or conference
 - Other _____
- 6. Tell us about the information you got about self-direction/making your own choices for your services and supports.**
- I got all the information I needed when I was starting
 - I got some information, but could have used more
 - I still have questions that I need answered
- 6a. If you need more information do you know who to ask?**
- Yes
 - No
 - N/A I have all the information I need
- 7. Do the people you hired do what you ask them to do? (For example, do the people you hire come on time? When you need help, do your staff help you the way you want them to?)**
- Yes
 - No
 - Not sure

8. Now that you're self-directing/making choices about your services and staff, what's better in your life? You can check more than one.

- I am making more choices in my life
- I hired my own staff
- I belong to some clubs in my community
- I have a job
- I have a girlfriend or a boyfriend
- I have more friends
- I feel better about myself
- My health is better
- I am learning new things
- Other _____

9. Are there things in your life that haven't changed or that you still want? Please explain. _____

10. Have you had any problems since you've been self-directing/making choices about your own support?

- No, everything is going well
- Yes, I've had problems but someone helped me with them
- Yes, I have had problems that no one has helped me with

11. If you have had problems, what are they? You can check more than one.

- Hard to find and keep good staff
- The process is complicated
- It takes a long time to make a change in my services
- I'm having problems with the agency I'm working with
- I still have questions about the process
- It is hard being the boss
- Other _____

12. Do you think you will continue to self-direct/make your own choices about your services and staff in the future?

- Yes
- No

- Not sure

13. Would you recommend or encourage others to self-direct the way you do?

- Yes
- No
- Not sure

The next questions ask about what it's like to work with your support broker.

14. Do you know who your DDS Support Broker/Service Coordinator is?

- Yes
- No
- If no, skip questions 15-17

15. Is it easy to get in contact with your Support Broker when you need to?

- Yes
- No

16. Which statement is true about the help you get from your Support Broker about self-direction? (Choose One)

- I get all the help I need from my Support Broker
- I get some help
- I could use more help
- Not sure

16a. If you answered yes, what additional help could you use?

Comment: _____

17. Overall, have you had a good experience working with your DDS Support Broker?

- Yes
- No

18. Did anyone help you to answer these questions?

- Yes, my family
- Yes, my DDS Support worker
- Yes, the support worker I hired
- Yes, someone else
- No, no one helped me
- Other: _____

Is there anything else you would like to tell us?

Thank you for your help!!



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Real Lives Evaluation

Survey from Massachusetts DDS regarding Self-Direction

You are receiving this confidential survey because you get services from the Massachusetts Department of Developmental Services (DDS). The purpose of the survey is to understand your thoughts about **self-direction**, a service delivery opportunity available to people receiving DDS services.

Self-direction allows people to have more control over the supports they receive from DDS. They can decide how to use some or all of the money in their budgets, choose the providers they want and the agencies they want to work with. Self-direction was part of a recent state law called the Real Lives bill. For a copy of the legislation, go to:

<https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>

Your answers will be used as part of an evaluation of self-direction conducted by Human Services Research Institute and funded by DDS. Thank you for answering these questions!

If you would prefer to complete this survey online, please go to:

<https://www.surveymonkey.com/r/RLNON>

This survey is for people who receive services from DDS. You can have a friend or family member help you answer the questions.

1. What is your zip code? _____

2. How old are you?

18 – 23

24 – 40

41 – 65

Over 65

3. Where do you live?

- With my family
- In my own home or apartment
- In a group home with other self-advocates
- With a foster family or in shared living
- Other _____

4. How long have you been receiving services from DDS?

- Just started (less than a year)
- A little while (1 to 3 years) just started
- A long time (4 to 6 years)
- A very long time (More than 6 years)
- Not sure

5. Has anyone told you that you could hire your own staff and make more choices about your services?

- Yes
- No
- Don't know

6. Have you gone to any meetings or classes to learn about hiring your own staff and making more choices about your services?

