



Year Two Report

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

October 16, 2018

Valerie J. Bradley
Alexandra Bonardi
Lee Vorderer
Cheryl Sartori
Bevin Croft
Henan Li
Kevin J. Mahoney, Consultant

Human Services Research Institute
www.hsri.org

Acknowledgments

This evaluation would not have been possible without the expertise and contributions of many people involved in self-direction in Massachusetts, including program participants, families, advocates, regional and area managers, central office staff, members of the Real Lives Advisory Committee, service coordinators, self-direction coordinators, and other key individuals in the state. We would also like to thank the staff in the Department of Developmental Services central office who provided documents, data, and assistance with the distribution of multiple mailings.

The Massachusetts Department of Developmental Services funded this research. However, any views expressed in the report are those of the research team alone.



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.

Contents

- Executive Summary 1**
- 1. Introduction 4**
- 2. Methodology 6**
 - Review of DDS Data on Self-Direction 6
 - Development of Mail and Online Surveys 6
 - Key Informant Interviews..... 7
 - Focus Groups With Families and People Self-Directing 7
 - Review of Best Practices 8
- 3. Characteristics of Participants: Statewide and By Region..... 9**
 - Characteristics of People Who Self-Direct 9
 - Regional Differences in Self-Direction Enrollment 10
- 4. Service Coordination and Support Brokerage 13**
 - Survey Respondents..... 13
 - Understanding of Self-Direction 13
 - Helping Families and Individuals Learn About Self-Direction 14
 - The Process of Self-Direction 14
 - Suggestions for Improvement..... 15
- 5. Service Plan and Budget 17**
 - Individual Assessments and Budget Development..... 17
 - Participant Understanding of the Budget..... 18
 - Budget Amounts 19
 - Adequacy of Funds..... 19
- 6. Services and Supports 20**
- 7. Person Directed Program 23**
 - Participant Perceptions..... 23
 - Strengths and Weaknesses of the Model 24
 - Prospects for Expansion..... 25

Ways to Improve the Model	26
8. Agency with Choice	27
Provider Point of View/Experience	27
Availability of Providers	28
Participant Perspectives.....	29
Strengths and Weaknesses of the Model	29
Prospects for Expansion.....	30
9. Fiscal management service.....	32
10. Stakeholder Oversight.....	33
11. Lessons From Other States	34
12. Recommendations	36
Support Brokers	36
Dedicated Funding	39
Knowledge of the Budget	39
Budget Preparation.....	40
Regional Variations in Numbers of Participants Enrolled in Self-Direction	40
Information About Self-Direction	40
Agency With Choice	41
Emphasize Self-Direction as a Statewide Priority	42
Ongoing Monitoring.....	42
Participant Advisory Group.....	43
Public Private Partnership.....	43
Appendix A: Sampling Design and Dissemination.....	44
Appendix B: Key Informant Interview Guide	45
Appendix C: Interviews with Agency with Choice Providers.....	46
Appendix D: Interview Guide for Best Practice States.....	51
Appendix E: Service Coordinator Survey Report	54
Appendix F: Participant Directed Program Participant Survey Report	85
Appendix G: Agency with Choice Participant Survey Report	110

Appendix H: Service Use Categories and Groupings Used in the Service Category Analysis137

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. The second year, detailed in this report, focused on the infrastructure to support self-direction.

DDS Accomplishments Since Year One Report

- DDS has worked to expand outreach and encourage peers and family members to share their experiences.
- DDS is building mentoring relationships and structures to for support brokers and service coordinators regarding self-direction
- DDS is improving materials for participants and service coordinators including the development of manuals and guides
- DDS has taken steps to improve outreach using social media and a web-based presence by hiring staff to produce two videos per region and a fraud/ abuse video.
- DDS is introducing self-direction to participants and families prior to transition in a variety of settings

Year 2 Methodology

The evaluation findings in the Year 2 report are based on the following data collection activities:

- Survey of Participant Directed Program participants
- Survey of Agency with Choice participants
- Survey of service coordinators
- Key informant interviews with DDS Central Office Leadership
- Key informant interviews with Agency with Choice providers
- Focus groups with participants in self-direction and families
- Review of best practices in self-direction in six states
- Analysis of statewide aggregate data on self-direction

Key Findings

Some key findings include:

- Individuals participating in the Person Directed Program and Area with Choice expressed satisfaction with their increased control over their lives, their ability to engage in activities that they choose, and an increased sense of empowerment
- Those who support individuals who are self-directing – including support brokers/service coordinators, AwC providers, and individual staff report their positive feelings about their work as well as the improvement in the lives of the individuals they are serving.

However:

- There is a need for additional resources to provide support brokerage if self-direction is to expand significantly in the state.
- There is no dedicated funding for self-direction and support that is available comes out unused or existing funds from preexisting provider contracts and the Turning 22 program.
- Many individuals and families reported a lack of familiarity with their budget amounts both before the development of the plan and over time.
- Everyone who receives services and supports is given a functional assessment; however, there is no standard parameter that links functional levels with individual budget amounts.
- There are significant regional variations in enrollment in the PDP and the Agency With Choice program.
- Though there has been real progress in the development of descriptive and educational material regarding the benefits and mechanics of self-direction, knowledge of self-direction is still not consistent across the state.
- The Agency With Choice program is a promising approach to self-direction but has been very slow to expand.
- Self-direction is still a very small part of the overall DDS service system even though there are high levels of satisfaction among those who are enrolled.
- Once the 3-year evaluation is complete, there will still be a need for DDS to track the implementation of self-direction and to determine whether capacity is being built among state staff and providers.
- DDS should consider convening a “users” group of participants and family members to provide advice on self-direction.
- There are continuing issues with PPL, including communication, redundancy, and complexity that should be addressed.

Recommendations

For years, the Massachusetts I/DD system has functioned more as a wholesale system by locking funding up into group contracts. Self-direction is a system built one person at a time, which requires individualized funding, a wider range of choices, employment and budget authority and other hand-

tailored elements. While it is not possible to reinvent the public I/DD system anew, it will be necessary, where possible, to create mechanisms, policies, funding streams, and practices that deviate from the existing infrastructure that supports traditional services. The following recommendations are offered in that spirit.

The major recommendations based on the Year Two assessment include:

- Explore the possibility of making support brokerage a waiver service to expand the availability of dedicated staff available to support people who are self-directing.
- Request additional funding to expand the number of state staff who are support brokers.
- Explore the feasibility of requesting that the Legislature create a line item in the DDS budget for self-direction.
- Ensure that individuals who are self-directing are appraised of their budget prior to finalization of the plan and know how to access the status of their budgets through the PPL portal.
- Examine current methodology regarding the development of individual self-directed budgets to determine whether there are more predictable and consistent ways of linking level of need to an individual budget amount.
- To encourage increased enrollment in self-direction across the state, each region should develop a long-range plan to facilitate the adoption of self-direction with timelines and enrollment targets.
- Continue to expand the availability of information on self-direction in a range of formats to educate participants, family members and support coordinators/support brokers.
- Take several steps to encourage participation in Agency With Choice both by participants and providers.
- Convene a statewide conference on self-direction to showcase both the PDP and AWC program and to highlight the experiences of individuals who are self-directing, providers that support self-direction, and support brokers.
- Continue to monitor the enrollment in self-direction through surveys of service coordinators and brokers as well as individual participants and review of regional data to assess whether self-direction targets are being met.

1. Introduction

As part of the requirements of the Real Lives legislation, passed and signed by Governor Patrick in 2014, the Department of Developmental Services (DDS) was required to contract for an evaluation of the implementation of the act. In 2016, the Human Services Research Institute was awarded the contract to conduct a three-year evaluation. The first year of the evaluation was devoted to analyzing the ways in which DDS was reaching out to potential participants in the Participant Directed Program (PDP) and the Agency with Choice Program (AWC) to let them know about the opportunity to participate. (See the sidebar on this page for a reminder of the Year 1 Recommendations.)

DDS Accomplishments Since Year 1 Report

- DDS has expanded outreach and encouraged peers and family members to share their experiences regarding self-direction. Outreach has included:
 - Informational sessions in each region almost monthly.
 - Sessions in multi-cultural Family Support Centers
 - Regular sessions through Family Support Centers
 - Public speaking training for self-advocates through the creation of a Speaker's Bureau
 - Inclusion of families and individuals in self-direction forums to tell their stories
 - Presentations in Russian, Spanish, Haitian
- DDS is building mentoring relationships and structures by continuing monthly support broker/service coordinator forums in each region, providing person-centered training for support brokers and service coordinators and holding an annual support broker conference

Reminder: Year 1 Recommendations

- 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/support broker capacity to facilitate 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

- DDS is improving materials for participants and service coordinators. DDS has issued guidance documents from the Central Office Self-Direction Leadership group and now has a process in place to release guidance in a consistent manner. Manuals and Guides are due to be finalized in December 2018.
- DDS has taken steps to improve outreach using social media and a web-based presence by hiring staff to produce two videos per region and a fraud/ abuse video.
- DDS is introducing self-direction to participants and families prior to transition by ensuring that SD Managers and Autism Leads attend transition fairs and forums and that bi-monthly meetings with transition coordinators and SD managers occur.

Year 2 Evaluation

The second year of the evaluation, detailed in this report, focused on the infrastructure for self-direction. This includes elements such as individual assessments, planning, budgeting, funding, service coordination/support brokerage, staff recruitment, and eligibility as well as other components of implementation of self-direction.

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

1. What are the **characteristics** of those who are self-directing?
2. Are there **regional differences** in the number of individuals who are self-directing?
3. What **services and supports** are people most likely to include in their individual budgets and how do the costs compare with traditional services?
4. What do service coordinators and support brokers see as the **challenges** to supporting people who are self-directing and what do they see as ways that the process can be **improved**?
5. What do participants, DDS staff, and families see as the **challenge and benefits** of self-direction and the ways in which the process can be **improved**?
6. What do stakeholders (participants, DDS staff, and families) see as the ways in which the process of self-direction can be **enhanced**?
7. How do **budgets** get developed for PDP and AWC participants?
8. Where does the **funding** come from for self-direction and is it **adequate**?
9. What types of **infrastructure** do other states have to support their self-direction programs and what can be translated into the Massachusetts context?

To answer these questions, HSRI carried out the data collection efforts detailed in the Methodology section on the following pages.

2. Methodology

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, which regions they are in, and which services and supports they are most likely to manage. HSRI received de-identified service utilization data for three years (FY15, FY16, FY17), beginning with the year the Real Lives Law was implemented (FY15). After cleaning the dataset to remove records that did not accurately identify the persons' eligibility type (ID or DD) and accounting for people coming in and out of the system, HSRI was working with a total, unduplicated N of 28,924 people with completed service use records in one or more of the three years of data.

The data analyses focused on three main areas:

1. Do characteristics of the self-directing population differ from the rest of the DDS service population? (Looking at demographics like age and gender, guardianship status, and assessed level of function.)
2. How many people enroll in self-direction compared to traditional services, and which type do they enroll in (AWC or PDP)? What regional differences are there in enrollment? Are there shifts in participation across the three years?
3. What type of services do people self-direct? And (an additional question), what do we know about the expenditures for services that are self-directed?

Development of Mail and Online Surveys

In Year 2, HSRI continued to survey participants in PDP and AWC as well as service coordinators and support brokers. The survey protocols were similar to those developed for Year 1 of the evaluation but were revised to focus more specifically on the mechanics of self-direction. (See Appendix A for a description of the sampling design, the questionnaire design, and the dissemination procedures.)

- **Survey of Participant Directed Program participants.** The PDP survey was mailed to 568 individuals who are participating in the Participant Directed Program. Participants were given the option of completing the paper survey or using a provided link to SurveyMonkey to complete the survey online. HSRI received 195 valid surveys between April 30, 2018 and July 23, 2018 for a 34% response rate. Participants were told in the cover letter that they could get help if they needed it from family or and friends and were offered translation services if they needed it.
- **Survey of Agency with Choice participants.** The AWC survey was mailed to 440 individuals who are participating in Agency with Choice. Participants were given the option of

completing the paper survey or using a link to SurveyMonkey to complete the survey online. HSRI received 126 valid surveys between April 13, 2018 and July 7, 2018 for a 29% response rate.

- **Survey of service coordinators.** DDS leadership emailed an introductory letter with the survey link to all 595 DDS employees identified as DDS Service Coordinators. HSRI received 117 valid surveys between March 30, 2018 and April 27, 2018 for a 19.7% response rate.

A preliminary analysis by HSRI shows that the mail and online survey respondents are representative of the larger groups of participants in PDP and AWC.

Key Informant Interviews

Interviews With Agency With Choice Providers

In the spring of 2018, HSRI staff invited each of the Regional Self-Directed Supports Managers to identify two or three providers in their regions that would be willing to take part in a half-hour telephone interview to discuss the AWC experience from their agency's point of view. Each Region identified two providers, and each provider agreed to talk with an HSRI staff member. HSRI staff developed 16 questions to guide the conversation. (To ensure the questions were clear and that providers could answer them while talking on the phone without having to resort to consulting their data files, the questions were field-tested with three organizations that were not taking part in the official interviews.)

Each phone interview lasted between 30 and 60 minutes, depending on the extent of the provider's responses. Anonymity was guaranteed to each person interviewed; all responses were combined into a final report (see Appendix C for the report, which is arranged by topic covered).

Interviews With DDS Central Office Staff

HSRI also conducted interviews with DDS Central Office staff to gain an understanding of key infrastructure issues, including assessment, budgeting, etc. HSRI also attended a Senior Leadership meeting to share some preliminary impressions. (See Appendix B for the Key Informant Interview Guide.)

Focus Groups With Families and People Self-Directing

During the winter spanning 2017-2018, HSRI staff asked each of the Regional Self-Directed Supports Managers to consider inviting HSRI to attend one of the regularly scheduled family and participant meetings held in each region. The HSRI team explained that they wanted about 45 minutes on the meeting's agenda to hold a kind of focus group with whoever attended that meeting to talk about self-direction. Each of the four meetings was held during the spring of 2018. In general, attendees at

each meeting included family members, participants in both PDP and AWC options, and DDS and provider agency staff. Rather than using detailed questions, focus group participants were asked to think about three major issues: getting started with self-direction, the ongoing process, and things that need fixing. All information was kept confidential, and individual participants were not quoted.

Review of Best Practices

With the assistance of national experts, HSRI identified six states in Year 1 that could provide information on promising practices in self-direction. These were Connecticut, Idaho, New Jersey, Ohio, Pennsylvania, and Tennessee. An important criterion for selection was that at least some of the states had characteristics like Massachusetts. In the first year, using a structured interview guide, HSRI staff asked public I/DD managers from these states about the ways in which they educated potential participants about the self-direction option. In the second year, HSRI directed questions to the same states, but this time focusing on budgeting, assessments, planning, and other issues related to the infrastructure of self-direction. (See Appendix D for the interview guide.)

3. Characteristics of Participants: Statewide and By Region

Characteristics of People Who Self-Direct

To better understand the characteristics of people who self-direct—and whether self-directing participants differ in some ways from people who don’t self-direct—we examined data on the available characteristics (demographics, guardianship status, and assessed functioning) of people who were self-directing in the most recent fiscal year (FY17). We also compared the self-directing population (1,034 people in FY17) to the larger population that receives services through DDS but does not self-direct (26,778 people). Finally, within the self-directing group, we compared those who used AWC with those who were enrolled in PDP in FY17 (383 people used AWC, and 651 PDP). The results are depicted in Exhibit 1.

Exhibit 1

Characteristics of DDS Service Recipients by Self-Direction Status (FY17)

	Not Self-Directing (n=26,778)	Self-Directing (n=1,034)	P value ² , Non-SD vs. SD	Self-Directing: PDP (n=651)	Self-Directing: AWC (n=383)	P value ² , PDP vs. AWC
Age (years) ¹	36.4	34.9	<.001	35.9	33.2	<.05
Gender (F)	39.8%	41.8%	NS	43.6%	38.6%	NS
Race ⁴						
White	78.2%	79.4%	<.01	74.7%	86.7%	<.01
Black	9.8%	9.2%	NS	12.6%	3.9%	<.01
Other	12.0%	11.4%	NS	12.5%	9.2%	NS
Language preference is non-English ⁴	12.2%	8.2%	<.001	8.3%	8.0%	NS
Spanish	7.1%	4.4%	<.05	3.8%	5.4%	NS
Other languages	5.2%	3.8%	NS	4.6%	5.1%	NS
Guardianship status						
Has a legal guardian	47.0%	53.4%	<.01	49.5%	60.1%	<.01
Legal guardian is a family member	38.4%	48.2%	<.01	45.2%	53.3%	<.05
Assessed Functioning						
ICAP Score ^{3,4}	53.0	46.9	<.01	48.2	45.2	NS

Notes:

1. Arithmetic mean; the Autism Waiver (ages 3-8) group (n=63) is removed from calculations due to their skewing effects. If included, the mean ages for SD and PDP would both be 33.2 yrs (AWC unaffected).
2. The p values are from chi square tests except for age and ICAP score, where the p values are from t-tests; NS= Not Significant (statistically)
3. Lower ICAP scores = lower functioning, higher need. Please note that about 74% of our sample did not have valid ICAP scores due to the limitations of the data system.
4. Due to the nature of self-reported data and limitations of the data, many service recipients had missing data on the following variables: race (58% missing), language preference (46% missing), ICAP score (74% missing).

On average, self-directing participants were younger than participants who weren't self-directing. AWC participants are on average significantly younger than PDP participants. Regarding race, self-directing participants were significantly more likely to be white than non-self-directing participants. However, among the self-directing group, PDP participants were significantly more likely to be non-white than AWC participants. This may be reflective of regional differences in demographics and the adoption of PDP versus AWC, which is discussed below. Self-directing participants were significantly more likely to indicate English as a primary language: only 8% of the self-directing group spoke a language other than English at home, compared to 12% of the DDS population.

Self-directing participants were more likely to have a guardian, and among those with a guardian, were more likely to have a guardian who is a family member. Among the self-directing group, PDP participants were less likely to have a guardian than those in AWC; about 50% of PDP participants had a guardian, and approximately 60% of AWC participants had a guardian. The large number of individuals who self-directing are who have a guardian begs the question of who is actually directing services and supports.

Self-directing participants also had lower average ICAP scores than non-self-directing individuals, indicating that self-directing participants had higher assessed need. This difference may reflect the higher proportion of self-directing participants with a guardianship arrangement.

Importantly, several variables had high levels of missing data: particularly race, language, and ICAP score. Therefore, these figures should be interpreted with caution.

Regional Differences in Self-Direction Enrollment

As with the Year 1 analysis, we detected regional differences in self-direction enrollment over time. Exhibit 2, on the following page, displays the proportion of the overall DDS population that was self-directing in the past three fiscal years. These differences can in part be explained by the fact that the Metro and Northeast regions initiated self-direction programs much earlier than the Central West and Southeast regions. The program in Metro region dates to the 1990s when Massachusetts was awarded a Robert Wood Johnson self-direction pilot grant.

As noted in the blue shaded box in Exhibit 2, the overall numbers of people who are self-directing has increased; however, the proportion of people who are self-directing DDS services has remained stable at around 4% over the past three fiscal years.