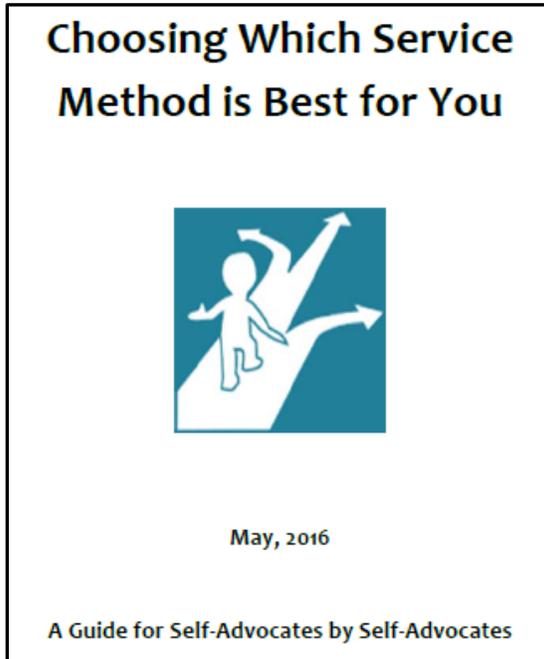
- Yes
- No
- Don't know

7. In your invitation from your DDS Service Coordinator to the Individual Support Plan (ISP) meeting, there is information about the "Self-Direction service delivery option for people receiving DDS services." Do you remember hearing about "self-direction" at your ISP meeting?

- Yes
- No

Don't know

8. Your invitation to your Individual Support Plan (ISP) meeting included a brochure titled "Choosing Which Service Method is Best for You" to provide more information about Self-Direction. The cover looked like this:



8a. Do you remember getting this brochure?

Yes

No

Don't know

9. Has your DDS Worker/service coordinator talked to you about hiring your own staff and making more choices about your services?

Yes

No

Maybe

Don't know

10. Have you tried to hire your own staff and manage your services?

Yes

No

Don't know

ONLY ANSWER THE NEXT TWO QUESTIONS IF YOU SAID YES TO QUESTION 10

11. If yes, what program were you in?

Person Directed Program

- Agency with Choice
- Don't know

12.. Why did you stop? You can check more than one.

- Too much paperwork
- Hiring staff was too hard
- Not enough help
- Liked traditional services better
- My family didn't like it
- I didn't have enough services
- Not enough choices

Other, please explain:

13. Would you like to learn more about hiring your own staff making more choices about your services?

- Yes
- No
- Don't know

14. If you answered no, why aren't you interested? You can check more than one.

- I don't know what it is
- I'm happy with the services I have
- I don't know who to ask about it
- My family isn't interested
- It's too hard to be in charge
- I'm afraid that things will not be as good as they are now

- Are there any other reasons why you're not interested in self-direction?

15. What might make you more interested in hiring your own staff and being in charge of your own services and money? You can check more than one.

- If I got more information about it
- If my friends did it
- If I knew that my choices would be followed
- If I trusted my staff from DDS/my agency
- If my family wanted me to do it
- If I knew I would have help when I needed it
- If I knew more about what choices I might have to make
- If I could talk to people who are already doing it
- If I knew I could go back to what I have now if I didn't like it
- Any other things that might help you decide? _____
- I'm not interested

16. How happy are you with the services you have now?

- Very happy
- Pretty happy
- Not very happy
- Unhappy

17. Is there a chance that you might try being in charge of your own services in the next few years (hiring your own staff, for instance)?

- Yes
- No

Maybe

18. Did anyone help you answer these questions?

Yes, my family

Yes, my DDS worker/ service broker/ service coordinator

Yes, my staff person

Yes, someone else

No, no one helped me

Is there anything else you would like to tell us?

Thank You!!



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Real Lives Evaluation

Service Coordinator/ Service Broker Survey

The Human Services Research Institute is currently conducting a 3-year evaluation of the Real Lives legislation that passed in 2014. For a copy of the legislation go to:

<https://malegislature.gov/Laws/SessionLaws/Acts/2014/Chapter255>.

During this first year of the evaluation we are particularly interested in assessing the various outreach strategies that the Department of Developmental Services (DDS) has employed to inform individuals and families about the option to self-direct and what self-directing entails. We are also interested in any constraints to self-direction and your suggestions about what improvements could be made to expand interest in self-direction.