Exhibit 2

Self-Direction by Region Over Time

Region/ Fiscal Year	Self- Directing	% ¹	Self- Directing: PDP	% ¹	Self- Directing: AWC	% ¹
Northeast						
FY15	432	7.9%	293	5.3%	139	2.5%
FY16	438	7.6%	279	4.8%	159	2.8%
FY17	440	7.2%	268	4.4%	172	2.8%
Metro						
FY15	191	3.8%	173	3.4%	18	0.4%
FY16	218	4.0%	197	3.6%	21	0.4%
FY17	232	4.0%	210	3.7%	22	0.4%
Central West						
FY15	217	2.7%	132	1.6%	85	1.1%
FY16	221	2.5%	119	1.4%	102	1.2%
FY17	229	2.4%	112	1.2%	117	1.2%
Southeast						
FY15	137	2.4%	89	1.6%	48	0.8%
FY16	150	2.4%	83	1.4%	67	1.1%
FY17	139	2.1%	65	1.0%	74	1.1%
All Regions						
FY15	977	4.0%	687	2.8%	290	1.2%
FY16	1027	3.9%	678	2.6%	349	1.3%
FY17	1040	3.7%	655	2.4%	385	1.4%

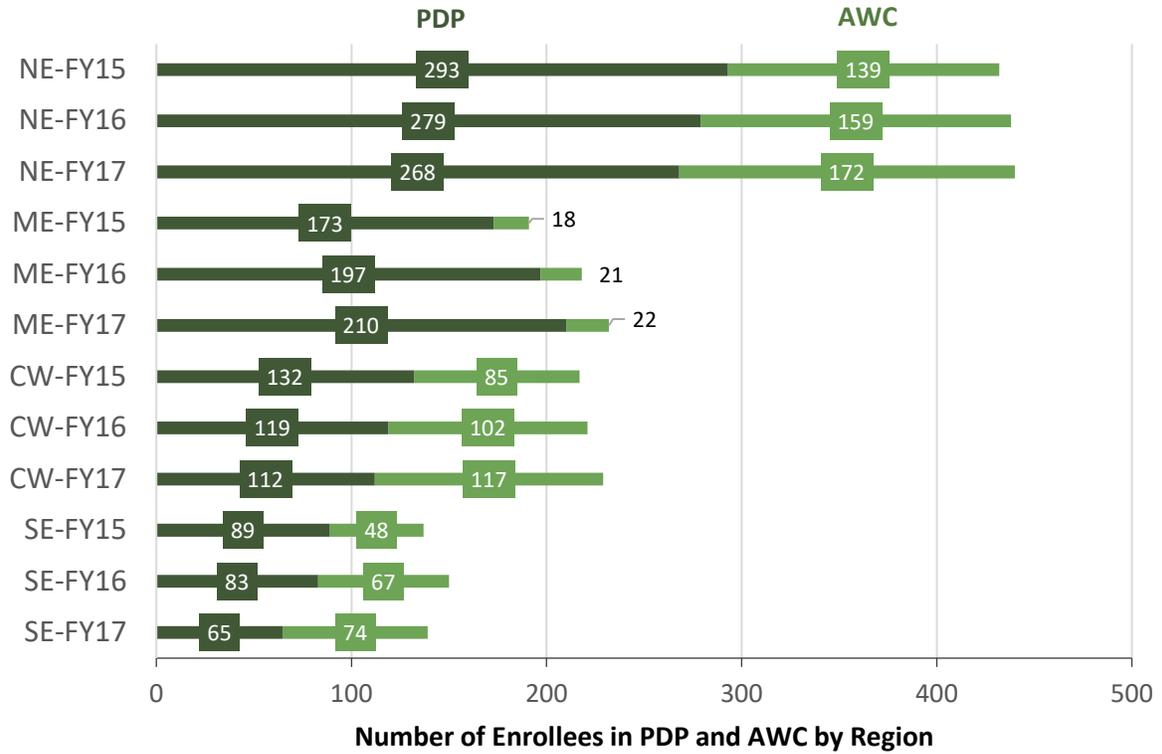
¹ The denominator is the number of all DDS service recipients in the region for that year.

Regional differences in self-direction enrollment are considerable: About 7% of people in the Northeast region were enrolled in self-direction. In comparison, only 2% of those in the Southeast region were enrolled in self-direction. There is also regional variation in the proportion of self-directing participants enrolled in PDP or AWC. Most individuals in Metro East are enrolled in PDP, whereas the other three regions are more evenly split between PDP and AWC.

Further, except for the Metro East region, the growth of PDP has been slower than the growth of AWC, which can be clearly seen in Exhibit 3.

Exhibit 3

Enrollment in PDP vs. AWC by Region Over Time



4. Service Coordination and Support Brokerage

Survey Respondents

The following narrative is based on the results from the service coordinator survey that was previously described. The tabulation of responses to the survey is included in Appendix E. Approximately 20% of those who received the survey completed and returned it; of those, about 85% were service coordinators and approximately 24% were support brokers. In terms of the composition of their caseloads, respondents were assisting an average of 53 people receiving traditional services, 4 people enrolled in PDP, and 2 people enrolled in AWC.

Understanding of Self-Direction

A significant theme in the responses to the service coordinator survey was a general lack of knowledge of or participation in supporting self-direction. Many respondents seemed unsure about what the model was intended to accomplish. Several talked about having a general idea about self-direction but said that it was difficult to determine what was and was not possible, which left them confused. Many respondents reported that there was only one dedicated person in their Area Office who handles self-direction. Since referrals are directed to that individual, other service coordinators don't have the opportunity to master the program. In other Area Offices there were no support brokers. A couple of commenters said, "I don't work with that population." The number of individuals on respondent caseloads who were self-directing ranged from 0-4.

Some respondents suggested that support brokers should have more of the responsibility for training their colleagues because they know about the model and how it works. Additional commenters suggested that there should be funding provided to pay for training when it was offered so that all service coordinators and support brokers would be more motivated to attend it.

While training is available to service coordinators and support brokers, there was disagreement among respondents about the nature of the training. Service coordinators did not agree on whether the training is available, whether it is required or optional, and what the training focus was. For example, some were under the impression that trainings may occur after work hours and would therefore be optional. Others said they have not been made aware of any training on self-direction. About half of the service coordinators who responded to the survey said that they could choose which trainings to attend. Those who did attend trainings reported the following topics were included: responsibilities of the participants, their families, service coordinators, and the agency (if using AWC); services that can be purchased through self-direction; how to recruit workers; where to get more information; and information on budgets. The fear is that if training doesn't reach all service coordinators, some may think they don't need to know about self-direction unless they have clients who are self-directing.

There was no mention of opportunities to learn to put these principles and processes into practice, and there was no mention of sources other than the formal trainings for information about the program that service coordinators could consult. Service coordinators suggested there should be concise information on what is and is not possible through self-directing. Finally, no one identified their own supervisors as sources for information or support in implementing self-direction.

Since the survey was conducted, DDS has been developing a guide for service coordinators that will describe what services can be self-directed, what goods and services can be made available, flexible funding for things not covered by waivers, items that are disallowable, and post-secondary education opportunities.

Helping Families and Individuals Learn About Self-Direction

There are many ways that individuals can learn about and enroll in self-direction. Several respondents mentioned the Regional Self-Directed Supports Managers as great sources of information and who are active in getting information out to families and potential participants. Many service coordinators said that they share the self-direction brochure with anyone interested, as part of the materials that are presented at ISP meetings. Many respondents also said that they discuss self-direction with anyone who expresses an interest in learning more about it. Some said that they routinely discuss self-direction with anyone on their caseload who is turning 22, because many of those young people are already self-directing to some extent in their school programs. Several respondents knowledgeable about self-direction said that they talk about the program only when they are “invited to the table” by the assigned service coordinator. (Notably, respondents to our participant surveys and members of our focus groups also noted that their service

We are all very grateful to have this to self-directed program option. Thank you

coordinators/support brokers have been helpful in negotiating self-direction.)

No one said that there is a standard approach to information-sharing when ISP meetings take place or when new families come to DDS. Further, no one identified the need for such standardization, even though, as noted above, service coordinators expressed the need for more standardized information.

The Process of Self-Direction

A majority of respondents to the service coordinator survey said that the process of self-direction was complicated, both to master and to implement. They reported that it takes too long to get the model in place once a family and participant identify their interest in doing self-direction. They suggest it would be helpful to learn directly from service coordinators/support brokers who have worked with PDP and AWC to learn what’s worked and what hasn’t. Many said that having “capable

families” was important to making the self-direction process work, while others had a broader sense of what was possible regardless of the family’s abilities.

In addition to learning from one another, service coordinators suggested that families and participants could also learn from one another by giving new families/participants or those considering self-direction a chance to speak with those who are already taking part in the process. They also suggested that meeting with potential providers would help families get a better idea of AWC, what their responsibilities would be, and what support families and participants could expect.

Some respondents noted that DDS should not be the only source of information about self-direction and suggested that the concept should be introduced during the IEP process a few years before individuals are making the transition to adulthood. Further, families with children receiving family support could be introduced to self-direction by their providers. While both strategies sometimes are used, there is a clear sense that *more information delivered earlier* would help the process work more smoothly and expand uptake of self-direction.

There was general agreement that the process does not need to be so complex, and that part of what puts some people off (both service coordinators and participants/families) is the impression that self-direction is very difficult to manage. Service coordinators say that younger people, people with ASD, people with involved families, and those who are unhappy with traditional services are most likely to want to self-direct their services. Several service coordinators expressed concern that self-direction could be abused if there were not strong natural supports in place. There was no mention of engaging older individuals or those currently receiving more traditional services.

Suggestions for Improvement

Service coordinators and support brokers are key to the success of self-direction—not only in Massachusetts but nationally. A recent study canvassed 58 state DD program administrators in 34 states with self-direction programs regarding the strengths and challenges of self-direction.¹ The findings reinforce the centrality of service coordinators/support broker in the success of the program.

Administrators in this study emphasized how critical well-trained and engaged case managers were to successful implementation of self-direction . . . administrators echo the importance of having “buy-in” from case managers, and that dissatisfied or negatively disposed case managers can limit access to self-direction by simply not mentioning it to potential participants. Moreover, case managers who harbor concerns or misconceptions

¹ DeCarlo, M.P., Bogenschutz, M.D., Hall-Lande, J.A. & Hewitt, A.S. (2018). Implementation of self-directed supports for people with intellectual and developmental disabilities in the United States. *Journal of Disability Policy Studies*. DOI: 10.1177/1044207318790061 jdps.sagepub.com

about self-direction may not present accurate information out of fear for their clients' safety . . . (p. 8)

There are several recommendations growing out of this evaluation that could expand the reach of self-direction and improve the functionality of the program:

- Increase training opportunities, especially for those implementing self-direction at the Area Office level, to ensure that information is consistent, available, and usable and that everyone understands the basics whether or not they have self-directed participants on their caseloads.
- Provide a repository of information on the standardized procedures that should govern self-direction and make it readily accessible to service coordinators/support brokers. The guidance currently being provided by DDS regarding the conduct of self-direction should be made broadly available to field staff and updated periodically.
- Support multiple sources of information for providers, participants, and families in user-friendly formats. The videos currently being developed featuring individuals who are self-directing will be very helpful in introducing potential participants and families to self-direction. The Speaker's Bureau that has been launched will also provide individuals who can inform their colleagues about self-direction.
- In addition to DDS, school personnel should be introducing students and families to self-direction before transition.
- There should be ongoing peer-to-peer support for everyone taking part in self-direction—service coordinators, brokers, families and participants, and agencies for Agency with Choice. There is a lot that may be learned from one another, and a lot of support to be had, if those connections are made and reinforced.
- There needs to be a reassessment of caseloads and the availability of service coordination. Given the large caseloads of service coordinators, it is difficult to imagine that the program will grow significantly. Further, the shortage of support brokers is another barrier. As we recommended in the Year One report, DDS has only so many choices: 1) seek more funding for service coordination/support brokers to expand the workforce; or 2) encourage participants to hire individual support brokers or brokers associated with brokerage agencies. This issue will be further explored in the section on lessons from other states.

5. Service Plan and Budget

Individual Assessments and Budget Development

Entry into the DDS service system begins at the Regional office with an application to the Intake and Eligibility Team. If individuals are found to be generally eligible, they are referred to the Area Office nearest their home. At the Area Office, staff assess the individual's needs and priority by administering the Massachusetts Comprehensive Assessment Profile (MASSCAP). The purpose of the multi-pronged assessment is to determine what services and supports an individual may need and how urgently those services are needed. The MASSCAP assessment provides information on the functional skills of the individual as well as the strengths and needs of the individual's caregivers.

The MASSCAP consists of three parts:

- 1) The Inventory of Client and Agency Planning (ICAP), which assesses an individual's adaptive functioning and the level of support and supervision the person needs; this assessment is completed by the Intake and Eligibility Team when DDS services are requested;
- 2) The Consumer and Caregiver Assessment (CCA), which assesses the resources and natural supports available to the individual and provides information to assist in evaluating the capacities of the caregivers; this assessment is completed at the Area Office after the individual has been determined eligible; and
- 3) Professional Judgment, the review by clinical and program professionals of the results of the ICAP and CCA to make a final decision on the level of support required.

The MASSCAP results don't yield a specific budget amount based on a formula that links need to a funding level; instead, the MASSCAP just assesses acuity and guarantees that there is a standardized functional measurement across the state.

According to DDS staff, most applicants want some form of day services, and some want residential supports. Depending on their needs, services required and priority level, individuals may be enrolled in one of three waivers: the Adults Supports Waiver, the Community Support Waiver, or the Intensive Supports Waiver. All three waivers offer the ability to self-direct. To receive residential services, an individual must receive a priority 1 and would be enrolled in the Intensive Supports Waiver—the only waiver that offers 24/7 support.

Since self-direction has come into my life, my housekeeping skills have improved. I have great social skills and arrive on time daily for my job

If individuals fall under the Turning 22 provisions and need day services, they may be given a priority right away. Of those coming to DDS as part of Turning 22, staff estimate that 15% to 20% get residential supports. If the individual applies for services at 21 years old, state funds alone are expended since waiver eligibility doesn't begin until the individual turns 22.

Most self-directed services are day supports. To determine the level of support, a service coordinator and the Area Office liaison review the person's MASSCAP assessment and the services they are requesting. A recommendation is made, and the Area Director suggests a potential allocation based on what would be spent on conventional services. The team then reviews rates and ranges and determines what the approximate figure should be. The service coordinator/support broker then goes to the applicant to discuss building a budget. According to staff interviewed, the participant doesn't always know the budget amount at the beginning of the process.

To be able to make an allocation available, the Area Director needs to identify available resources, either from Turning 22 or from an existing contract if there is unused capacity. Residential funding cannot be moved out of the residential contract since the rates are predicated on a staffing pattern. If the capacity of a group home is reduced, DDS must "re-slot it" according to the state rate structure. Taking money out of existing contracts is difficult given provider resistance. As a result, the Area Director can only extract a small amount of money to avoid destabilizing the services in the home. Some families would like to take the residential funding and apply it to self-direction, but there are challenges when the service request includes the need for 24/7 supervision. While it is possible to self-direct 24/7 supports under the Intensive Supports Waiver (home sharing, or live-in caregiver), creating a residential self-directed 24/7 residence for one person would, according to DDS staff, be cost-prohibitive.

Participant Understanding of the Budget

According to PPL staff interviewed, participants in the Person Directed Program know how much money is in their budget. According to PPL, they mail out a monthly budget statement and their support brokers will confirm with participants that they have received the statement. In addition to the monthly mailout, PPL said the budget information is on their portal, which participants can access at any time. The monthly statement is meant to ensure that participants don't go over their budgets.

Some parents have reported that they have not received the monthly budget document which is, according to PPL staff, standard operating practice. There may be a few reasons for these differing perspectives. The first is that families and people with disabilities may not have been sufficiently oriented to the ongoing budget process and therefore do not recognize the significance of the monthly document. The second is the possibility that mailing lists are not sufficiently up to date. The third is that not all participants have been entered in PPL's distribution software.

A further question is whether individuals, even if they have knowledge of their budget, are supported to take control of the allocation. One participant in PDP said “I still feel like [I’m being] taken advantage [of]. I want more control of my own budget. Budget person tells me what I am going to do rather than help me or support what I want.”

Budget Amounts

Once the services and related costs have been identified, one of the 3 waivers is identified by central office staff. The Adult Supports Waiver is capped at \$40,000; the Community Supports Waiver at \$70,000; and the Intensive Supports Waiver at \$70,000 and above. According to the 2018 DDS Annual Self-Determination Legislative Report (prepared in response to a requirement in the Real Lives legislation), the ranges and averages for expenditures from all individual self-directed budgets were as follows:

In the FY 2018 Participant Directed Program with PPL, the smallest allocation spent was \$55. The smallest allocations are typically for a partial year, new enrollment program or short-term expenditures appropriate for this service model. The largest two allocations were at \$222,205 and \$204,429; however, these cases represent unique circumstances. Other than these two outliers, the highest allocation spent was \$158,000. The average allocation was \$17,299.65.

In the FY 2018 Agency With Choice program, the lowest allocation was \$1,511.39, the highest allocation was \$124,765, and the statewide average was \$23,295.07.

Adequacy of Funds

Since there is not a dedicated funding stream for the PDP and AWC programs, resources for self-direction are drawn from unused funds in existing contracts or from the Turning 22 program. The extent to which such funds are available may vary from region to region and from area to area. Further, neither the traditional provider contracts nor the Turning 22 program were originally structured to support self-direction.

Some families who are interested in self-direction were told that funds were not available in their area. This may be because the participant was not given a priority, or it could be that there are insufficient funds to cover all individuals and families who are interested in self-direction. One DDS staff member estimated that of those who were enrolled in services over the past year, one individual entered the PDP or AWC program compared to two individuals who were enrolled in traditional services and supports.

According to DDS staff, there was an allocation specific to autism services a few years ago for self-direction, but dedicated funding hasn’t been available lately.

6. Services and Supports

(included as Appendix H). HSRI evaluators worked with DDS to arrange the multiple service categories into groups, or “buckets,” to allow a clearer analysis of the service codes. The crosswalk that shows how the DDS service codes were grouped is shown in Appendix H.

Next, we examined service use data to understand which types of services people self-direct and whether self-directed services types differ for PDP participants and AWC participants. Exhibit 4 depicts the types of services that individuals self-directed in the past three fiscal years, broken out by PDP and AWC. The same list is presented in Exhibit 5, alongside the associated expenditures.

Of all the services that self-direction participants used in FY15-17, what proportion was self-directed?

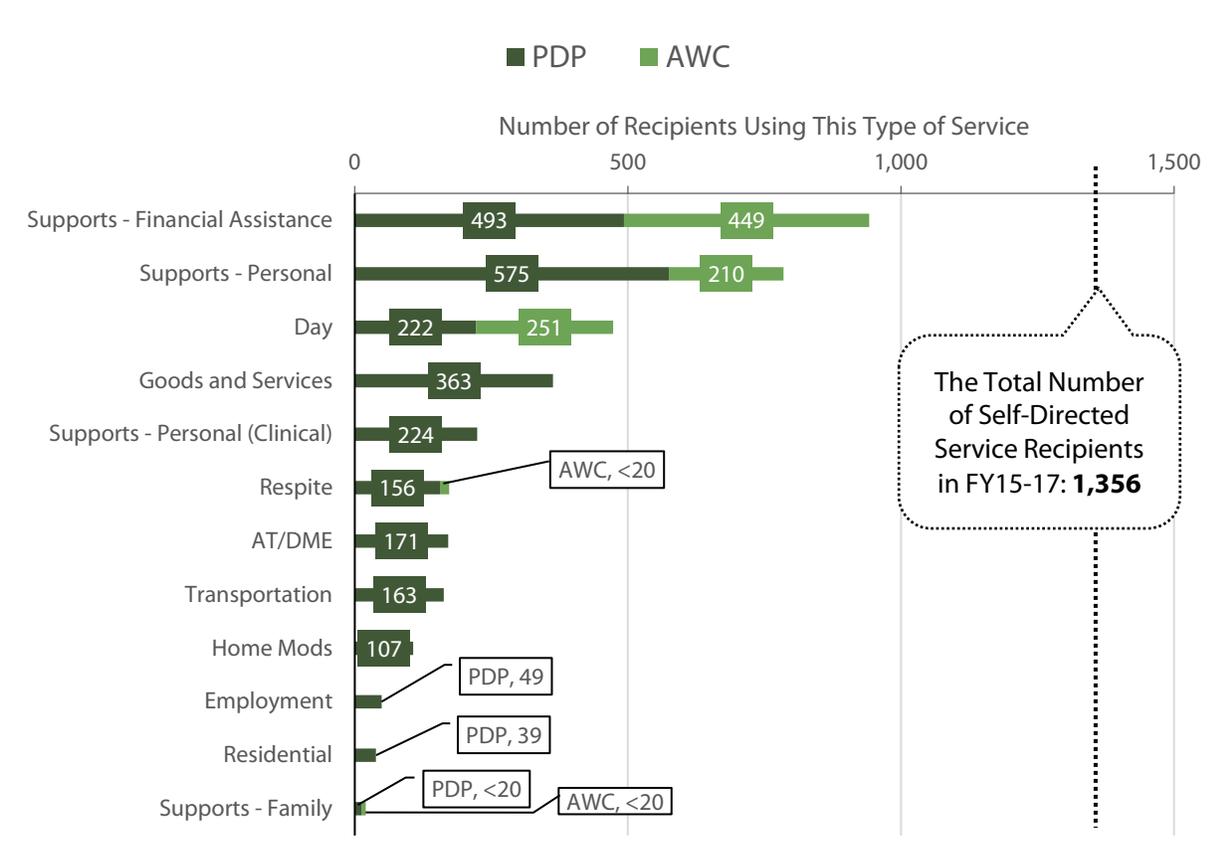
PDP 70.0%

AWC 51.2%

Overall 62.7%

Exhibit 4

Service Types by Self-Direction Status, FY15-17



As is clear from Exhibit 4, individuals self-directed a broad range of service types. AWC participants, however, self-directed a more limited number of service types. The most commonly self-directed service type was Financial Assistance, with 942 participants self-directing this service; the numbers were roughly the same for PDP and AWC. Personal supports were also commonly self-directed.

Exhibit 5 presents the most commonly used self-directed services and the associated expenditures. The top three most-used types of services in both PDP and AWC (Supports – Financial Assistance, Supports – Personal, and Day Services) were also the ones with the highest expenditures. Despite similarities across the PDP and AWC groups, there were some key differences in the actual breakdown. For example, in PDP, the service accessed by the highest percentage of the people (Supports – Personal; 61.5%) also received highest funding (~\$3.9 million). In AWC, on the other hand, almost everyone (>99%) used Financial Assistance, but it was not the type of service with the highest amount of expenditures. Another example is that Respite services only cost about \$11,000 in PDP and were used by 156 people, meanwhile fewer than 20 people in AWC accessed Respite services in AWC but the cost was more than \$150,000—suggesting that PDP and AWC, though both self-directed, may have had very different service options under the same names/categories. Overall, AWC only had five services categories and the spending appeared more evenly structured whereas PDP had a wide range of expenditures spread across twelve categories. In both PDP and AWC, very few (<20) individuals self-directed family supports services.

Exhibit 5

Types of Self-Directed Services and Annual Spending by PDP and AWC Status

Type of Service	#PDP	% of PDP	Annualized Expenditures (PDP)	#AWC	% of AWC	Annualized Expenditures (AWC)
Supports - Financial Assistance	493	52.7%	\$1,655,184	449	99.1%	\$1,301,181
Supports - Personal	575	61.5%	\$3,899,185	210	46.4%	\$1,900,540
Day	222	23.7%	\$1,898,868	251	55.4%	\$2,222,230
Goods and Services	363	38.8%	\$272,912	-	-	-
Supports - Personal (Clinical)	224	24.0%	\$106,919	-	-	-
Respite	156	16.7%	\$10,772	<20	3.8%	\$151,089
Assistive Technology/Durable Medical Equipment	171	18.3%	\$50,898	-	-	-
Transportation	163	17.4%	\$178,716	-	-	-
Home Mods	107	11.4%	\$25,152	-	-	-
Employment	49	5.2%	\$158,894	-	-	-
Residential	39	4.2%	\$942,619	-	-	-
Supports - Family	<20	1.4%	(Unknown)	<20	1.5%	\$6,320
Total	935			453		

Note: PDP annualized expenditures are calculated based on averaged FY16-18 figures provided by the MA DDS; AWC DDS spending numbers are based on averaged FY16-17 figures. Small cell counts (<20) were censored.

7. Person Directed Program

Participant Perceptions

Although several participants in the focus groups took part in the Participant Directed Program, none had anything specific to say about it. Consequently, the findings presented here are informed by the survey results of PDP participants and by their extensive comments about their own experiences.

Themes of being in control and being connected dominated the comments about PDP. Feeling more independent and in charge of life, feeling self-confident and connected to other people and activities, and in general, feeling better about one's self and one's life are the themes that emerged from the surveys. Growth in skills and more security in perceptions of situations and feelings were also mentioned often. These kinds of independence measures are often absent from more traditional services, and their regular mention in the PDP survey says that these goals, which are primary to the Department of Developmental Services and the advocacy community, are ones that actually motivate people to self-direct. Comments like, "I want to live on my own but I know I need help," or "I'm able to adjust to new people and new activities," suggest that self-direction gives individuals the support they need to embrace new experiences.

I'm an individual person who needs a specialized individualized day. This self-directed program has changed my life for the best!

While there is much about the model to celebrate, respondents also pointed out areas in which their expectations weren't realized. A comment that was made in focus groups by just about everyone who is self-directing was reinforced in survey findings: "I want new friends and I want to go out more." Even though control is important, many respondents mentioned loneliness as a common and unwelcome experience. In part this is explained by the fact that individuals making the transition to self-direction had been used to participating in a range of group activities as part of day programs.

Coupled with loneliness is a desire for more—more hours to do more things, more opportunities to learn specific skills, like cooking or playing music, to have more significant relationships, like good friends and boy/girlfriends, and more money in their allocation to enable them to travel or take classes. They talked about running out of money early when they make such choices.

Several people talked about wanting to have their own jobs and their own apartments and commented that self-direction hadn't helped them realize these goals. This speaks more to the economy in which people live than it does to the model's faults. Apartments for single people are very expensive, and jobs that pay well are hard to come by, so even though efforts are being made to make sure that people are ready to live on their own or to work, opportunities to actually do so are limited. For example, of the individuals who used DDS Employment Services in FY16, those in

individual supported jobs receive an average hourly wage \$10.90 and work an average of 12 hours per week; those in group supported jobs receive an average hourly wage \$7.70 and work an average of 10 hours per week.² Meanwhile, according to the U.S. Department of Housing & Urban Development *FY 2018 Section 8 Fair Market Rents (FMRs) in Massachusetts*,³ monthly rent for a 1 bedroom ranges from \$730 in Western Worcester County to \$1,421 in the Boston-Cambridge-Quincy areas.

Strengths and Weaknesses of the Model

A consistent strength identified for all self-directed services was the joy found in being in control of aspects of support that were previously managed by others. Opportunities to try new things, to make decisions, and to experience the consequences of those decisions is something that is highly valued and that most participants report as being part of their PDP involvement. Most people feel supported by DDS as they make their way in the PDP model. Staff hired can make a big difference in people's lives when they are committed to their success. When they can identify them, community-based activities are welcome additions to schedules and offer chances to try new things.

When it works well, the staffing for PDP has been identified as critical to the success of the model. Staff members who participated in our focus group meetings and participants who responded to our survey spoke to the perceived importance of their work and the ways that increased skill and capacity reward their efforts. Having a chance to choose the people called staff is an essential component of the PDP program, and having the responsibility for directing them, and firing them if necessary, is something that was mentioned often as an important component of the program. Several PDP participants said that it sometimes took a while for staff to learn how to listen to them; they felt that staff are more used to working with people who they see as needing direction. This comment was made about DDS staff as well, suggesting the DDS staff may not trust the people involved to make their own decisions about their own lives.

While not unique to self-direction, one of the most significant challenges is finding staff and supervising them. Having to find their own staff is a challenge, both because people haven't recruited staff before and because the model isn't especially attractive to potential staff. Rates of pay vary, according to the decisions of the participants, but are rarely sufficient to enable staff to purchase benefits on the open market, and the hours required by one participant are frequently too great to enable a staff person to work for more than one person. The lack of benefits when working for individuals and, for that matter, for the Agency with Choice program, discourages many qualified and capable applicants from seeking this work. Finding back-up staff when primary staff are out sick is

² Retrieved from: https://shriver.umassmed.edu/sites/shriver.umassmed.edu/files/Employment_final%20May%202018_Taggedv2.pdf

³ Retrieved from: https://www.masshousing.com/portal/server.pt/document/14243/hud_fy_2018_section_8_fair_market_rents_%28fmr%29_for_machusetts

especially challenging, and often people report having to do nothing because they can't find staff to work with them.

Although several people said that the PPL services have improved, many also mentioned that it takes too long to get paid, that the paperwork is still cumbersome, they need more help managing it than they are getting, and they feel like they have to wait for communication from PPL too much of the time. Several identified the completion of forms for transportation as especially tedious, since they travel to the same places and have to complete the same forms time after time. Even though these same areas were identified as improved, there still appear to be residual issues.

Although many people talked about their great DDS service coordinators from DDS, several respondents also cited problems. Some noted that their support brokers/coordinators are too busy to get back to them. Often the problem seems to be communication, as reflected in statements such as "It takes too long to get an answer to my questions," and "My coordinator has to talk with the supervisor and that all takes too long and I don't know what I have to do," and "The service coordinator/support broker always seems to be working against my wishes." Sometimes it seems that participants aren't sure whose job is what; they don't know whether to talk with DDS or with their staff people. They say, "I need more help" and "I have to find resources myself." It's not clear whether additional training and preparation for participants would be useful or whether additional training and preparation of DDS staff would be useful in resolving this concern.

More funding was mentioned frequently, usually as tied to a specific activity. Needing more money for groceries, or for travelling around in the community was mentioned, as was money for special trips and activities. People mentioned that they didn't know how to get more money as things they wished could be fixed. While there may be a general sense that overall funding is tied to the state budget and to DDS allocations, there is very little understanding of how decisions at levels above them affect what happens on a day-to-day basis in their own lives.

Prospects for Expansion

Most people talked about being excited about speaking with others about self-direction because

Without this service I would not be able to have the support necessary to live my life at home or in the community.

they think it would help others choose the model. Staff people at focus groups said over and over how much they appreciated the positive changes in the people they worked with, and how much they enjoyed their work. However, for the model to expand in any significant way, several issues need to be resolved. The first is adequate funding so that those who choose self-direction can support themselves better in having the lives they wish. The second is finding ways to hire, pay adequately,

and otherwise support the staff who would like to do the work but who can't, at present, afford to do it. Finally, the experience of loneliness should be addressed. Although participants love their new

lives in many ways, they do not know how to address how lonely they feel. Several talked about longing for group trips or the parties they had when they were in more traditional models. Without resorting to those more traditional responses, the Department should find ways to enlarge the opportunities for PDP participants to connect with other people in ways they presently do not. DDS has been part of a Friendship initiative for several years that should provide some useful approaches.

Ways to Improve the Model

Several areas of improvement have been identified. Better training for DDS staff about what self-direction is and isn't would help participants experience self-control of the model in ways that some at present do not. Better information about funding—what is available, how far it will go, what it will pay for, and where additional funding can come from—would enable participants to better understand how their budget is developed. Grappling with the staffing issue at the statewide level and dealing with benefits issues and adequate rates of pay could expand the pool of candidates and help alleviate staffing challenges for those who elect self-direction under the PDP or Agency with Choice models.

Continued improvement in PPL's capacity to get back to participants with concerns, to expedite paperwork, to identify problems promptly and to help resolve them would encourage participants to have confidence in PPL and to feel comfortable having more frequent communication with PPL.

With respect to ameliorating some of the expressed loneliness, DDS could convene a group – including participants – to explore some ideas including lessons learned from the Friendship initiative that has been prominent in the state for a number of years. DDS staff (or provider staff) could be involved in trying out ideas so that data-driven decisions could inform future planning or practice. DDS could also cast a net for information about how other states are dealing with self-direction and the experience of loneliness on the part of participants, to see if there are solutions that could be applied in Massachusetts.

8. Agency with Choice

Provider Point of View/Experience

Interviews conducted with eight providers across the state yielded some remarkably similar points of view about the Agency with Choice (AWC) model. All of them said that their agency's interest in the model continues to be sparked by the alignment of the model's values with those of the provider

Agency with Choice has allowed me to have a life and receive the necessary supports to help me continue to grow and thrive in my own community . . . This was the very best choice for me when I graduated last year and continues to be.

agency: the importance of choice, the power of self-control, and the capacity for growth that is inspired by working toward a vision for the future. They report on the unexpected personal growth of both participants and families, both in skills and self-esteem. They share planning with participants and families in ways that give honest voices to dreams and concerns, and they use those plans as actual foundations for services and supports.

Almost every provider spoke of the family and participant as the fundamental driver of Agency with Choice services. This level of control of what happens in one's own life is something that all providers spoke of favorably, and several shared stories of participants whose experience in more traditional services significantly limited their willingness to take part in their own lives. Families for the most part were perceived as interested in helping their family members live the lives they wanted to

live; and providers spoke about family involvement in planning as giving families a chance to support their family members in ways they'd been unable to before using Agency with Choice.

Providers were equally clear about the drawbacks of the model. As with PDP, there was consistency across all the interviews about some of these drawbacks. Principle among them was the inconsistency among Area Offices in the way that money is allocated, the way(s) in which families are informed and involved, and how support brokers connect with families and participants on an ongoing basis. Some Area Offices tell families up front how much money they have to work with; others do not and it's up to the provider organization to negotiate the final allocations. Some areas allow only certain costs; others don't allow those same costs. Many AWC providers offer other kinds of family support services and therefore have ongoing relationships with families who may be interested in AWC. These families are always referred to the Area Office; many of them come back to the provider with no more information about AWC than when they made their initial inquiry.

Some Area Offices help families understand what self-direction and Agency with Choice mean, while many others tell families to talk with providers about the model. Providers find that families come to them from Area Offices with vague notions about what AWC is, yet other families from other Area

Offices know a lot about what's possible. They have talked with other families that take part in the model and have a clear idea of what they'd like to accomplish.

An equally strong concern is the *inconsistency of commitment to AWC* across the state. Many providers commented that there are areas where not all service coordinators know about the model and/or where service coordinators don't believe in the model, don't see it as having wide applicability, and don't share it as an option at ISP meetings. Since providers talk with one another, these inconsistencies are well known and well shared throughout the provider community. While the outcomes for participants are very positive, the environment in which these outcomes take place is very much evolving and hard to predict, so many agencies say their interest in AWC will have to wait until the model is more settled.

Availability of Providers

Opinions about the number of providers varied across the provider community interviewed. Several said there were plenty, especially since providers feel there is a critical number of AWC participants that is financially viable for an organization. Some see no need at this point for more providers in the mix. Others say that more providers would offer wider opportunities to families, and that different provider expertise will only make the program richer for participants.

A common theme was the lack of training for providers who are interested in offering AWC. Even providers who see themselves as very experienced with AWC said they felt like they were inventing it as they went along. Also, everyone mentioned that the Regional Self-Directed Supports Manager was doing great work, but they all said that providers who need to learn the nuts and bolts of offering the model would do well to be paired with experienced providers. Several providers offered to assume these mentor roles, and several said they would be happy to offer regular provider training within the regions where they work.

Another challenge to the model is liability. Staff persons chosen by families work for the families but are employed by the provider agency. Families who hire their friends and family members are often reluctant to really supervise those staff, and when problems arise, they don't know how to handle them. Provider policies and procedures have to be followed, and many families have a hard time doing this. This tension between who is in charge and who is the employer of record is a real challenge for many providers, and one that stresses the relationship with families and those staff that the family selects. Many of the providers interviewed said that they would not recommend that more providers join the group offering AWC until the model was clearer, until costs allowed or not allowed was consistent, and until the issue of liability for employees was more transparent.

Participant Perspectives

Participants in the model include both providers and DDS clients and their families. Providers have detailed (see above) their reasons for supporting the model and their reasons for reluctance to support it; and while there are real problems to solve, there is general agreement among providers about the many ways that AWC has enhanced the skills, self-awareness, and self-confidence of participants and their families. Some providers talked about the need for contracts to offer additional administrative and navigation funding that would enable the actual choices of participants to be realized; some providers mentioned they currently use funds from other contracts to support these activities. These financial suggestions tie into the notion expressed by many providers that there needs to be a “critical mass” of AWC clients before the model can be seen within the organization as financially viable.

Responses to the AWC participant survey painted a picture of satisfaction in some areas and frustrations in others. People are enjoying more independence now that they are self-directing, they talked about making more choices in their lives, feeling better about themselves, and learning new things. Increases in access to social activities and transportation and with their budgets were a few of the areas where people still need help. Of people who reported having had problems, the issues they noted were with finding and keeping good staff, not having enough money in their budgets, and experiencing the process as long and complicated, among other more specific problems. Participants know whom to contact and feel it is easy to get in touch with those who can help them. Overall, they have had a good experience working with the agency, and most said they would recommend self-direction to others.

Individuals using AWC and their families spoke about their experiences with Agency with Choice at the four regional focus groups organized by the Regional Self-Directed Supports Managers. People spoke about how much they liked being in charge of their own lives and how they were getting to do what they wanted to do more often than they used to. They shared stories about doing jobs they cared about, being able to spend time with their aging parents, having staff whom they trusted and liked, and feeling a new kind of collaboration building with their families and staff. Not many spoke about their involvement in new personal relationships, and many talked about feeling lonely. They wished the provider, or the Regional Office, would arrange social gatherings where they could meet other people like themselves. They also wished there were ways for families and participants to inform and mentor one another as they embark on AWC.

Strengths and Weaknesses of the Model

The principal strengths of the model are growth for families and participants and living their values for agencies. Participants and families all spoke about their pleasure at the new skills they developed and the new sense of capacity they experienced. Having a way to move one’s life toward what is desired affected both families and participants across the state. Several spoke about being proud of

themselves for what they'd accomplished, and they mentioned that this sense of pride in their own skills was new for them. Appreciating that the Department was interested in helping this happen, and that providers were excited about supporting this kind of growth was exciting for families and participants. For providers, while there were some struggles in getting the model going, all of them spoke to their real joy in seeing the people they serve have lives that were more of their own design and feeling like the agency was really living its values.

Weaknesses of the model fall into three categories. The first is the inconsistent support provided for the model at the Area level. This lack of support includes the provision of information to participants and families about funding, optional supports, and the process of using the model; consistent information to providers about what is and what is not allowed under the model; and inclusion of funding adequate to enable providers to do the information provision and management that the Area Offices seem to expect.

The second weakness falls under mutual support. Finding ways for providers to collaborate to solve problems, families to share information and support one another, and participants to learn more effectively from one another would strengthen the model across all its constituents. No one, neither those interviewed nor those who participated in focus groups, spoke about using the website the Department offers. Perhaps better marketing of the website, along with related connection-making among users of the model, would address some of these weak areas.

It's good to be in charge of my life and have support I need.

The final area of weakness involves staffing. Families have trouble finding staff, and even with agency assistance, finding staff who are interested in and capable of doing the work required is a challenge. Many families and participants report that they can't find staff who work well for them. Because the hours are usually less than full time, and often less than 20 hours per week, staff don't have access to benefits. While working for more than one participant might seem to be the solution to this issue—giving staff enough hours to be eligible for benefits—the scheduling usually doesn't work out well. Even with higher rates per hour, staff cannot afford to work without benefits and will leave for positions where benefits are available to them.

Prospects for Expansion

Most of the providers interviewed said that the model offers something from which just about anyone can benefit. There was a general commitment to helping other organizations figure out how to afford the model and manage it, and, if DDS Area Offices can become more consistent in their support for the model, there is no real reason to think that the model cannot expand. For those in more traditional DDS services, funding can be reallocated to AWC from contracts, and, should funding for new participants be made available, the paperwork has already been developed to

expand AWC supports and services. Staffing problems, both in finding appropriate staff and keeping them employed, are problems that DDS needs to grapple with if the model is going to work for all the people who might be interested in it.

9. Fiscal management service

Satisfaction with the Fiscal Management Service

Being involved in PDP means that participants use PPL as a fiscal management service. As part of the PDP survey, respondents were asked questions about their experiences with PPL. Participants reported on PPL's accuracy and timeliness in paying their employees; their own comfort in calling PPL with problems; and the information they receive from PPL.

Participants reported that PPL always or very often processes their employees' timesheets correctly and pays their employees on time and accurately. Half of the respondents said they always feel comfortable calling PPL if they have a problem and about a third said they do not talk to PPL, that the support worker they hired talks to PPL. Overall, communication with PPL was either satisfactory or not really existent for participants. One person said, "PPL is not reliable and does not communicate." Of those who talked with PPL, they seemed happy with the information they received or the solutions to problems they were having. For example, one person said, "PPL staff is always very professional when I call them." The others did not work with PPL directly and replied that they did not know how they felt about issues because they don't talk with PPL, their staff person does. These responses are detailed in Appendix F, the Participant Directed Program Participant Survey Report.

In addition to participants, Service Coordinators offered feedback on PPL. Their comments spoke to the need to "clean up PPL" to reduce repeat mistakes; that PPL's communications are difficult to decipher because they are "too wordy and confusing;" and "there are too many glitches with the PPL online service provider." Others saw difficulty for all parties involved: "I think we have a great opportunity and a great product. The biggest challenge is that it is complex. PPL cannot possibly anticipate all needs or problems. They fix things when they arise, but the 'fix' does not always stick. This is very frustrating and time-consuming for Support Brokers."

10. Stakeholder Oversight

Real Lives legislation required the development of an advisory board comprised of a range of volunteer stakeholders. Members were first appointed in 2015, and the Board has met quarterly since then. The Board has been kept up to date on the achievement of milestones in the legislation, policy development surrounding self-direction, outreach and information dissemination regarding the benefits of self-direction, and implementation of specific aspects of the legislation such as the development of fraud and abuse guidelines and information. Additionally, they've been informed of individual family and participant success stories and preliminary results of the mandatory Real Lives evaluation.

At this juncture, the milestones in the 2014 Real Lives legislation have been met and a range of policies have been put in place. The question now is what role the Real Lives Advisory Board should play in the future. There are several possibilities, both in terms of process and content. One possibility, given the current 2-hour format, is to expand the meetings to 3 hours to generate more in-depth conversations on specific issues. Further, instead of having DDS define the agenda, DDS could canvass the advisory board members to determine priority issues they would like to focus on. In any event, any changes in the conduct of the advisory board should be done in consultation with members. The future role and structure of the Advisory Board should be taken up with the current

In addition to the legislatively mandated advisory board, DDS should consider developing a group of participants and families who are participating in self-direction to form a "users" group that could advise the state office on the experience, benefits, and challenges to self-direction.