We are hoping that you can complete this survey by _____, 2017. This is an anonymous survey but if you are interested contacting us directly or if you have questions, you can email us at vbradley@hsri.org.

As a service coordinator and/or service broker, you play a critical role in the DDS system. Your opinions are very important. Thank you in advance for being part of this important study!

1. What region do you work in?

- Metro
- Northeast
- Southwest
- Central West

2. Describe your function (check all that apply)

- Service coordinator
- Service broker
- Supervisor
- Other

3. What is your caseload (provide numbers for each category if appropriate)

- Caseload of people who are not self-directing
- Caseload of individuals in the Person Directed Program
- People enrolled in Agency with Choice

4. How do you introduce self-direction to potential participants and families (check all that apply)?

- I discuss the self-direction option at ISP meetings
 - I discuss the self-direction when I take part in IEP meetings
 - I discuss the self-direction option when individuals enroll in services
 - I hand out a brochure about self-direction
 - I let prospective participants/families know about orientation sessions that are going on in my area
 - I suggest to family members that they talk to other families who are self-directing
 - I suggest to individuals that they talk to other self-advocates who are self-directing
 - Other _____
-
-

5. Have there been outreach/educational sessions about self-direction in your area/region for potential participants in the Person Directed Program (PDP) or Agency with Choice (AWC)?

- Yes
- No

6. If you answered yes to question #5 above, and you attended, what information did the session(s) cover? (check all that apply)

- Who can participate?
 - How to enroll
 - Description of the fiscal role of Public Private Partnerships Limited (PPL) if enrolled in PDP
 - Responsibilities of the participant (e.g., hiring staff, etc.)
 - Responsibilities of the family members
 - Responsibilities of the service coordinator
 - Responsibilities of the agency if participating in Agency with Choice
 - Types of services and supports that can be included in the budget
 - Provisions for backup
 - Where to get more information if needed
 - The family's role in making choices/monitoring, etc.
 - How the budget is determined
 - How to recruit workers
 - A step by step checklist of the process
 - Other _____
-
-

7. How much do you agree with each statement regarding steps that could be taken to increase the number of individuals who opt to self-direct?

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
Simplify the process	<input type="radio"/>				
Conduct more outreach/educational sessions	<input type="radio"/>				
Encourage more communication among service coordinators/brokers about best practices and to share information	<input type="radio"/>				
Reduce caseloads	<input type="radio"/>				
Use people who are self-directing and family members as mentors	<input type="radio"/>				
Provide more training to service coordinators/service brokers	<input type="radio"/>				
Simplify service codes	<input type="radio"/>				
Provide more opportunities for participants and families to share information and problem solve	<input type="radio"/>				

8. Do you have any other suggestions regarding how to expand self-direction in Massachusetts?

If you have any individuals on your caseload who are self-directing, please answer questions 9 through 12 in reference to those individuals.

9. How much do you agree with each statement about the impact of self-direction?

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
People are more empowered and make their own choices	<input type="radio"/>				
People are more included in their communities than before self-direction	<input type="radio"/>				
People have more friends than they did before self-direction	<input type="radio"/>				

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
People are learning new things	<input type="radio"/>				
People have boyfriends/girl friends	<input type="radio"/>				
People have a job	<input type="radio"/>				
People are happier than they were before self-direction	<input type="radio"/>				
People have more opportunities to participate in activities	<input type="radio"/>				
People are less lonely	<input type="radio"/>				

10. Are there other benefits that you see to self-direction?

11. How much do you agree with each statement regarding the process of self-direction?

	Completely Disagree	Somewhat Disagree	Disagree	Somewhat Agree	Completely Agree
The self-direction process is complicated to implement	<input type="radio"/>				
I have all of the information that I need to support people who are self-directing	<input type="radio"/>				
It is hard to know what services can be self-directed and which cannot	<input type="radio"/>				
Supporting people who are self-directing takes about the same amount of time as for someone on a regular caseload	<input type="radio"/>				
The fiscal intermediary, PPL, is efficient and responsive	<input type="radio"/>				
Self-direction is good for only a select number of participants	<input type="radio"/>				

12. Are particular individuals more attracted to self-direction? (answer all that apply)

People on the autism spectrum ___Yes ___No

Young people making the transition from school to adult services ___Yes ___No

People who are unhappy with traditional services ___Yes ___No

People who have involved and capable families ____ Yes ____ No

____ There are no differences

____ Don't know

____ Other _____

13. Is there anything else you would like to add?

Thank you so much for participating in this survey – your feedback will help to improve self-direction for people who are self-directing or are considering self-direction and their families in Massachusetts!

Real Lives Evaluation

Questions for State SD Staff Re: Best Practices

1. Please provide some history for self-direction in your state (time line, political forces, etc.) Who were the major advocates? Was there organized resistance? If so, from where?
2. How many people are self-directing in your state? What percentage is that of the eligible population? How many have budget authority, employer authority; agency with choice?
3. How do you make individuals and family members aware of the self-direction option? (presentations, brochures, IHP Meeting, etc.)
4. What have you found to be the most successful outreach strategies to educating people about self-direction? Can you give us two examples? What role do families and self-advocates play in outreach and/or helping individuals get comfortable with early experiences?
5. Please describe the fiscal intermediary/fiscal intermediaries. What tasks does this organization perform? How do they interface with support brokers? With assessors? With state staff?
6. What services and supports do people typically direct? PROBE: Are any like MA where people can phase in or self-direct portions of services?
7. Who provides services brokerage? Do participants have a choice of support brokers? Can individuals use their budgets to hire service brokers? Or to purchase additional hours of support? What kind of training do service brokers receive? Can we have a copy of any training materials? Which training approaches have been the most successful? Is there ongoing training or support? Is there special training for supervisors? What is the typical caseload size for service brokers?

8. What kinds of service participants are most likely to self-direct? (e.g., people unhappy with their services? Younger individuals?). Where do they typically live?
9. Do you know what the average budget is for individuals who self-direct? Typical range? How is the budget set for each individual?
10. What are some of the constraints to self-direction (e.g., recruiting staff, complexity, budget committed to traditional providers, etc.)?
11. Do you expect the numbers of individuals who self-direct will grow in the next several years? If so, why? If not, why?
12. What kinds of quality assurance mechanisms do you have in place for self-direction (e.g., consumer surveys, staff training protocols, individuals reviews?)
13. What kind of training do individuals and families receive regarding the process of self-direction?
14. Do you use peer mentors or families as trainers?
15. Are there any co-ops or micro boards to manage staff?

Appendix I: Review of Real Lives presence on the Web

Exploration of 'Real Lives' and 'Self Determination' on publicly available Websites



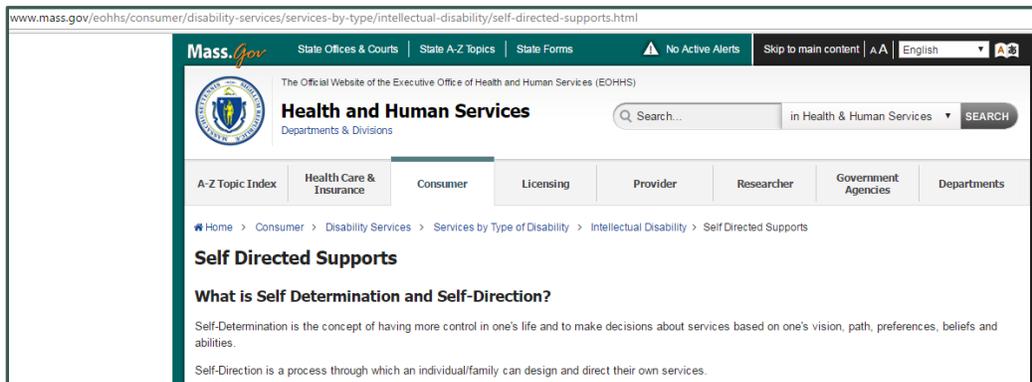
May 2017

As part of HSRI's evaluation of Real Lives information dissemination, HSRI reviewed relevant publicly available web sources that describe information pertinent to people who are self-directing and their families. We limited our review to those websites that are Massachusetts-specific. This report includes a summary of five websites that have information about the Real Lives Law and Self Determination in Massachusetts, links, and a summary of the content that is included.