11. Lessons From Other States

As noted previously, project staff interviewed public managers familiar with the administration of self-direction in six states: Connecticut, Idaho, New Jersey, Ohio, Pennsylvania, and Tennessee. What follows is a summary of major findings from those conversations:

- All states make support brokers available to participants in self-direction through a variety of means including private agencies, through the fiscal management service, employed by the state, or recruited from certified individual providers. In Tennessee, the rate per hour is \$18.50.
- Most of the states, as part of the planning process, let the individual know their budget amount prior to the development of the plan.
- States use a standardized assessment—either “home grown” or the SIS—to develop budgets. In New Jersey, the assessment yields budget levels.
- Several states have created consumer advisory boards. Some of these boards review broad practices of the I/DD program including self-direction, and some are there to advise on self-direction specifically.
- While most state interviewees noted that the process of self-direction can be difficult in the beginning, it becomes easier as time goes on and as the support broker becomes more knowledgeable.
- In most states, people can hire family members as staff to support them. In a few states, guardians are excluded.
- In some states, participants can direct residential services (in supported settings not group settings); in others, participants can only direct day and other non-residential services.
- Where there were caps on support broker caseloads, they ranged from 30 to 35 participants; one state had no caps; and in other states, individuals hire their own support broker.
- To be a support broker, most states require some training on person-centered planning. In Pennsylvania, support brokers (who are self-employed or employed by an agency) are required to attend periodic webinars on specific topics.
- Some states take fees for support brokers out of the budget, and some states supply it outside of the budget.
- With respect to training requirements for support staff, one state, Connecticut, requires potential staff to complete online courses via the College of Direct Support.
- Most states train individuals and families on fraud and abuse.

- Some states only allow self-direction in a specific waiver; other states have no such constraints.

One of the most interesting states with respect to self-direction is New Jersey. Because New Jersey's providers are all fee-for-service and there are no preexisting or "bulk" contracts, technically everyone is self-directing since they are free to choose among providers and can move funding if they are not satisfied. Each individual can choose to hire their own staff, purchase services from an agency, or approach an agency to designate a staff person. Because New Jersey's program is part of an 1115 waiver, there are no waiting lists.

12. Recommendations

The intent behind the Real Lives legislation was to facilitate the expansion of self-direction in the Commonwealth. Since the legislation passed in 2014, there have been increases in enrollment in the PDP and AWC programs that can be attributed to the bill and the hard work on the part of the leadership of DDS and DDS staff. However, real challenges to continued expansion remain. Recognizing that self-direction has been retrofitted or grafted onto a traditional system of services and supports allows for a clearer picture of these challenges. The program has relied on traditional service coordinators (plus a small number of support brokers) who have much more experience in assisting people to enroll in traditional services than in self-direction. Funding is, with some exceptions, concentrated in provider contracts to serve groups of individuals. Further, families and self-advocates are in general much more conversant with the traditional service system than self-direction.

For years, the Massachusetts I/DD system has functioned more as a wholesale system by concentrating funding into provider contracts that support groups of individuals. Self-direction is a system built one person at a time, which requires individualized funding, a wider range of choices, employment and budget authority and other hand-tailored elements. While it is not possible to invent the public I/DD system anew, it will be necessary, where possible, to create mechanisms, policies, funding streams, and practices that deviate from the existing infrastructure that supports traditional services. The following recommendations are offered in that spirit.

Support Brokers

To ensure that self-direction becomes a robust opportunity, it will be necessary to develop a cadre of individuals solely committed to supporting individuals who are self-directing and who are deeply knowledgeable about program requirements. While there are a few support brokers who are dedicated to self-direction, they are few and far between. Unfortunately, without additional funds from the legislature, the number of brokers is not likely to grow significantly. Therefore, many participants are assigned to regular service coordinators who—though well-intentioned—have large and demanding caseloads that make it difficult to master the fine points of the self-directed option. Further, the less experienced a service coordinator is in supporting self-direction, the more daunting and time-consuming the task.

It can also be argued that service coordinators are not the most appropriate individuals to guide self-direction. The following is language from CMS guidance on self-direction:

A supports broker/consultant/counselor must be available to each individual who elects the self-direction option. The supports broker/consultant/counselor supports the individual in directing their services and serves as a liaison between the individual and the program,

assisting individuals with whatever is needed to identify potential personnel requirements, resources to meet those requirements, and the services and supports to sustain individuals as they direct their own services and supports. The supports broker/consultant/counselor acts as an agent of the individual and takes direction from the individual.⁴

Strictly speaking, service coordinators are not “agents” of the individual nor do they take direction from the individual. Service coordinators with individuals who are self-directing on their caseloads are therefore both carrying out their required administrative functions but also attempting to live up to the aspirations in the above guidance. It is possible to argue that there is a conflict between those two functions.

In the states that we examined as part of this evaluation, all employ support brokers to aid individuals who are self-directing. Support brokers in these states also co-exist with traditional case managers/service coordinators. Tennessee described its system as follows:

We have Medicaid approved providers that are employed by a DD Targeted Service Coordination Agency to deliver plan development/service coordination services to participants accessing traditional DD services. . . Service Coordinators must be employed by a Service Coordination Agency, but Support Brokers are independents who are certified by DHW but are individually employed by participants who self-direct [support brokers are employed by the fiscal management service].

Pennsylvania explained its system this way:

. . .we have both Supports Coordinators and Supports Brokers. Supports Coordination involves the primary functions of locating, coordinating, and monitoring needed services and supports for all participants. The Supports Broker service is a direct and indirect service available to participants who elect to self-direct their own services utilizing one of ODP’s participant-directed options. The Supports Broker service is designed to assist participants or their designated surrogate with employer-related functions in order to be successful in self-directing some or all of the participants’ needed services. All waiver participants have a Supports Coordinator; only self-directing participants may have a Supports Broker.

It could be argued that there is a potential conflict or redundancy if an individual has both a service coordinator and a supports broker. CMS has weighed in on this issue, according to Robin Cooper, author of a recent monograph on case management published by the National Association of State Directors of Developmental Disabilities Services (2018).

⁴ Medicaid.gov. “Self-Directed Services.” 2018, www.medicaid.gov/medicaid/ltss/self-directed/index.html.

CMS does not require that service definitions be fashioned to eliminate all potential overlap [between case managers and support brokers] (e.g., by only permitting support brokers or case managers to provide assistance in locating providers but not both). However, service definitions should be structured so that they prevent the duplicative performance of and billing for the same activity undertaken on behalf of a waiver participant by multiple providers. For example, it is permissible for a case manager to bill for the time that the case manager spends in developing a service plan and for a support broker to bill for the time spent advising the participant during the service plan development process. It would not be permissible for both the case manager and the support broker to bill for the preparation of the service plan. When there is the potential for duplicative billing for the performance of overlapping functions, states are advised to specify clearly in the relevant service definitions how the underlying activities are distinct and/or how duplicative billing will be prevented.⁵

Currently, support brokerage is not a waiver service in any of the three I/DD waivers. According to DDS staff, support brokerage was a service option in the past, but it was eliminated because so few individuals took advantage of it. However, there are “service navigators” in family support centers, AWC agencies, autism centers and in the DESE program. Service navigators provide some of the same services and supports that support brokers provide in other states. Service navigation is also not included as a waiver service; instead, it is paid for with state funds.

Recommendation 1

People who are self-directing need assistance from individuals committed to the option and who are thoroughly familiar with the mechanics of the program. To expand the number of individuals who can perform that function, it is recommended that **DDS explore including support brokerage as a waiver service in each of the three waivers**. Given that service navigation already exists and shares similar features to support brokerage, pilots could be explored using capacity at the family support and autism centers. To develop a specific proposal, it is recommended that DDS create a task force made up of individuals and families who are enrolled in PDP or AWC, service navigators, state support brokers, and DDS staff to think through options, service definitions, and rates. It is further recommended that the task force consult staff at Applied Self-Direction who are familiar with support brokerage around the country.

⁵ National Association of State Directors of Developmental Disabilities Services (December 2018). *Medicaid and Case Management for People with Developmental Disabilities: Structure, Practice, and Issues Third Edition*

Recommendation 2

In addition to exploring the possibility of adding support brokerage as a waiver service, DDS should also **request additional funding for the legislature to support the deployment of additional state support brokers** around the state. Connecticut currently supports 10 support brokers in each state region to work solely with individuals who are self-directing.

Dedicated Funding

Funding for self-direction is currently dependent on the availability of Turning 22 funding (which can only be used for a very small group of individuals), unused funds in provider contracts, and state only dollars. As noted in the introduction to these recommendations, self-direction has been grafted onto the traditional system including in the way the program is funded.

Recommendation 3

To give self-direction a more stable foundation—and one that doesn't compete with existing funding—it is recommended that DDS staff **request a dedicated line item for self-directed services and supports**.

Knowledge of the Budget

There are two issues with respect to participant knowledge of the individual budget amount. The first issue is whether the person is informed of the budget amount at the time of the development of the individual plan. CMS technical guidance is clear on this point. In the 1915(c) instructions, the application asks the state to “describe how the State informs each participant of the amount of the participant-directed budget and the procedures by which the participant may request an adjustment in the budget amount (Appendix E-2-b-iii).” Specifically,

The participant must be informed of the amount of his/her budget. This may be done during the service plan development process or through an alternate means. This information should be provided to the participant before the service plan is finalized (p. 218).

The second issue has to do with accessibility of ongoing budget information. Some families told the evaluators that they are not kept up to date on the amounts of their budgets over time.

Recommendation 4

In line with CMS requirements, DDS should **develop guidelines to ensure that individuals**—both in their initial planning process and in yearly updates—**are aware of the amount of the individual budget**. Further, though PPL has stated that they routinely send out monthly budget statements, some individuals and families say they have no knowledge of these statements. DDS should consult

with PPL to determine whether there is a need for better training of participants regarding what they will be receiving and what it means, whether mailing lists are up to date, or whether there is some other explanation for this feedback regarding budget information.

Budget Preparation

Again, the preparation of the budget for individuals who are self-directing is derivative of the budget allocation process for individuals seeking traditional services. This process adds to the complexity and lack of transparency of the process.

Recommendation 5

Many states around the country have begun to tie budget allocations to functional needs using an algorithm to develop individual budgets and/or budget levels. It is recommended that DDS **explore developing a budget/rate methodology that ties the magnitude of need** (as measured by standardized testing such as the MASSCAP) **to budget levels or individual budget amounts.**

Regional Variations in Numbers of Participants Enrolled in Self-Direction

The analysis of the statewide data described in this report shows that there are significant regional differences in utilization of the self-directed options. Some of the differences are historical, which partially explains the higher numbers in the Northeast (the self-direction pilot was implemented there) and Metro East (the RWJ pilot was housed there). However, it will be important going forward to ensure that the ability to self-direct and the requisite capacity to support self-direction is equally available statewide.

Recommendation 6

It is recommended that each **regional director**, in consultation with Area Offices, **develops an implementation plan** that -- in addition to the current regional goals/targets for the numbers of individuals who are self-directing -- outlines the tasks necessary to accomplish the goals, milestones, and those responsible for specific initiatives. **DDS should review state data to monitor progress on achieving regional goals** to inform outreach and education activities with an aim to ensuring more equitable uptake across regions and groups. This **review should also include an examination of types of individuals** who are self-directing to make sure that education regarding self-direction is reaching a range of audiences.

Information About Self-Direction

The survey data presented in this report suggests there is still a need for more information on self-direction in user-friendly and consistent formats. As was noted in the Y1 report, DDS has made progress in creating web-based material, as well as in producing videos that can be used at in-person

meetings and conferences to highlight and promote models of self-direction. The websites that may inform people about the Real Lives Law and self-direction in MA, however, do not align well. For example, the website <https://massreallives.org/> provides a listing of agencies that offer Agency with Choice. The website links directly to agencies and to a page describing the Real Lives Law, but it does not inform people about the process for beginning to self-direct or access services.

Recommendation 7

To make sure that information on self-direction meets the needs of people administering the program as well as individuals and families, DDS should convene focus groups, including diverse populations, to **review existing materials, including the manual and brochures, to determine whether revisions are necessary**. DDS should make sure that each Area Office has an individual or individuals with specific knowledge of the self-direction option who can provide consultation and assistance to service coordinators.

DDS should continue its efforts to align web resources to create a clear pathway for people and families to access information about self-direction.

Agency With Choice

The Agency With Choice program offers a promising opportunity for individuals to self-direct their staff. However, this evaluation indicates that there are still challenges to expanding the option in any significant fashion.

Recommendations 8-14

- Make information about the model more available to families and potential participants, by ensuring the AWC website is kept up to date and accurate and making sure potential participants are made aware of it; by holding open meetings regularly at Regional/Area Offices so those involved and those interested can talk about the model; by requiring that service coordinators actually discuss the model with participants and families at ISP meetings; and by collecting and disseminating stories about successes and problems with the model.
- Encourage and facilitate mentoring by providers, families, and participants about the model. This recommendation was also put forward in HSRI's Year 1 report.
- Require clear and consistent responses at the Area level to families and participants about the model, what is and what is not possible under the AWC framework and insuring that happens consistently across the state.
- Find ways for agencies to hire staff at a higher rate so they can purchase benefits, or work with agencies to enable staff to work enough hours to make them eligible for benefits.

- Deploy agency staff with experience in AWC to mentor other providers and reimburse them for their consultation.
- Develop standardized protocols to ensure that the AWC program is introduced and managed in a similar fashion across Area Offices.
- Refer those interested in AWC to knowledgeable case managers.

Emphasize Self-Direction as a Statewide Priority

There is still a need to spread the word about the availability and advantages of self-direction across the Commonwealth. As the statewide and regional data show, the proportion of people self-directing is still very small compared to those enrolled in traditional services. In fact, the proportion of participants is declining in some regions. If DDS is committed to a greater utilization of the self-directed option, there needs to be a message to stakeholders that this is a priority.

Recommendation 15

DDS should—with other stakeholders—**sponsor a state-wide convention on self-direction** that would showcase individuals who are self-directing, provide educational informational about the self-directing options, include presentations by AWC providers, give support brokers the opportunity to talk about their experiences, etc. The conference would also give stakeholders the opportunity to give feedback to DDS regarding the program.

Ongoing Monitoring

There is an ongoing need to monitor the implementation of self-direction to ensure that the program is achieving desired outcomes and that DDS staff and stakeholders are knowledgeable and committed to the option.

Recommendation 16

The results of the service coordinator survey suggest there are still some state staff who are not fully familiar with the self-directed option and/or have had very little experience supporting individuals who are self-directing. It is recommended that DDS **continue to survey service coordinators** after this evaluation is completed **to track any changes in attitudes, experience, and understanding** regarding self-direction.

Recommendation 17

To determine whether valued outcomes are being achieved, it is suggested that DDS, at least for the foreseeable future, **over sample individuals who are self-directing as part of the National Core Indicators In-Person Survey**. Results of both the service coordinator and NCI survey should be shared with the Real Lives Advisory Committee.

Participant Advisory Group

In addition to the legislatively mandated advisory committee, DDS should consider convening a group of participants and families who are self-directing either on a regular or ad hoc basis. Many of the state self-direction programs reviewed for this evaluation have created such “user” groups and have benefited from their advice and review of policies.

Recommendation 18

DDS should **consider convening a “users” group of individuals and family members participating in self-direction to provide feedback** on a range of topics including self-direction materials, policies, and experiences with self-direction.

Public Private Partnership (PPL)

Though there have been improvements in the performance of PPL, responses from participants, families and support/service coordinators suggest that there are still problems including timeliness of communication, redundant paperwork, and glitches with the online service provider.

Recommendation 19

DDS should review comments from respondents including participants and state staff and convene a meeting with PPL managers to review possible performance improvements.

Appendix A: Sampling Design and Dissemination

Mail-out surveys were developed through reviewing the evaluation goals and research questions, drafting samples for each survey, pilot testing with users who completed the survey themselves and provided comments, and with self-advocates in a focus group format.

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 Directed Program Survey	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. A total of 568 surveys were sent (195 valid surveys returned)
Real Lives Agency with Choice Survey	All participants in the AWC program, including those participating in AWC plus Traditional Services. A total of 440 surveys were sent (126 valid surveys returned)
Service Coordinator Survey	All DDS employees identified as DDS Service Coordinators. A total of 595 surveys were sent (117 valid surveys returned)

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 management service. 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 (SurveyMonkey).

An introductory letter with the survey link was sent via email to Service Coordinators from DDS leadership. There were at least two reminder emails sent out asking Service Coordinators to complete the survey. Participants entered their responses into an online data collection tool (SurveyMonkey).

Summary reports were prepared for each survey, with highlights included in this final report.

Appendix B: Key Informant Interview Guide

Questions for DDS Staff Real Lives Evaluation

Not all areas will necessarily be relevant to all interviewees.

Chronology of the Application/Eligibility Process

Please provide an overview of the steps involved in the typical process of service intake from eligibility to plan development. We then want to discuss each aspect of the process

Assessment

In addition to a level of care assessment, what type of formal and/or informal assessment is carried out when a person applies for services and supports to assess level of support needs?

Self-Direction Option

At what point is the self-direction option introduced? Is this standard across the state? Are both PDP and AwC introduced at the same time? Are service coordinators more likely to stress self-direction with some types of participants versus others?

Budget/Plan

What happens first, the development of the budget or the determination of what services and supports will be provided? What role does the assessment play in the development of the budget? Of the services and supports identified in the plan?

Budget Allocation

Please describe the way in which individual budgets for people who are self-directing are developed? Is this process different from how budgets are developed for individuals using conventional services and supports? Are there budget caps? What is the typical budget? What is the range?

Waivers

There are 3 DD waivers -- MA Adult Supports, Intensive Supports, and Community Living, and one children's autism waiver. Except for the autism waiver, is it possible to self-direct services and supports in each of the 3 waivers? If self-direction is not available in a waiver, why not? The 3 adult waivers all expire in June. Will all 3 waivers be renewed? Some consolidation? Will there be any changes in the language in the waivers with respect to self-direction?

Are there any plans to simplify waiver codes generally? For self-direction?

Available Services and Supports

Are there specific services/supports that are not available for self-direction? If not, why not? Can someone self-direct in foster care or other residential setting?

Appropriations

Does each region/area office have discretion regarding how much money is allocated for self-direction versus traditional services or is there a set amount set aside for self-direction? Has there been any move to request additional funding for self-direction from the Legislature? If not, why not?

Service Coordination

Are there plans to deploy additional resources to field more service brokers (caseload size 1/30)? As an alternative, has there been any consideration of using waiver funding to allow individuals to purchase non-state service brokers? Are there plans to revise the service coordination manual on self-direction?

People in Traditional Services

How are people in traditional services informed about self-direction? Has there been much interest among people receiving traditional services? If not, why not? When someone leaves traditional services and decides to self-direct, how is the budget calculated?

RFR for AwC

Have the services that can be directed through AwC changed because of changes in the RFR? Do you anticipate that the numbers of agencies doing AwC will increase or decrease by the end of June? Why?

Monitoring

Please describe any changes that are being made to monitor the implementation of self-direction in terms of services authorized, etc.

Abuse/Neglect

In analyzing incident data, are there any differences in terms of incidents between those self-directing and those who aren't? If so what are the differences? To what do you attribute the differences.

PPL

What are the strengths of the PPL? What things could be improved?

Autism/DESE

What bridges are being built between young people and their families who are self-directing as part of the DESE and Autism program and entry into adult self-direction? Are there any plans to make the transition more seamless?

Appendix C: Interviews with Agency with Choice Providers

Report of interviews with providers of Agency with Choice services

Eight interviews were conducted with providers of Agency with Choice (AWC) services from across the state. The DDS Regional Self Direction managers identified providers that HSRI should interview; when the provider's main office was in a DDS Region, HSRI identified the provider as based in that Region. Questions were asked of each interviewee, most of whom were the provider agency's AWC managers, and the responses collected are presented below. All the providers of AWC work with several areas; many work in several regions as well.

Why providers are interested in Agency with Choice: Providers who are interested in Agency With Choice say it is consistent with the values of their agencies. These include independence and control, family involvement, and choice, and they see AWC as offering the best way for families and participants to express and act on their own choices. Providers also say they are doing the work they want to do when a family makes choices that result in successful growth and movement towards goals for the participants they serve. They say they see enormous positive changes in participants in the AWC model.

Why many providers are not interested: Almost all the providers identified the same factors as limiting more agencies' participation in AWC. These factors included the *liability* that agencies have for the employees: since agencies are employers of record, and families are the supervisors of staff, agencies say they are co-employing when the real employment responsibility rests on them. This co-employment model is difficult for some providers to find attractive. The co-supervision is a challenge as well. Families hire people they know—often these are family members—to provide supports but then they can't accept their responsibility to supervise family members. Agencies say they try to help families in such situations, but families are reluctant to provide the supervision and feedback that related staff require. The tension between employment and supervision is a challenge.

An equally strong concern is the *inconsistency of implementation* of AWC across the state. Many providers commented that within areas, all service coordinators don't know about the model, don't believe in the model, and don't share it as an option at ISPs. Across areas, information given to families and providers is different about how the model works, how funding works, how budgets are set. Some areas don't tell families how much money is available, some do; some areas allow certain cost items, while others do not. Since providers talk with one another, these inconsistencies are well known and well shared throughout the provider community. While the outcomes for participants are very positive, the environment in which these outcomes take place is very much evolving and hard to predict, so many agencies say that their interest in AWC will have to wait until the model is more settled.

Providers say that helping to recruit staff is very difficult, because pay rates and hours vary from family to family, and in some cases, different rates are supported for the same service in different areas. Because staff are in family houses, personality conflicts arise more frequently than in other

service types, so staff are less permanent than in other service types. Providers also say that the model seems to be complicated to manage, although most agree that once they've been doing it for a while, the implementation gets easier.

Providers also said that, financially, the model is more manageable once an agency has a certain number of AWC participants, although this number varies from provider agency to provider agency. When an agency is getting started, almost every provider said that the AWC model was a loss leader and had to be defended to administration and boards of directors.

Finally, several people interviewed pointed out that many suggestions from the provider community have been made to DDS about how to make AWC more attractive, and there hasn't been any action on these suggestions, one way or another. Providers say they don't always feel *in partnership* with DDS to offer this service type. They describe getting into AWC as "a leap of faith."

How families get started with Agency with Choice: In almost all cases, providers are connected with families and participants interested in AWC through their local Area Offices. Those families who already work with a provider may come to the provider directly, but these families are always re-directed to the Area Office as the starting point for becoming involved in the AWC model. Then providers are connected with families by DDS, and the provider begins the detailed process of explaining the model: how it works, how the family might think about what it wants and needs, what a typical day might look like, how the money works, and the rest of the specifics about hiring, supervising, and keeping track of what's happening.

Many families come to agencies after leaving high school with clear ideas about what they want as alternatives to more traditional models. They and their children have been doing non-traditional things at school, and as they've talked with other parents, they expect that the non-traditional options will be available to them through DDS. For families who have been encouraged to dream about their futures, the meetings with provider agencies are exciting and hopeful; people have a sense of where they want to go and the provider feels like it is possible to help that family move in the direction they select. For these families, the provider's job of explaining the model in all its detail takes on new energy.

However, many families and participants come to DDS knowing nothing about the AWC model. They haven't discussed it in an IEP/ISP meeting, although they may have the brochure. They haven't really ever thought about the future dreams and goals they might have beyond basic health and safety, or beyond solving an existing problem in the family. They come worried about whether DDS will have anything for them, and so are not prepared in any way to move ahead with the AWC opportunity. For families that don't really know about the model, the initial discussion about the model with the provider is challenging. DDS doesn't seem to take the responsibility for helping families find out

what the model does at the area level and depends on provider agencies to do this, both for families that are prepared and for those families that are completely unprepared.

Several providers talked about how effective examples of AWC from families can help new families appreciate the possibilities that AWC offers. Most often, these examples come from that particular agency's experience, but other stories are useful when they're available. Many said that some kind of storybook for families, with success stories as well as what you can't do (if that were consistent across the state) would be a huge help.

Several identified area-to-area inconsistencies as a challenge in getting families started because what families can and can't do within the model is different area to area. Since families often talk with one another about their needs and services, many come to the provider meetings with plans that AWC can't necessarily be used to implement.

No one said they use the Real Lives website, and no one could think of any families they work with who use it either.

How Agency with Choice mixes with traditional services: Most providers identified this as a way that many families, especially those who are receiving more traditional services, start using Agency with Choice. Either because they aren't satisfied with what they're getting, or because they have heard about the model from other families, families open the conversation with the provider agency about looking for a blend of traditional and AWC supports. Sometimes the provider suggests that AWC would be a way to try new things, too, and sometimes the suggestion comes from the family. Then DDS is involved because of contracts and funding, and the planning specifics happen with the provider. Sometimes the AWC piece works so well for the family that they seek to leave traditional models and move all their supports into Agency with Choice.

Several providers also pointed out that those coming from school are used to more individualized supports these days, and so they often find themselves dissatisfied with more traditional services because the level of individualization they are expecting is not available. For those students, a mix may be suggested, but soon more traditional services are abandoned so participants can be doing more individualized, interesting things with their time.

Providers identified several ways that Agency with Choice funding was being used. For some people, it augments existing family support funding to yield more in-home support hours, during which new skills can be built; it pays for durable goods and services (like medical equipment) beyond what insurance will pay for. It supports connection making within the community—with new activities and interests, with college and other kinds of course work. It provides staff for skill building inside and outside the home, for job coaching and employment exploration. As a result of these opportunities,

some people dramatically change their lives, finding new jobs, new interests, and new people to connect with. And everyone develops a new self of self-control and self-worth.

What drives Agency with Choice supports: Everyone said it is the families and participants who are the fundamental drivers of supports, but choices are mitigated by funding available and whether supports end up being available/allowable or not. What also seems to drive AWC is the experience families have in thinking creatively about the future. Some families find it terrifying and really don't want to consider anything other than traditional models, while others who have either had training in more future-oriented thinking or who have been encouraged to do that through school are ready to take the step to planning and managing their own supports.

While the DDS contract addresses issues of funding, agreements are written by the providers with each family/participant that detail the specifics of supports, number of hours, rates, activities to be undertaken within those hours, roles and responsibilities of the agency and the family and the participant and staff and so on. These agreements are led by the family in terms of supports and by the provider in terms of roles and responsibilities. The agreement makes concrete what the supports will be and helps everyone be clear right from the beginning about all aspects of the program, and it serves as a reminder down the road if it's needed. This agreement can always be amended as things change, but having something written helps everyone to be clear. This is especially important around issues of staffing, back-up staffing, and supervision, which fall under the family role, and actual hiring and firing, which falls to the provider (along with all other HR functions).

Where is Agency with Choice within the provider organization: There are providers that offer family support, and it is under this umbrella where their Agency with Choice program is located. Each provider said that this structure made great sense. First, many families already know the provider and trust its values and services. They are involved in services that are individualized to their wishes and needs—and therefore somewhat similar to what AWC offers. If the agency is also a site for autism supports, those families find that the trust they've built over time makes them feel confident in undertaking AWC supports with that agency. An additional benefit to this structure: when providers begin offering AWC, their costs are likely not going to be completely met, so some of the costs can be covered under their family support or autism contracts.

Agency with Choice growing or not: All providers see the model as a wonderful one, from the point of view of the family and participant, promoting self-awareness, skill building, confidence, and offering a way for families and participants to actually control the supports they want and need. Even though they say that there are some families who cannot use the model because the family does not have skills in managing money and time, for the most part, families and participants can learn to use the model successfully. Providers also appreciate its consistency with the values and missions that the agencies have defined for themselves. Growth from this point of view should be promoted.

But providers also mentioned that the program is so inconsistent, has so few real guidelines, and is so fraught with problems about what one can and can't do that it is not really ready to grow, and that new providers won't be especially interested in taking part until these bugs are worked out.

Suggestions for DDS to consider:

- Compile stories from successful AWC participants and families to be shared with those learning about the model
- Pay experienced AWC providers to mentor those that are new to the model so new providers don't always have to reinvent the wheel and have a source of assistance if they need it.
- Make concrete what is and what is not possible under the AWC framework and make sure that that happens consistently across the state.
- Develop and require a standard introduction to self-direction that happens for all families so that everyone has a chance to begin to think about the model in advance of making choices.
- Pay providers to offer "open meetings" with existing AWC participants and families so that new families or those considering the model can talk with peers about their experiences and questions.
- Expect all service coordinators to at least introduce the model to families coming into the system and allow them to refer those interested families to service coordinators who are more experienced with it or more supportive of it.

Appendix D: Interview Guide for Best Practice States

Key Informant Questions Out of State Self Direction Managers Phase II – Infrastructure

The State of Massachusetts, Department of Developmental Disabilities Services, has contracted with the Human Services Research Institute (HSRI) to conduct an evaluation of a self-direction initiative, the Real Lives legislation. The evaluation is now in the second of three years. In this phase, HSRI is looking at the elements that are necessary to ensure there is an adequate infrastructure to support self-direction. We are interested in the following issues and how you've dealt with them in your state. Thanks for your time!

Service Coordination:

How do you regulate caseload size for service coordinators/case managers who are supporting people who are self-directing? Do you think that supporting someone is more

time consuming than supporting individuals in traditional services? Do those service coordinators/case managers who support people self-directing have smaller caseloads? Do they have mixed traditional and self-direction caseloads? How were caseload sizes determined?

Service Brokerage

Do you have individuals serving as service brokers who are separate from service coordinators/case managers? Are these contracted or state staff? Is it possible for an individual to hire their own service broker? Does that cost come out of the individual's budget? If you have service brokers, what are their responsibilities?

Service Plan and Budget

How are budgets for people who are self-directing developed? Are they based on a standardized assessment? Are resources allocated by levels? Does the individual/family that is self-directing know what the budget amount is during the service planning process? Who approves the budget? What is the average budget amount?

Services and Supports

What services and supports are on the menu for people who are self-directing? Can people mix traditional and self-directed services? Has the service menu changed over time? Was that done with input from participants? Can people self-direct residential services? What are the most common services and supports that people self-direct?

Agency with Choice

Do you offer people an Agency with Choice option? If so, how are agencies designated? What role does the agency play? How many individuals are enrolled in Agency with Choice? Is this an option you would like to see expanded over time? Any challenges in implementation?

Staff Recruitment

Can people hire relatives as support staff? Does the state or other agency assist people to recruit, train, and retain staff? How much of a problem has staff recruitment been in your state? What training is required for personal support staff?

Quality Assurance

Have you put any quality assurance processes in place specifically for people who are self-directing? If so, what? How do you handle incidents and abuse/neglect for people who are self-directing? Do SD participants receive any training in fraud and abuse?

Fiscal management service

Do you have more than one fiscal management service? Is the fiscal management service(ies) for profit or not for profit? In addition to payroll functions, what functions do they perform (e.g., help with staff recruitment, individual counseling, service brokerage, satisfaction surveys, etc.)? Have you changed fiscal intermediaries over the past few years? If so, why?

Evaluation

Have you or anyone else in your state conducted an evaluation of self-direction? If so what did the evaluation cover (costs, services, satisfaction?)? Did the results cause you to make modifications in the conduct of self-direction?

Stakeholder Oversight

Do you have any formal advisory body that provides input on self-direction in your state? If so, who are the members? What is the charge for the group? Have they made any recommendations that have resulted in changes in the self-direction program?

Cross Population

Are there self-direction programs for other groups in your state (i.e., aging, disability, TBI)? Is there any coordination between your program and those other programs?

Thank you so much for your help!!

MA Real Lives Evaluation

For internal review. DDS Quality Assurance Evaluation

Service Coordinator Survey Results

May 2018

Prepared for:

Massachusetts Department of Developmental Disabilities
Services

Prepared by:

HUMAN SERVICES RESEARCH INSTITUTE

May 31, 2018

Background

The following data were collected using an online survey that was distributed to DDS Service Coordinators in Massachusetts. An introductory letter with the survey link was sent via email to Service Coordinators from DDS leadership to all 595 DDS employees identified as DDS

Service Coordinators. HSRI received 117 valid surveys between March 30, 2018 and April 27, 2018, resulting in a 19.7% response rate.

Summary of Findings

Of the survey respondents, 23.9% of respondents identified themselves as **service brokers**, 10.7% identified themselves as **supervisors** and 11.7% chose other; some examples given were Trainer, Program Coordinator, and Compliance Officer. All responses were included in the analyses below.

Reporting on their current caseload, service coordinators reported a range of 0 to 70 people who are not self-directing; 0 to 57 people participating in the Participant Directed Program; and a range of 0 to 18 people participating in Agency with Choice.

Introducing and Launching Service Coordination

Service Coordinators were asked how someone who is interested in self-directing is assigned to a service coordinator/service broker. Almost half (47.37%) said there are specific service coordinators/service brokers who support people interested in self-directing. Just over a third (34.21%) said supervisors assigned people to service coordinators/service brokers; 28% said that there are service coordinators/service brokers who volunteer to work with people interested in self-directing.

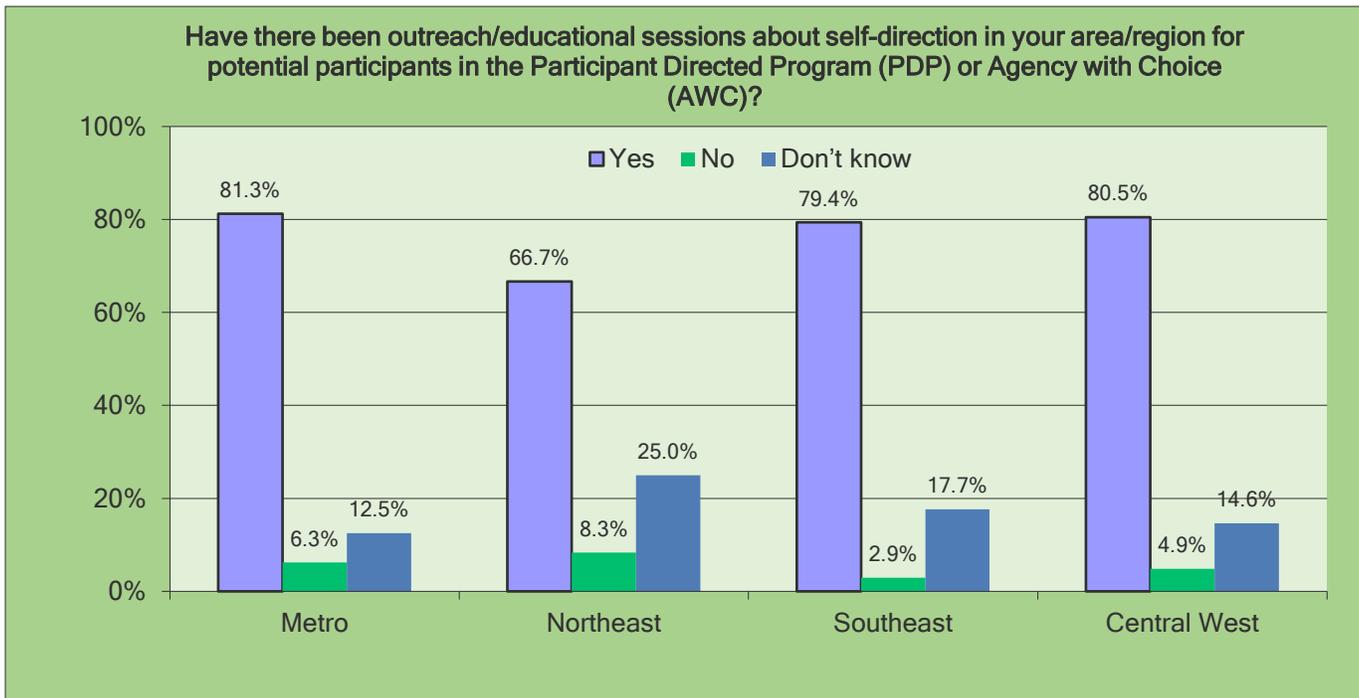
When asked how they introduce self-direction to potential participants and families, the majority (63.5%) of Service Coordinators said they hand out a brochure about self-direction. The next most frequent introduction strategy involved discussing the option with people who are dissatisfied with their current services (59.3%). Similarly, nearly 60% (58.3%) of respondents said they discuss the option to self-direct at ISP meetings.

Reporting on the characteristics of people who are self-directing, service coordinators reported a roughly equal division between people who are new to DDS services and people who have previously received traditional services from DDS: 29.8% said the individuals are new to DDS services, 34% said they were previous recipients of DDS services, but new to self-direction, and 36% said Other. Of the 17 respondents who selected *Other*, 13 of those respondents wrote in “both.”

The survey asked respondents who they felt were most likely to be attracted to self-direction. Almost 80% (79.8%) said people who are unhappy with traditional services. About three quarters (74%) said people who have involved and capable families. Followed by young people making the transition from school to adult services (68.3%).

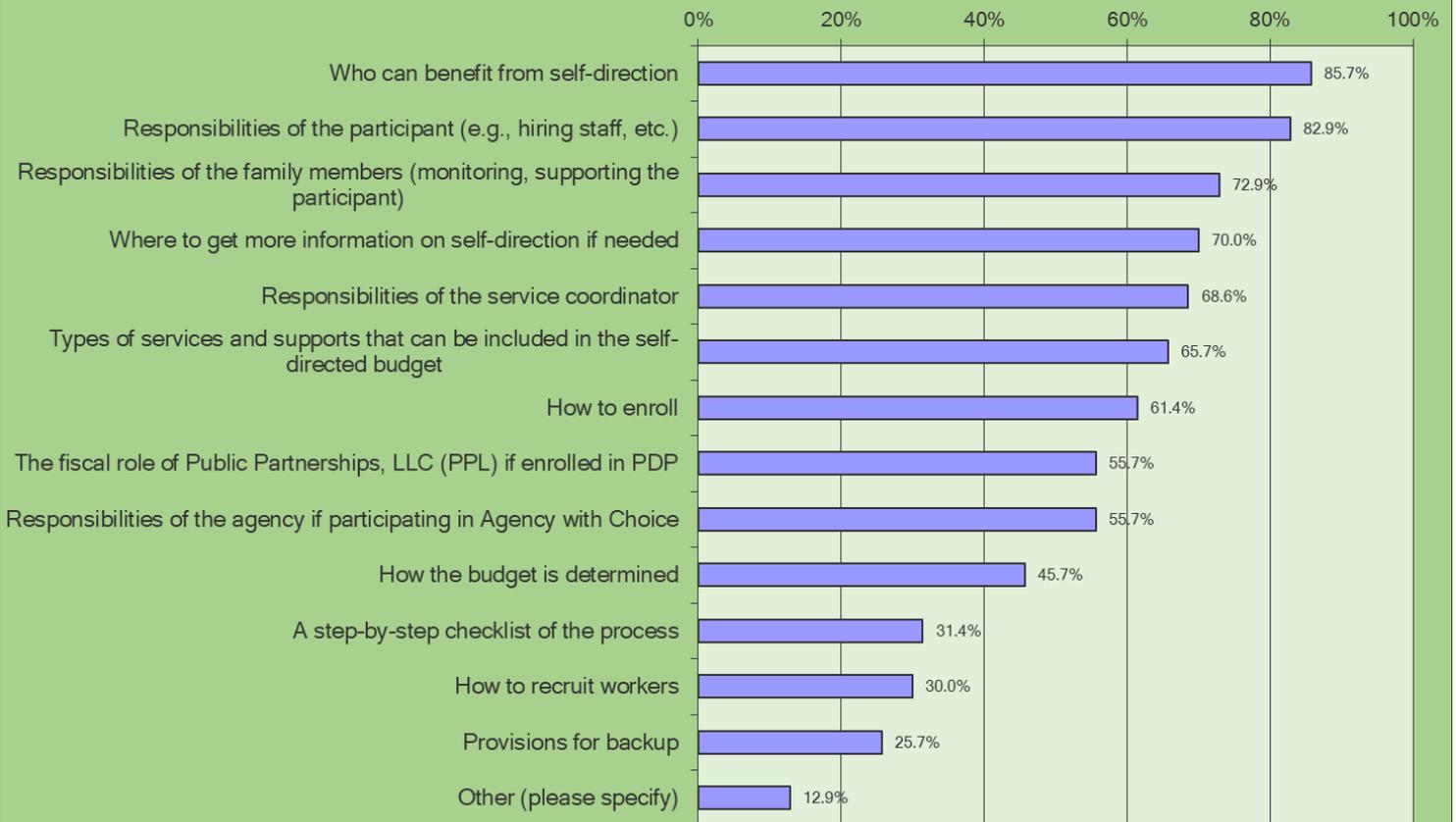
Service coordinators were asked about DDS trainings related to self-direction. About half (49.6%) said they can choose what trainings they want to go to; 29.2% said that all training is mandatory and 4.4% said they can opt out of all trainings.

The majority of respondents in all regions were aware of available trainings; 77.4% of respondents said there have been outreach/educational sessions about self-direction in their area, 17.4% said they didn't know if there had been any sessions and 5.2% said there had not been. The chart below breaks this question down by region.



Those that said there had been sessions that they attended were asked about the information the session covered. The highest ranked topic with 85.7% was who can benefit from self-direction. Responsibilities of the participant (82.9%), responsibilities of the family members (72.9%), and responsibilities of the service coordinator (68.6%) were covered; 12.9% chose *Other*, their responses are listed beneath the chart in the *Results by Question* section.

If you attended a training/session, what information did the session cover?