HHS Self Directed Supports Page

<http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/self-directed-supports.html>

From the DDS home page, under 'Special Initiatives', click 'Self Directed Supports'



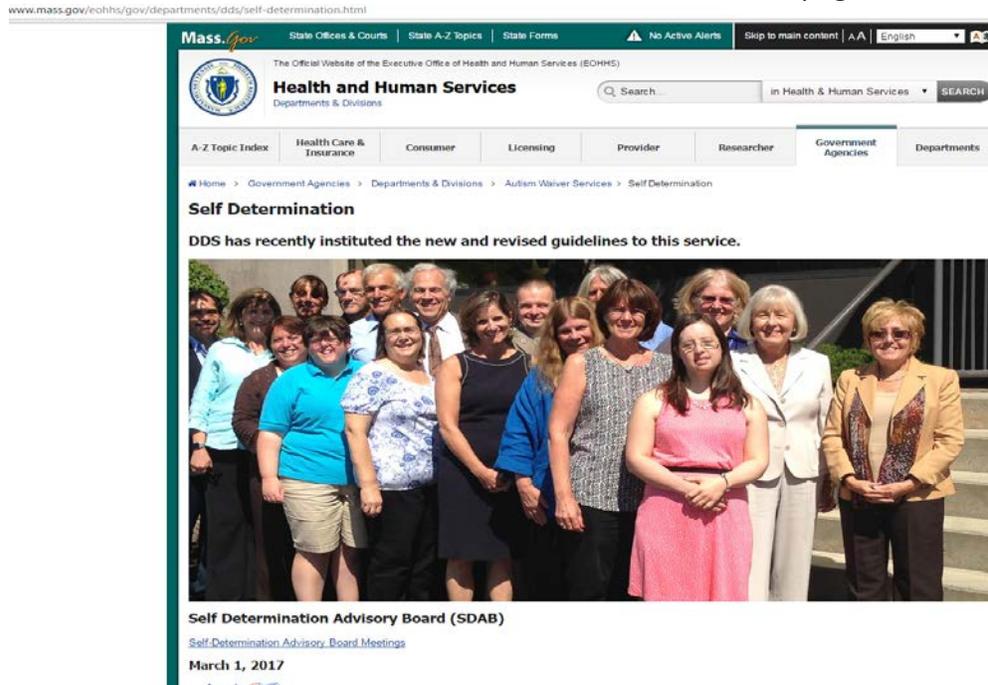
This includes

- Definition of Self Determination and link to the *Overview of Self Direction and DDS Service Models Training Module*
- Participant Profiles (under development)
- Regional Self Directed Support Managers (photograph with link to *contact information*)
- Link to the Self Directed Supports Training and Support Activity Calendar
- Link to Area Office Locator

Self Determination Advisory Board (SDAB)

<http://www.mass.gov/eohhs/gov/departments/dds/self-determination.html>

This can be accessed using a browser search for 'DDS Real Lives Advisory Board' or 'DDS Self Determination'. It does not seem accessible from the DDS Home page.



This page includes links to all materials that have been distributed at SD Advisory Board meetings. The links include numerous terrific resources, but they require scrolling through and reading all links to figure out what is most relevant as the resources are combined with project and status updates.