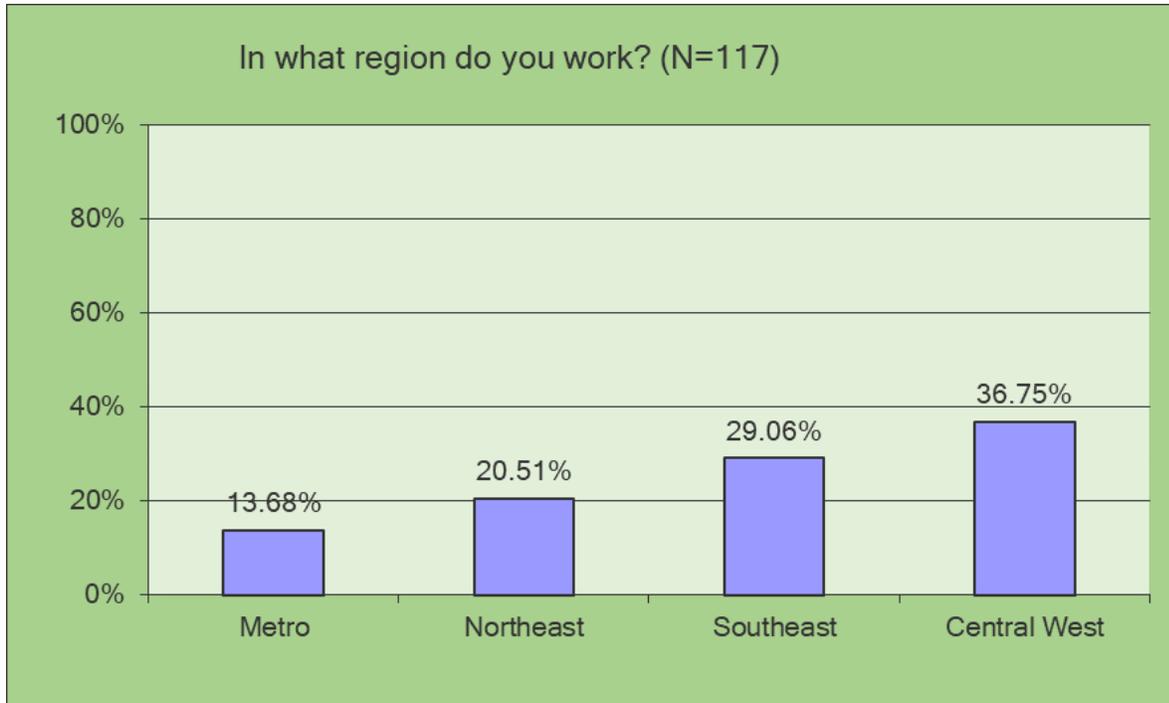
Service Coordinators/Service Brokers were asked questions about the Process, Training and Education, Communication, Impact of Self-Direction. The questions were posed with a scale from Completely Agree to Completely Disagree. For example, 68% of respondents completely agree that the process needs to be simplified, 30% somewhat agreed.

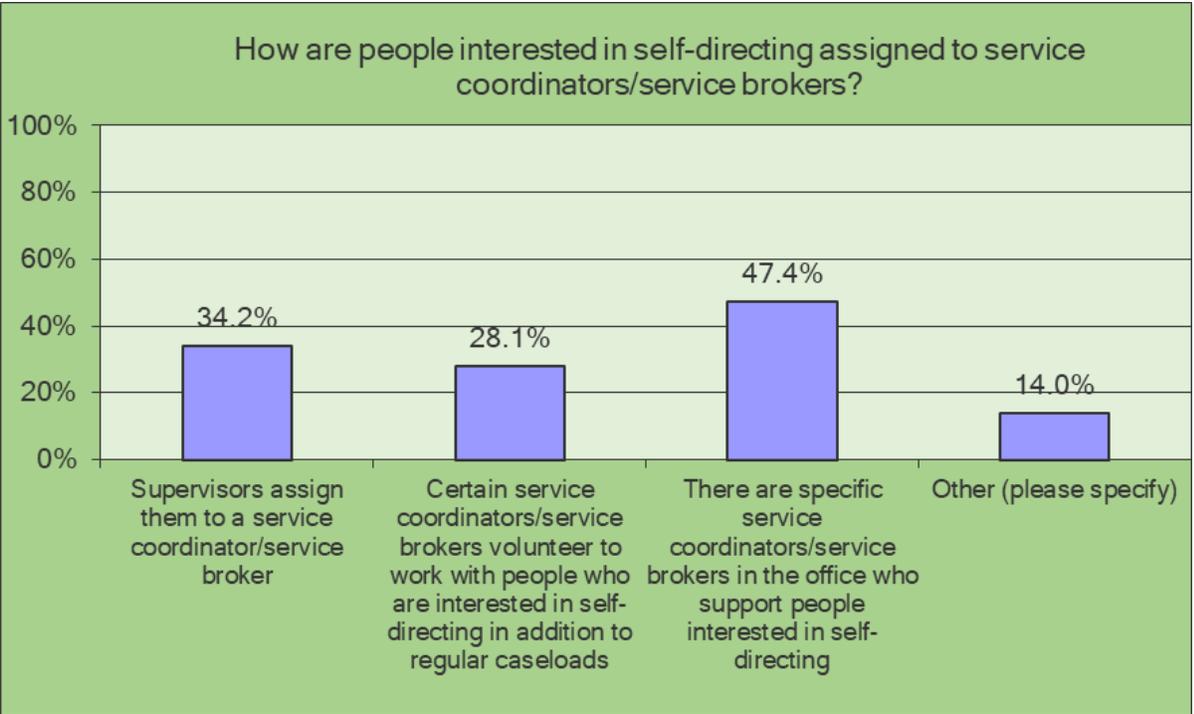
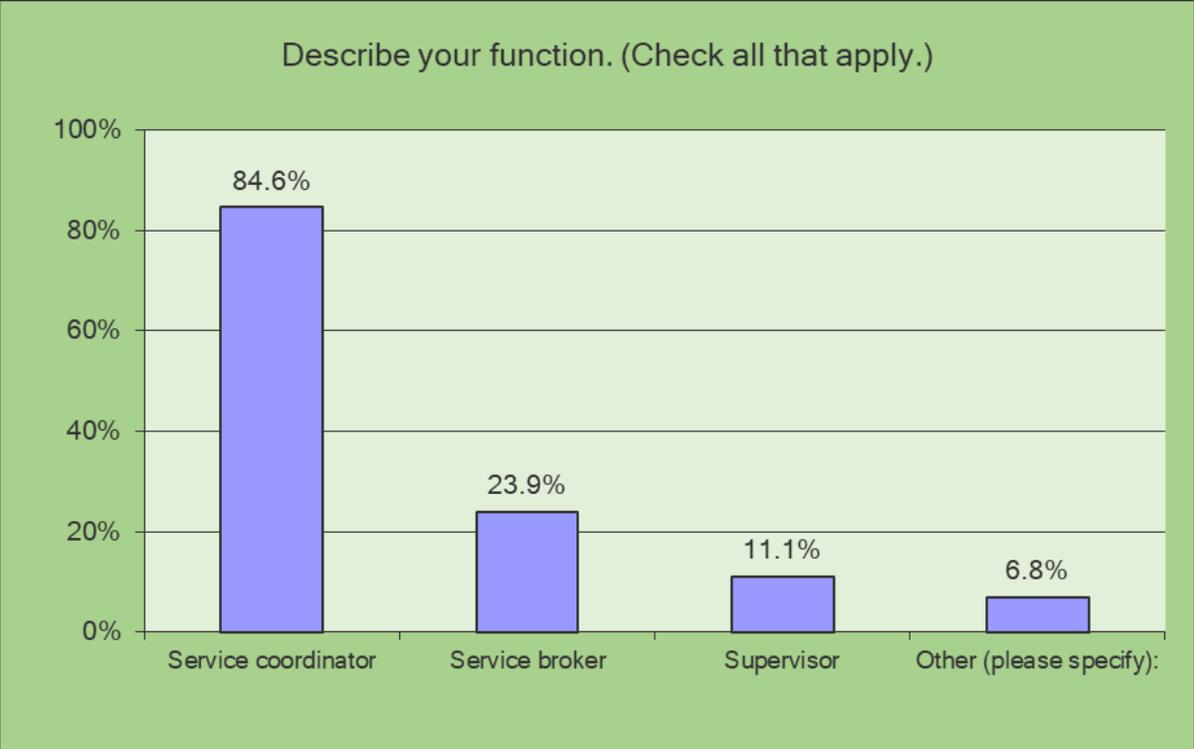
Survey respondents were given the opportunity to leave comments and answer open-ended questions. Many of the responses spoke to a need for more training for service coordinators, families, and individuals. An issue that came up several times is the amount of work it takes to serve individuals who are self-directing and the caseload sizes being too large. The lack of funding for the self-direction program is a concern for service coordinators. Service

Coordinators discussed the need to simplify the process for people and that the outreach needs to start before turning 22. All of the open response questions and answers are listed below, in the *Results by Question* section.

Results by Question

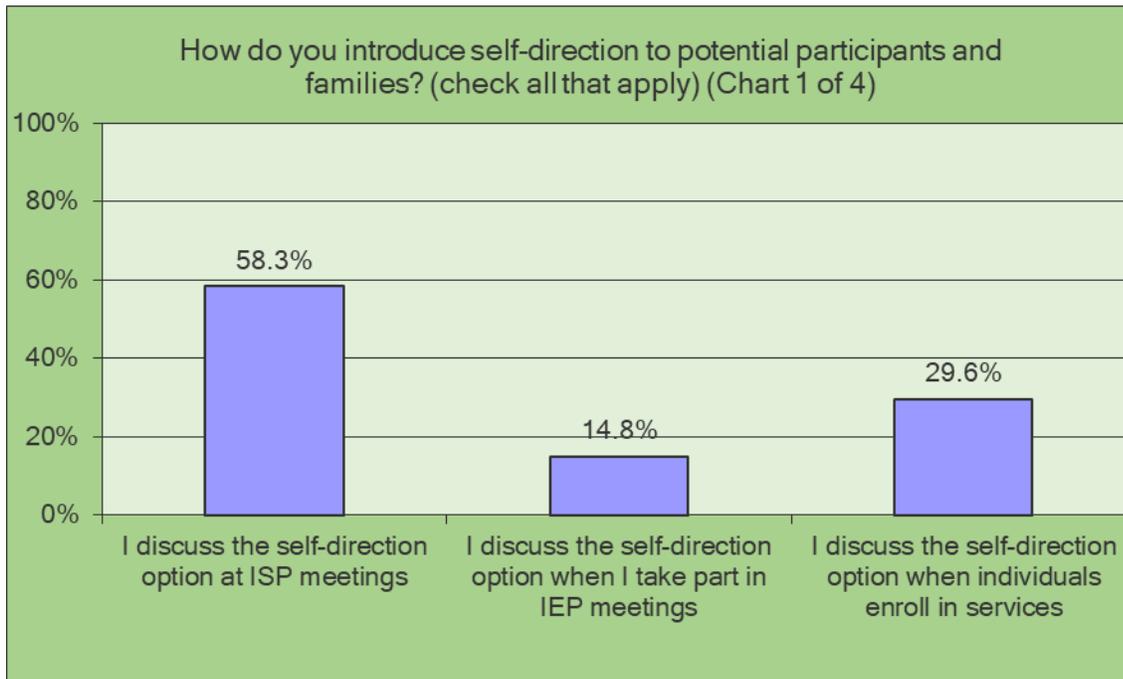
Detailed results and graphs for each question on the survey are presented below.

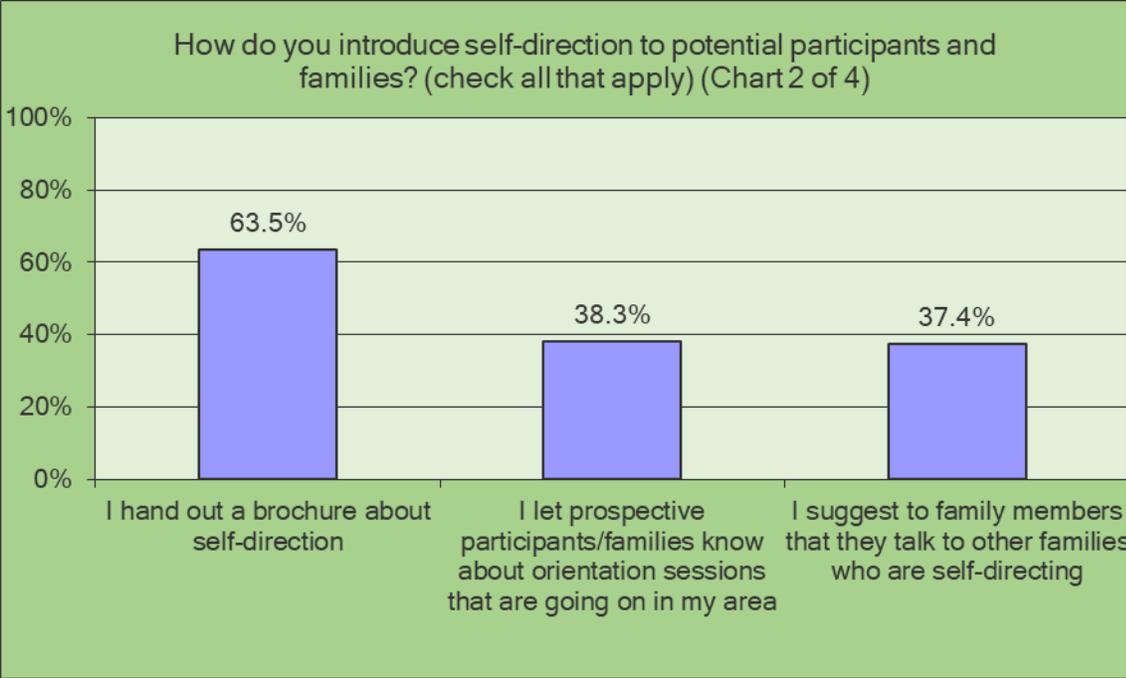


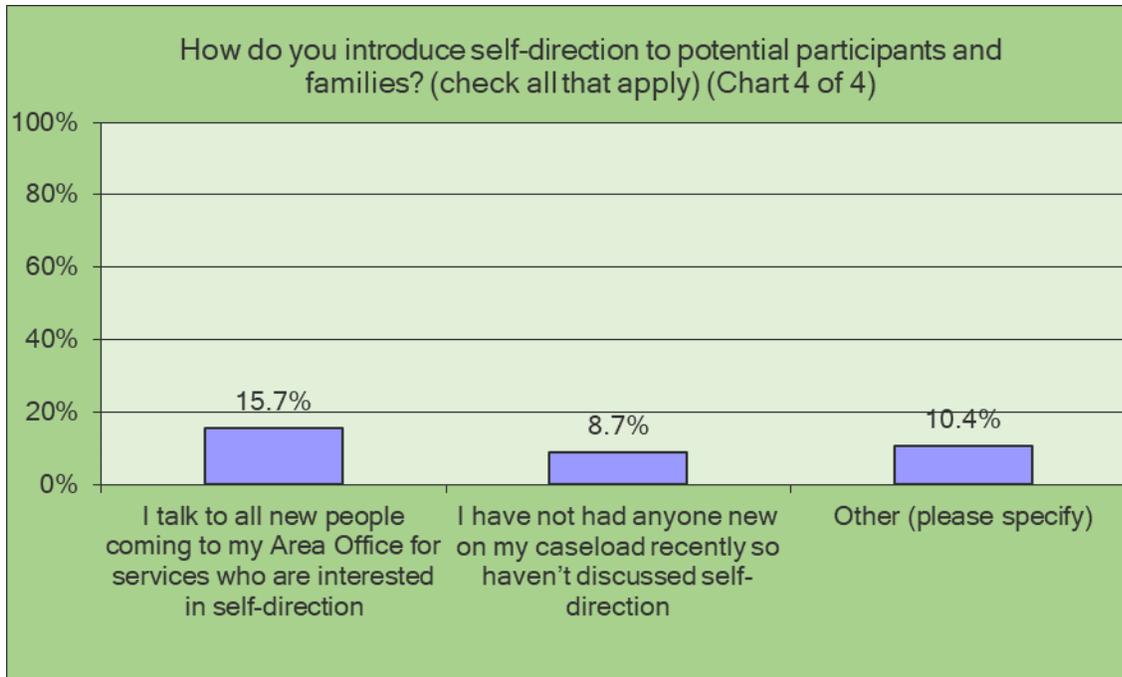


Other responses:

- If people are already on my caseload and expressed interest, I think I'd volunteer to keep them and do it. Supervisors assign cases for clients turning 22.
- I don't work with that population
- my caseload is asd individuals and I have the discussion with them about service options
- Are office is moving towards having specific Service Coordinators in these roles who have expressed interest in handling these caseloads
- We have a PC2 and AAD who also serve as support Brokers
- N/A (children's SC)
- already on my caseload and decide to go into Self Directed upon my presenting them with this option. They continue to remain on my caseload no matter their category of services..
- I'm new so I really don't know yet.
- In my Area Office there seems to be no rhyme or reason on how they are assigned. I volunteered almost a year ago to be the Support Broker in the office and no discussions to move that forward happened.
- I am the Program Coordinator II for our office. In this role, I function as our Area Office's Support Broker. I do not carry a Case Load. As the Support Broker, I work with all Clients and Service Coordinators that are involved with Self Direction.
- ASD only SC
- ID Clients are assigned to Support Brokers who only work on PDP, ASD clients are assigned to Service Coordinators who manage a mixed caseload of clients in a variety of programs including PDP
- We do not have a service broker in our office.
- Many folks with ASD are searching for person centered services due to the fact that some individuals are not as successful in traditional services
- We usually already have the person on our caseload before they choose self-direction or in my case they come to me as ASD-only and then choose to self-direct