Examples of helpful resources that reference Self Direction:

- Important Transition Information Every Family should know (2015)
<http://www.mass.gov/eohhs/consumer/disability-services/services-by-type/intellectual-disability/newsroom/may2015-transition-sheets.pdf>
- A Guide to Self-Direction
<http://www.mass.gov/eohhs/docs/dmr/board-meetings/sdab-sd-guide-may2016.pdf>
- Choosing Which Service Is Best For You (Self Advocates Brochure)
<http://www.mass.gov/eohhs/docs/dmr/board-meetings/sdab-sa-brochure-may2016.pdf>
- Self-Directed Supports Allocation Methodology
<http://www.mass.gov/eohhs/docs/dmr/board-meetings/sdab-methodology-draft-nov2016.pdf>

Real Lives Massachusetts Program Locator Website

www.massreallives.org

This is not easily retrievable through a web search for 'MA Real Lives Program Locator'

The screenshot shows the homepage of the Real Lives Massachusetts website. At the top, there is a navigation bar with the site's logo, contact information (info@massreallives.org and 800-642-0249), and the tagline 'Empowering People with Intellectual and Developmental Disabilities'. Below this is a secondary navigation menu with links for 'Home', 'Help us make this website better!', and 'Definitions of program types'. The main content area features a search form titled 'Find a Program Near You:' with input fields for 'Town/City' and 'Distance' (currently set to 5 miles), and a 'Search' button. To the right of the search form is a photograph of a man with glasses sitting at a desk and working on a laptop. At the bottom of the page, there is a dark blue footer with three white text boxes: 'What are the Real Lives Agencies?' with a link to 'see a complete list of agencies and their programs.', 'What is MassRealLives.org?' with the text 'This website helps you find a program. You can decide which program is best for you.', and 'What is the Real Lives Law?' with the text 'The Real Lives Law helps people with IDD decide how they want to live. Learn more about'.

- Searchable database of providers allows for searching by distance from a particular town.
- Provider listings include contact information and the types of services provided
- Providers are grouped by types of services such as 'Employment Services', 'Job Placement'. There is a listing of 32 Service categories; however, these do not seem to align with groupings of providers that result from a search.
- By clicking on 'See complete list of agencies and their programs', we can see the providers listed as well as a link to the DDS webpage with links to Licensure Reports.

PCG Public Partnerships MA DDS Website

<http://www.publicpartnerships.com/programs/massachusetts/PDP/index.html>

The screenshot shows the website's interface for the Participant-direction Program. At the top, there is a navigation bar with 'Home | Contact | Search' and 'BetterOnline™ Web Portal: Sign Up | Login'. Below this is a teal header with 'PCG PUBLIC PARTNERSHIPS' and a menu for 'SERVICES PROGRAMS ABOUT'. A breadcrumb trail reads 'Home / Programs by State / Massachusetts / Participant-direction Program, Massachusetts Department of Developmental'. The main heading is 'Participant-direction Program, Massachusetts Department of Developmental'. Two tabs are visible: 'Overview' (selected) and 'Program Documents'. The 'Overview' section includes: 'Who We Serve' (Adults with development disabilities and their families), 'Services' (Employer of Record, Employment tax requirements, Spending reports, Enrollment support, Payroll, Monthly Budget Management, Customer service), and 'Participants can:' (Develop a budget, Select services, Work with their Support Broker, Recruit, hire, and manage service workers, Monitor their spending, Submit timesheets online). On the right, there is a 'BetterOnline™ Web Portal Login' section with a 'Login' button and a 'Contact Your Customer Service Team' section with the phone number 1-888-866-0869. At the bottom right, there is a 'News & Announcements' section with a link to 'USCIS Form I-9 Changes'.

- This website provides reference material and the needed forms for people participating in the Participant-direction Program (PDP).
- The 'Program Documents' Tab includes links to a great many resources, including a 13-page Frequently Asked Question document.
<http://www.publicpartnerships.com/programs/massachusetts/PDP/documents/Frequently%20Asked%20Questions.pdf>

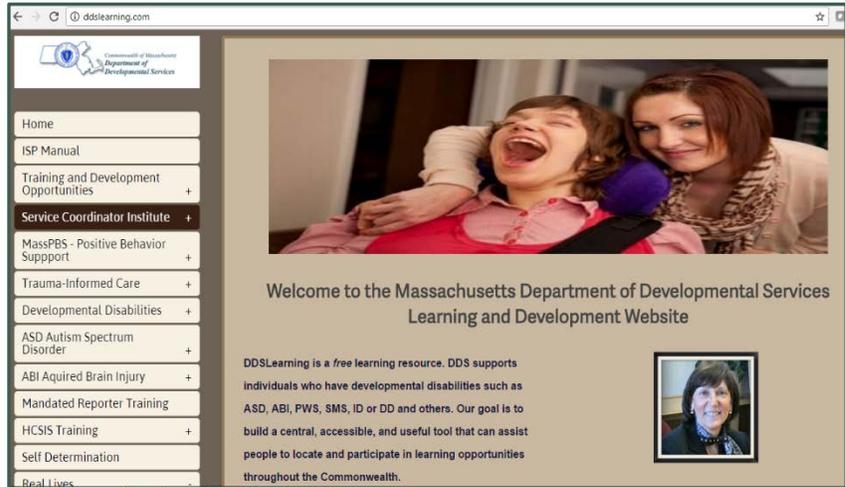
DDS Learning Website

<http://ddslearning.com/>

The 'Self Determination' Tab www.ddslearning.com/self-determination/ includes a link to a good

overview of DDS service models:

<http://ddslearning.com/s/PACEupdated-May-2017.pptx>



The **Real Lives (+)** tab can be extended to reveal a drop-down list of additional pages.

Real Lives (-)

Person-Centered Practices

Real Lives Bill www.ddslearning.com/real-lives-bill/ includes a link to the 'Real Lives Bill', and video clips from the signing of the Real Lives Bill

Friendships

Hiring your own Staff <http://ddslearning.com/find/> includes a link to a toolkit produced by the University of Minnesota called 'Find, Choose, and Keep Great DSPs'
<https://static1.squarespace.com/static/518bb7cde4b0d1e7bd9c37b5/t/563cf3eae4b00c9a5ef6ce4f/1446835178349/ToolkitforPeoplewithDisabilities.pdf>

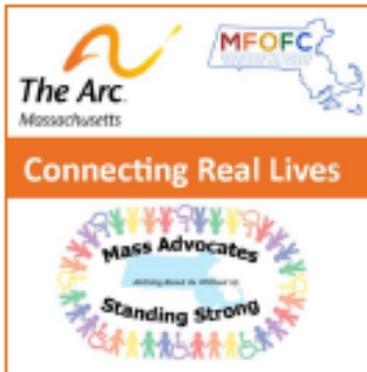
Transition

Sexuality

Considerations

This brief summary shows the multiple websites that include valuable information related to the implementation of the Real Lives Law and to Self-Direction for people who receive services from MA DDS. These are not easy to find, and are not centrally located or easy to access. Cross-linking to the multiple sites may increase the availability of resources; however, DDS should consider creating a short list of the best and most relevant materials—including training guides, links to PPL, and the resource locator website—and making those available in one place.

Connecting Real Lives Facebook Community



Connecting Real Lives is a Facebook community about self-directing services in Massachusetts.

We learn from each other by sharing news, personal stories, and training information.

We share success stories to encourage others to try self-direction.

We also share problems to help one another and to improve self-direction in Massachusetts.

Follow us! Share your self-directing experiences!



<https://www.facebook.com/ConnectingRealLives/>

What is self-direction? People with intellectual and developmental disabilities, including autism, design and direct their own services. There are 2 self-direction options through the Massachusetts Department of Developmental Services -- Agency With Choice (AWC) and Participant Directed Program (PDP). Find out if one of these works for you. Using self-direction, people are more likely to live full and productive lives in their communities.

Connecting Real Lives Facebook community is an initiative of the Massachusetts Alliance for 21st Century Disability Policy (MA21) coalition. MA21's mission is to advance full community participation for individuals with disabilities. MA21 is a partnership of leaders in the Commonwealth's disability advocacy arena including: The Arc of Massachusetts, Mass. Families Organizing for Change, Advocates for Autism of Massachusetts, Mass. Advocates Standing Strong, Massachusetts Developmental Disabilities Council, Disability Law Center, Federation for Children with Special Needs, Massachusetts Down Syndrome Congress and Massachusetts Sibling Support Network. For more information about MA21: <http://thearcofmass.org/self-determination-and-self-direction/>

The Arc of Massachusetts | 217 South Street, Waltham, MA 02453 | arcmass.org | 781-891-6270