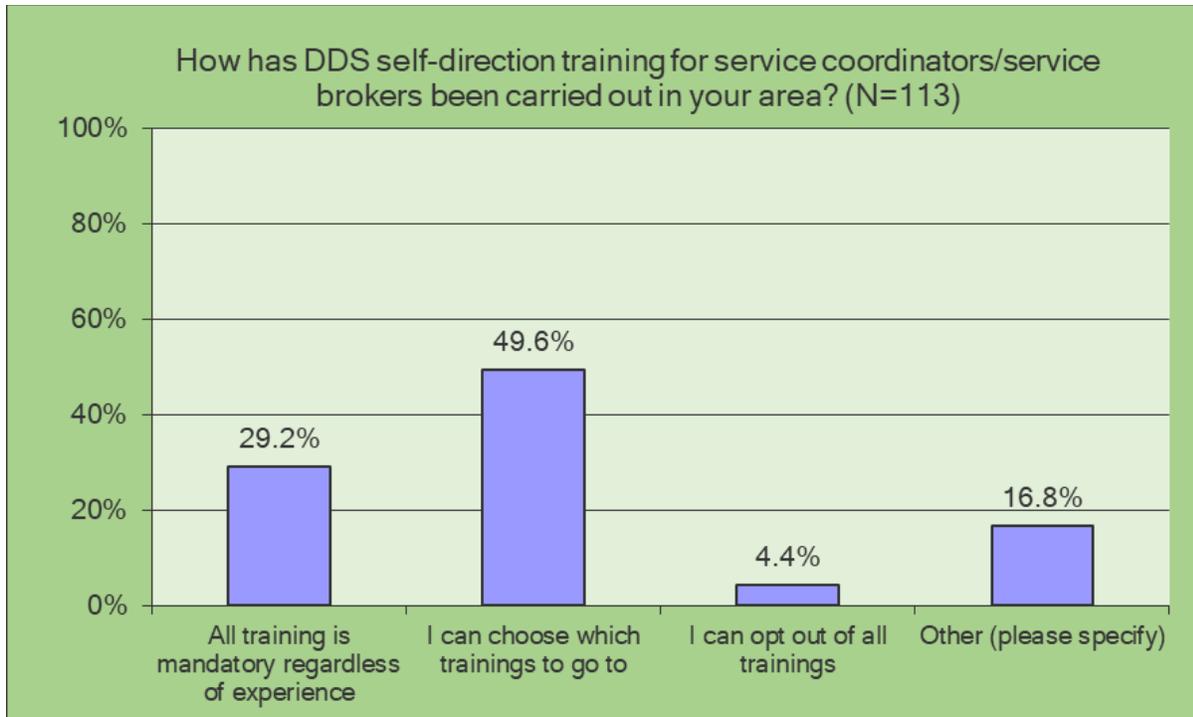






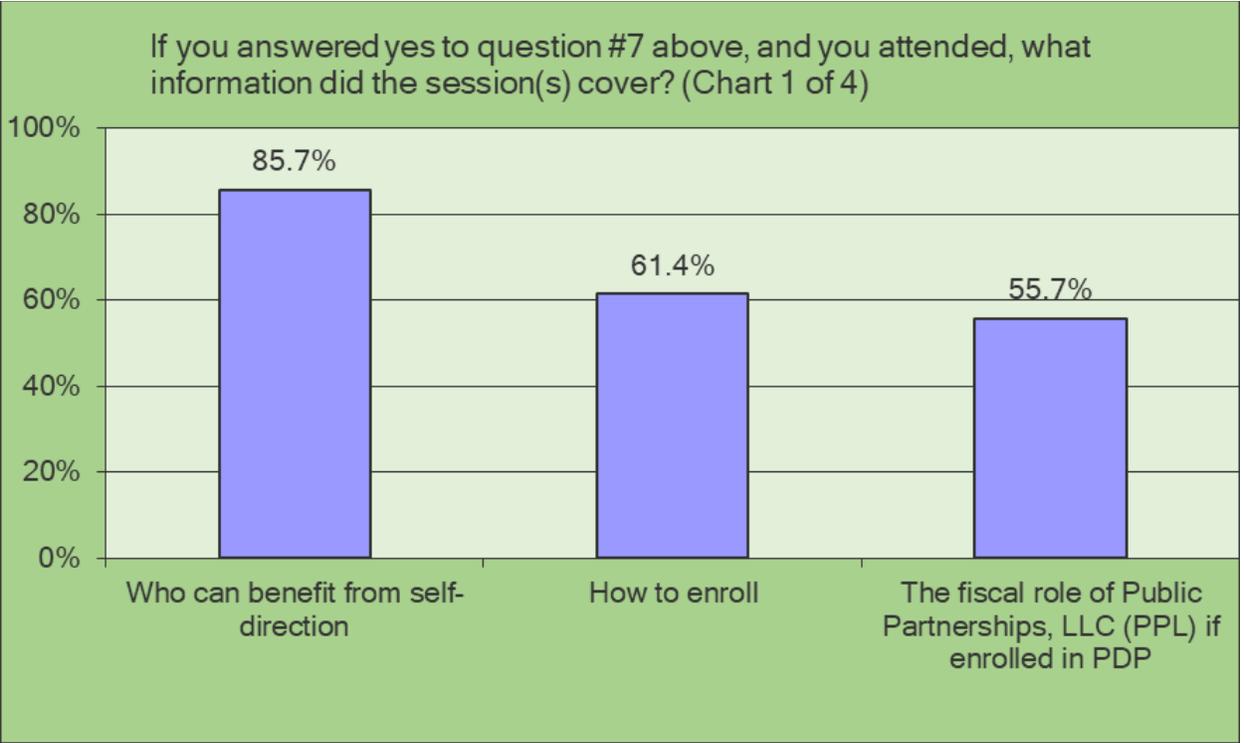
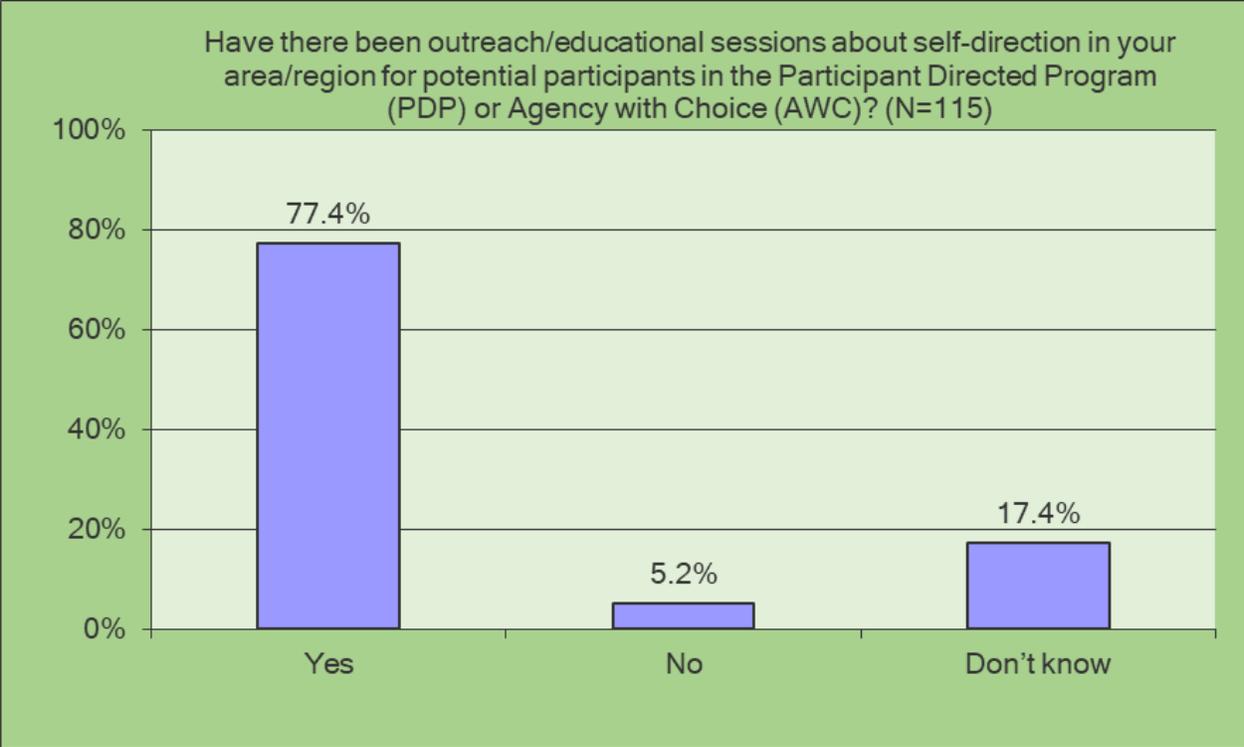
Other responses:

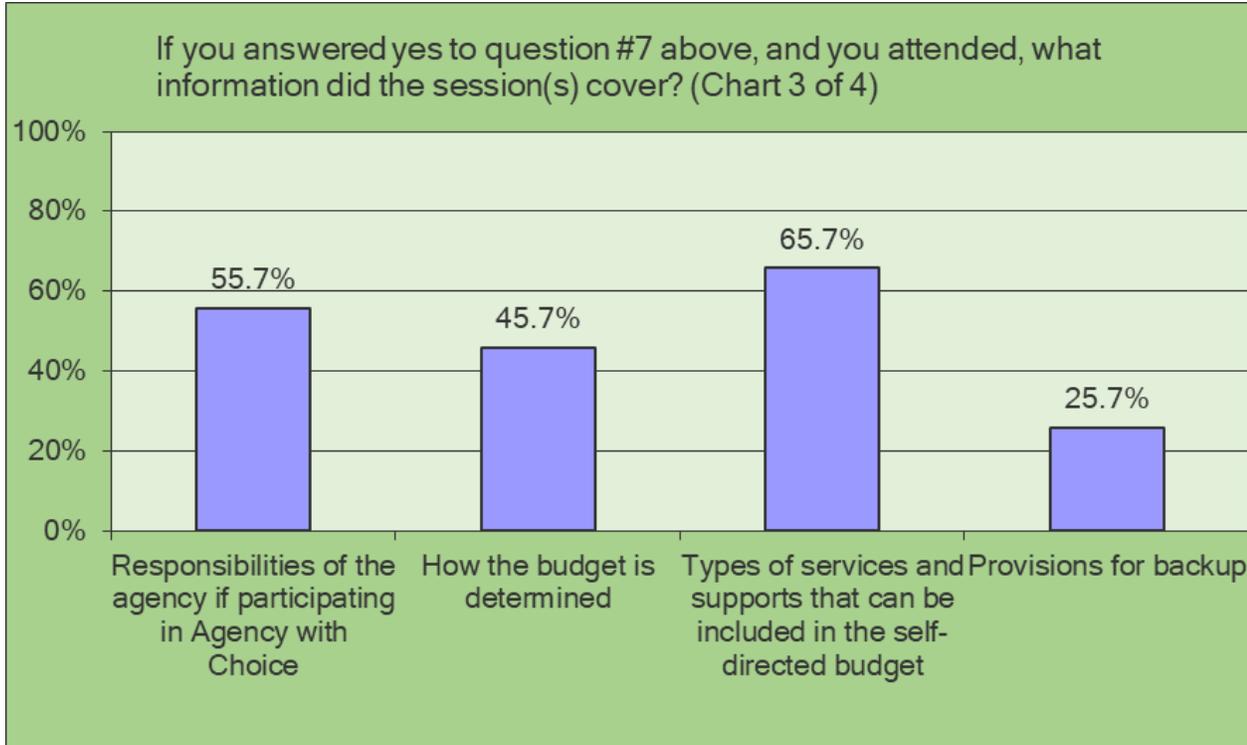
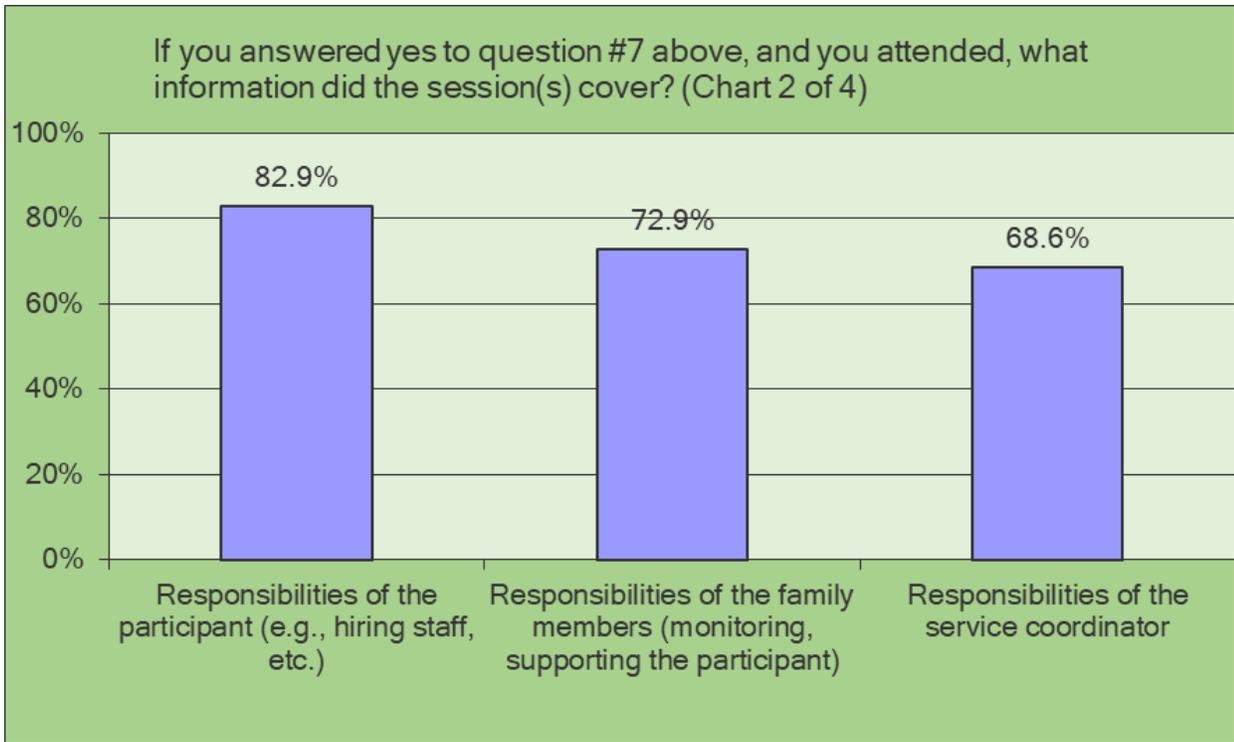
- I am a Children's Coordinator, this topic does not come up.
- Prior to SC assignment the self-direction conversation and whether or not the individual would like to participate has already taken place.
- Request Area Director's approval to pursue SD
- I don't work with that population
- N/A; children's SC
- I have on-going discussions with Service Coordinators around potential families that may interested in self direction
- I discuss with person who have turned 22 and land on my caseload.
- I meet with an individual only after their Service Coordinator has identified an interest in self direction, and has invited me "to the table" to talk specifics with the client.
- I present at local and out-of-district schools on DDS and Self-Direction services.
- I send out Self-Direction Brochures with ISP invitations; discuss Self-Direction at ISPs if individual/family/guardian is interested.
- Discuss all DDS Service Models when folks are initially assigned to me
- I discuss self-direction with families who are private paying services and assume that applying for DDS would mean losing long term support staff and having no flexibility in services

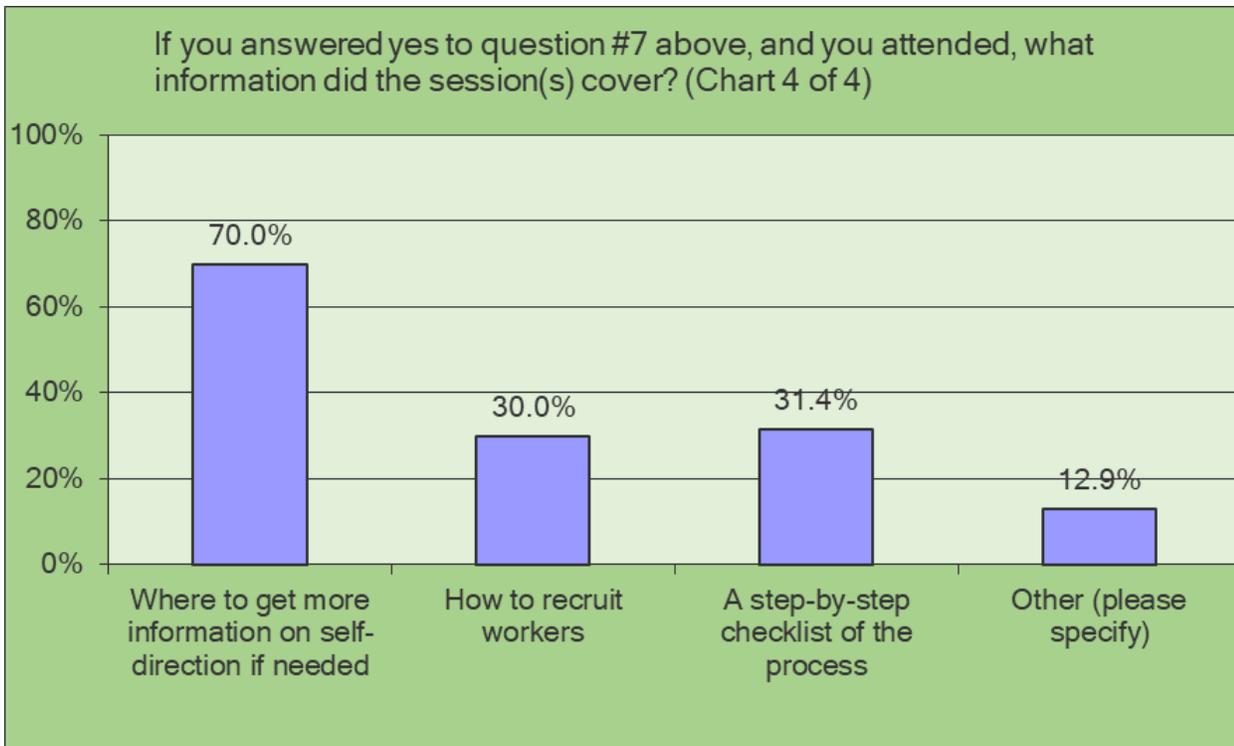


Other responses:

- has not yet been required of me
- manager directive
- As requested
- Sometimes schedule conflicts affect my ability to attend trainings.
- Just started at DDS
- I have not been offered a single training on this topic. I've had to rely on the knowledge of our service broker in the office to answer questions on the program.
- Getting to all the training is tough i feel there should be a S.C. who has only self-directed service individuals on their caseload.
- staff meetings
- There have been no trainings that I am aware of. There are optional meetings after work hours we can attend if we choose to do so.
- Provided to SCs who are interested in this type of service.
- I do not have anyone on my caseload that is self-directing
- We had mandates training in the beginning but have not had a group "full" training in a while.
- I haven't received official training, other staff teach me how to manage the program
- There was 1 mandatory training; other trainings/meetings are optional.
- All HSC had an introductory training
- Trainings are split between coordinators and assistant area director
- training at staff meetings
- I am unaware of self-direction trainings
- At least one mandatory online training annually

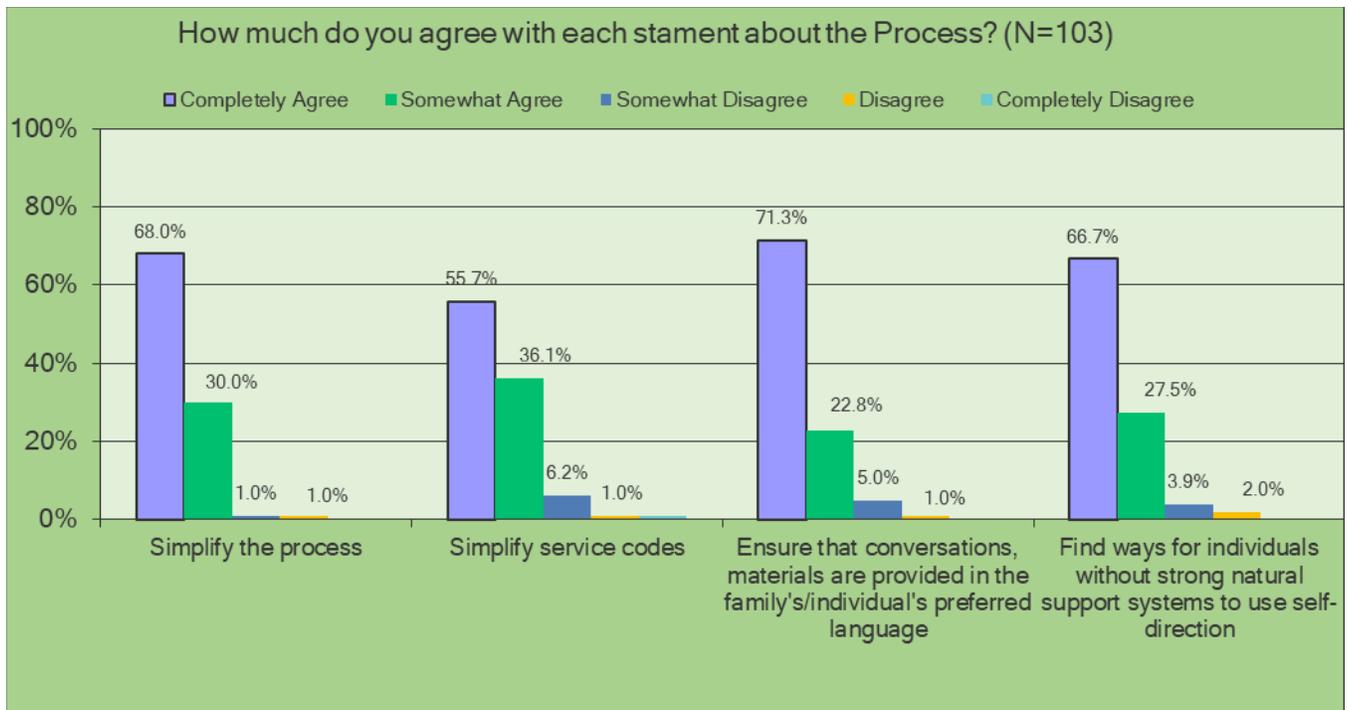






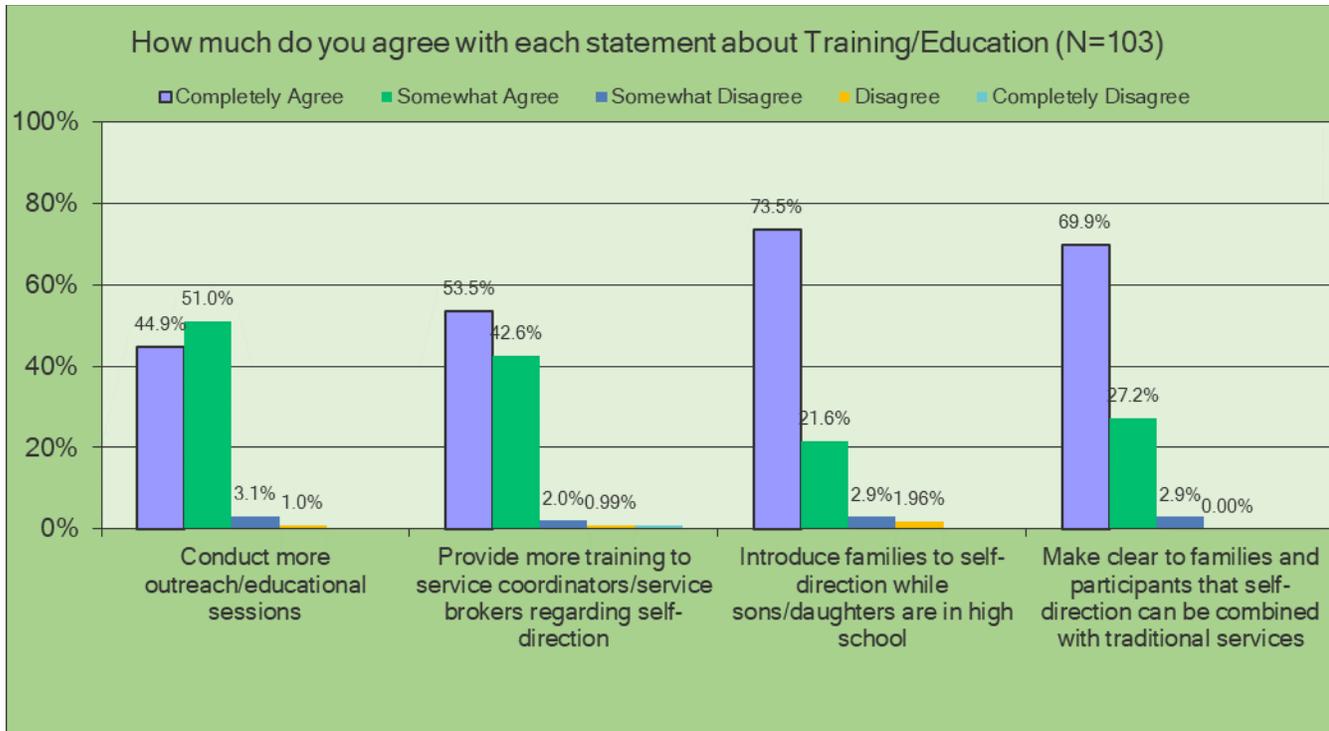
Other responses:

- All of the above
- never attended outreach sessions
- It was helpful to understand
- dates and times of meetings for families participating in self-direction
- I did not attend because they are after work hours and I have prior commitments with my family in the evenings.
- I did not attend but do know that they were held.
- Examples of others who have self-directed.
- The benefits of creating individual programs



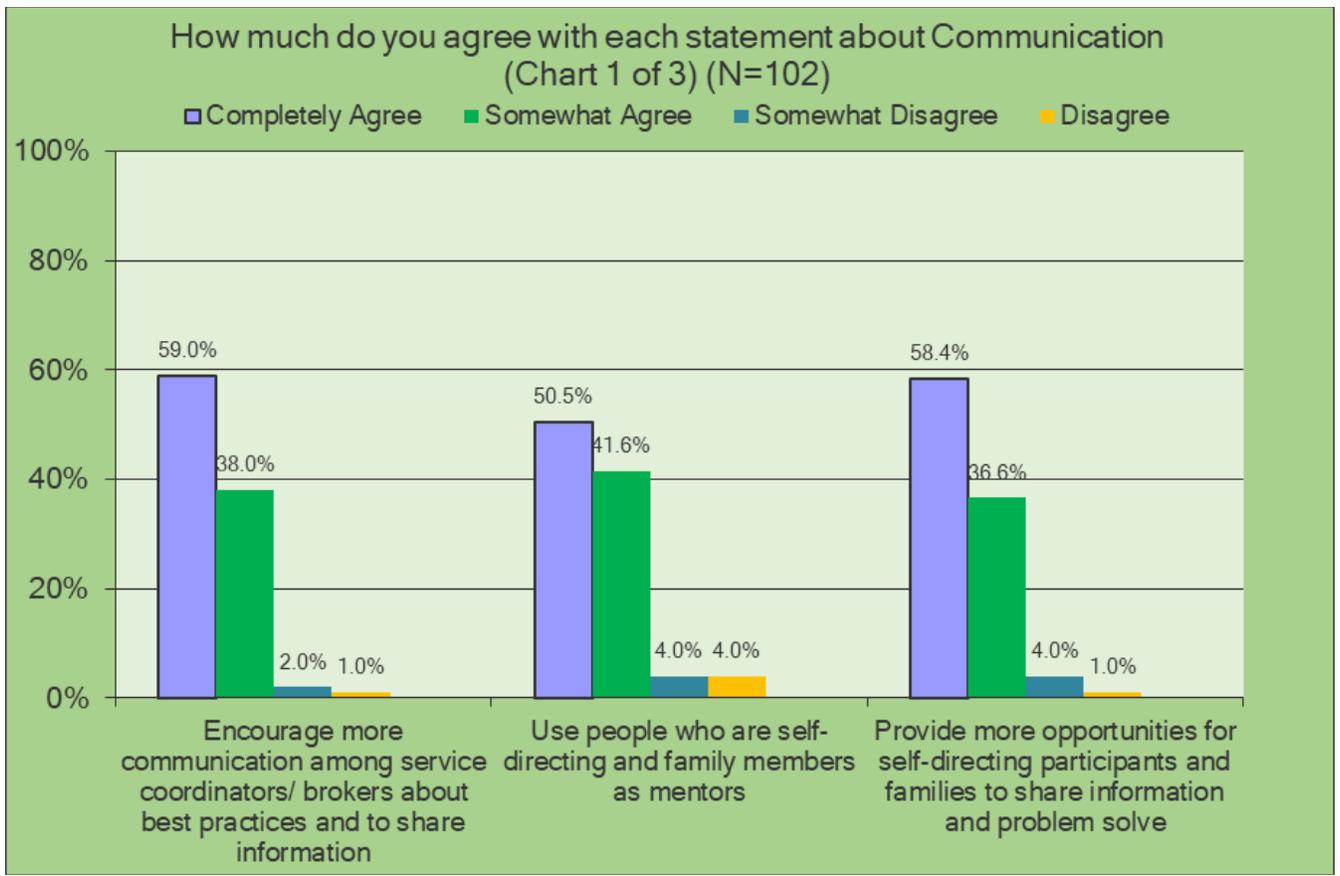
Other responses:

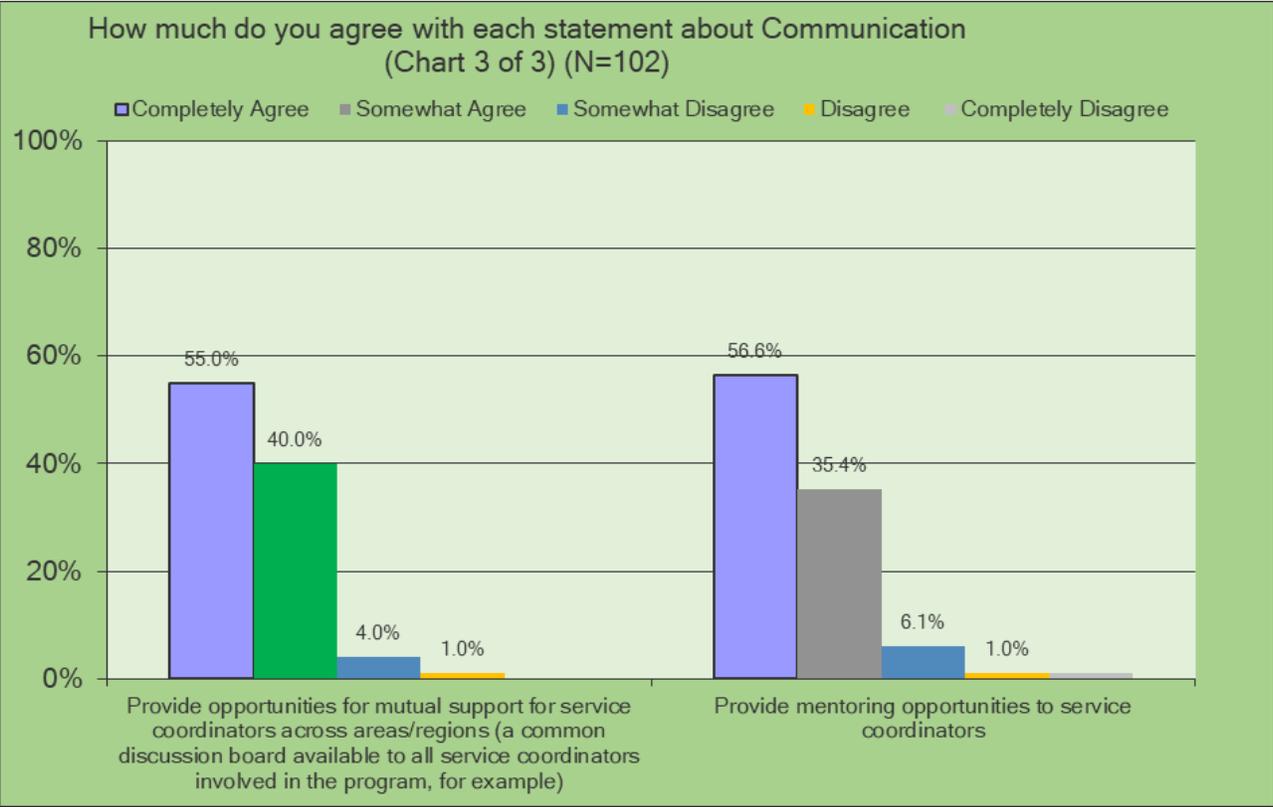
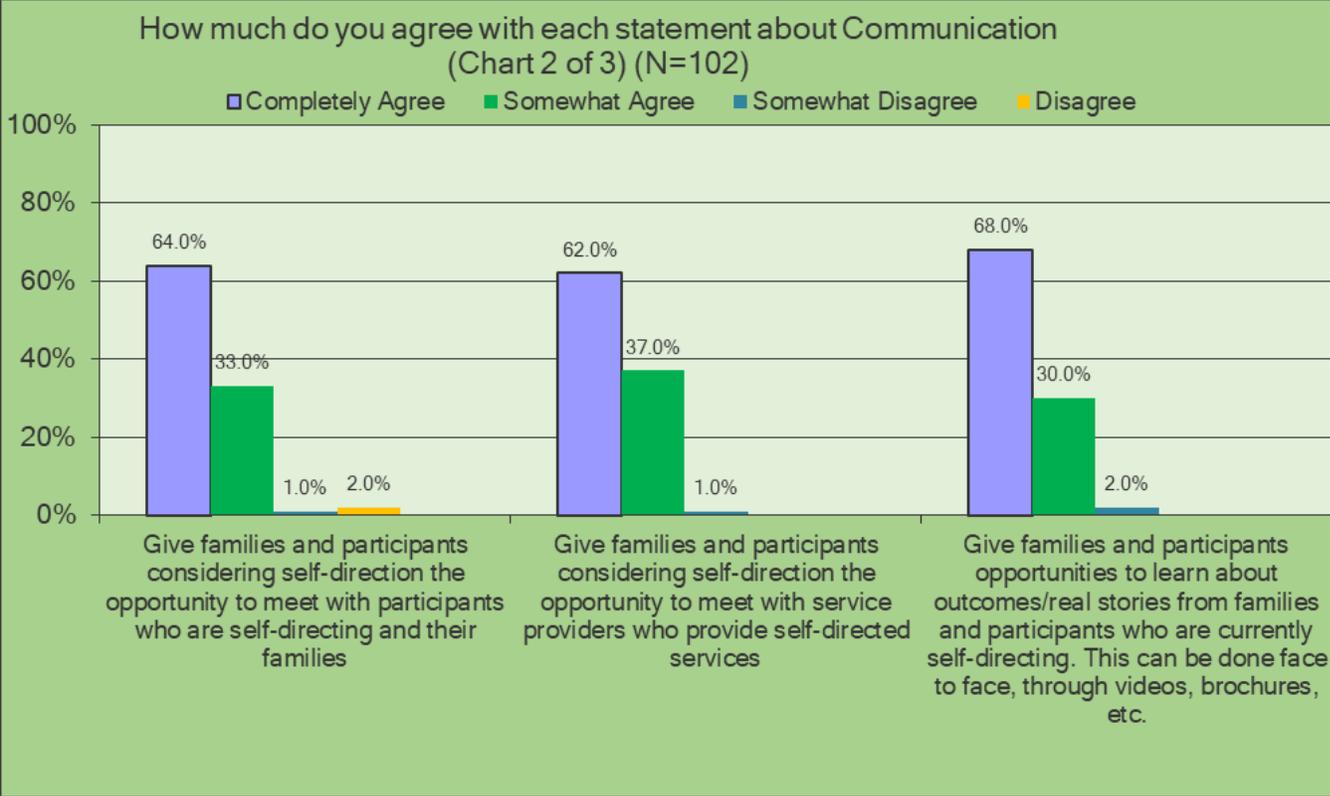
- A list of examples of covered services to include in the brochure.
- I fear the system could be abused without strong natural support systems.
- Provide funding for PDP services.
- Have a simplified "Big Picture" of what self-direction is. What are the benefits of self-direction vs traditional models by providing real life examples.
- Training! Training! Training for Service Coordinators such that they understand how to manage the process. Training should be mandatory. Have a question to cover this option as part of the ISP, to determine whether or not this option has been offered.
- Provide area offices with Service Brokers who are able to receive training and have the time to focus on self-direction.
- Provide funding for those that are interested.
- upfront clarity about what can and cannot be paid for through self-direction i.e. college classes, personal purchases, prescription copays, etc. Ensure the individual is actually actively participating in directing their program and does not just have their family member controlling the decisions.
- Better training for all concerned.
- Individuals/Families need clear, specific examples of how self-direction may open up new opportunities - hearing case studies, talking to other people who self-direct, etc.
- Improve the training of Service Coordinators. If SC's do not fully understand self-direction, they will fear the change and will not speak to it in a positive manner. Also, improve the training as a whole.
- make the allocation financially meaningful.
- have an area office "expert" in self direction and talk more with service coordinators about how self-direction works
- Clean up PPL so that there are fewer repeat-mistakes.
- Help Support Brokers access systems to help post job descriptions and look for resumes for those clients who can't afford to do this on their own. For those clients we are unable to find and hire people for them and they can wait for months before finding/hiring a worker. This is too bad because people who need services right away, and don't have the funds for AWC, can't engage in PDP. This is such a fantastic program, especially for ASD clients, we see such great success when they can use this program, it's too bad more aren't able to access it.
- Allocate far more money statewide. Encouraging Service Coordinators to help families to pursue this by ensuring it is not overwhelmingly time-consuming for them to do so. Reduce Caseloads.
- increase opportunities to educate families



Other responses:

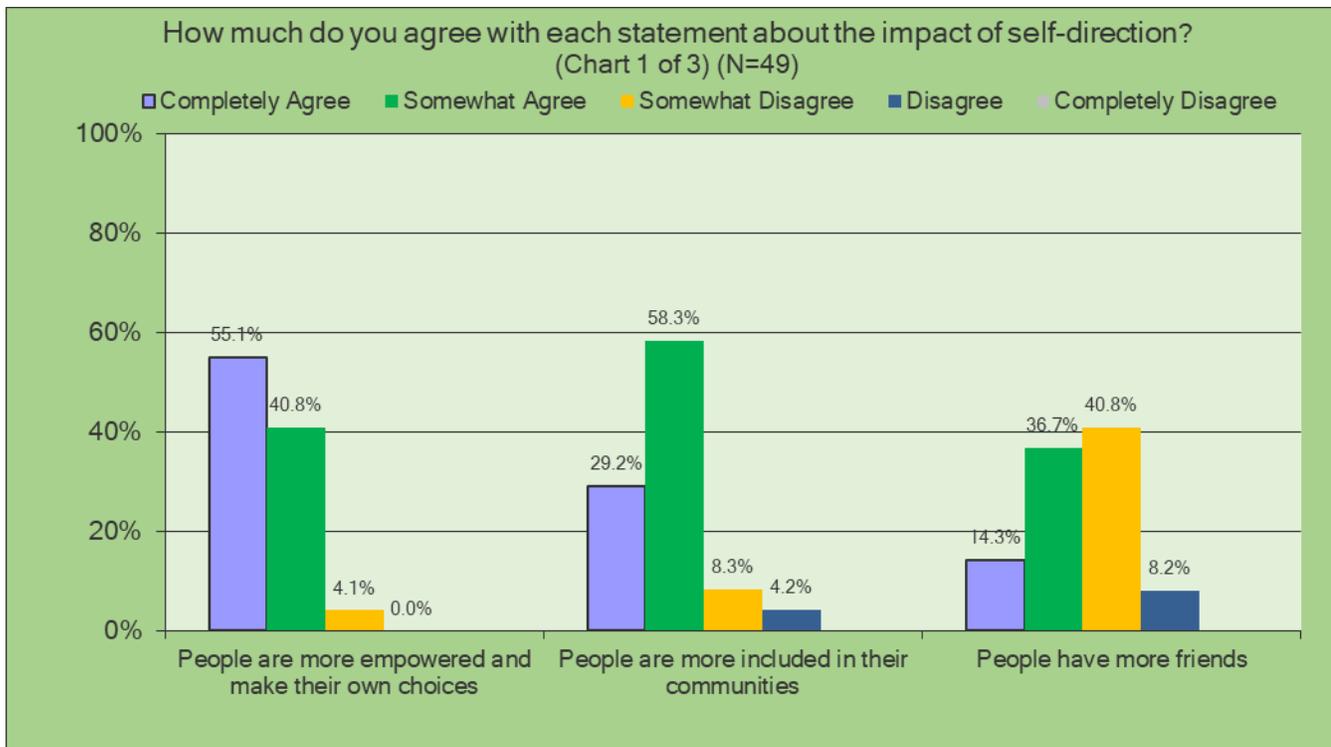
- Have more local trainings for staff and families
- Dedicated supervisors for SCs that manages PDP cases. Supervisors that can be a source of support and guidance for support brokers (as opposed to a supervisor that feels their only role is to monitor SC for mistakes)
- Having S.C.'s that deal with traditional services and are doing self-directed services seems to be a real huge undertaking
- Provide more case scenarios (e.g videos) to accentuate the benefits of self direction to provide potential individuals/families a clearer picture of what the PDP program is able to offer
- Each area office should have designated service brokers not volunteers to do work we are already expected to do.
- Information sessions need to be more in-depth about the process of self-direction and not just about the general concept. Families need to understand the responsibilities they are taking on. Once people are enrolled, they need additional training on how to be an employer and how to manage their services to recruit and maintain staff as well as track ISP progress.
- Specialize caseloads.
- Betsy Irwin is in our area and has done a great job educating families and hosting info sessions for families in multiple languages. There is some confusion with ASD folks because they don't get as much funding and therefore can't use PDP with traditional service. Perhaps having separate literature/info for ASD service coordinators to give to ASD clients would be helpful so they don't think they are being short changed when they can't get as much as the ID clients.
- Service coordinators need assistance on PPL cases due to their extremely high caseloads.
- Allocate far more money statewide. Encouraging Service Coordinators to help families to pursue this by ensuring it is not overwhelmingly time-consuming for them to do so. Reduce Caseloads.



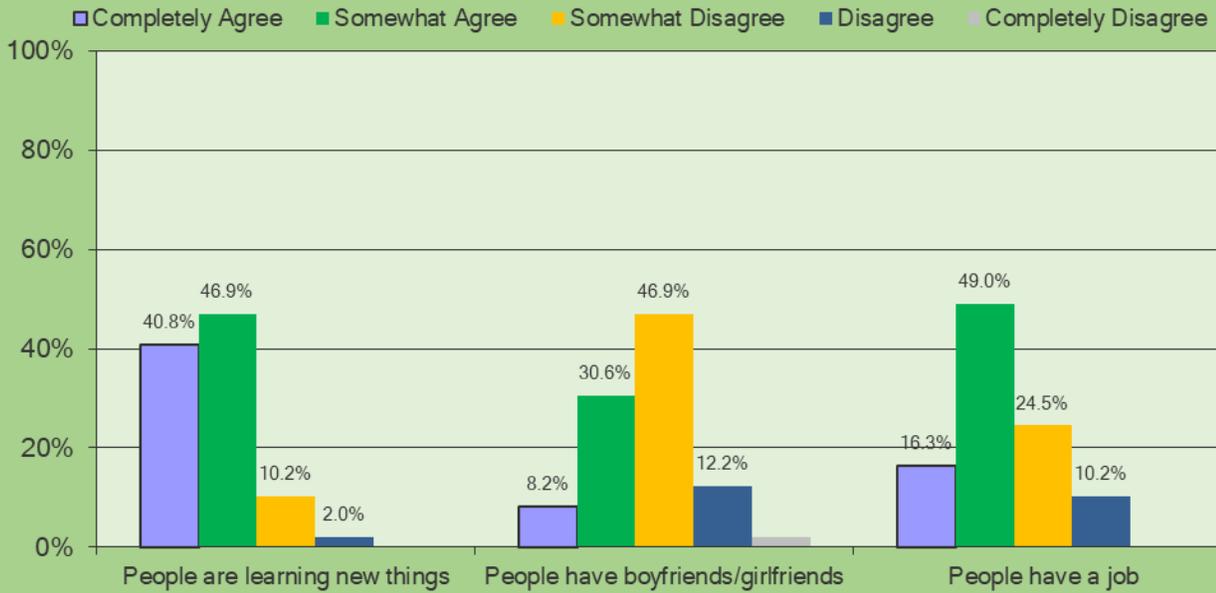


Other Responses:

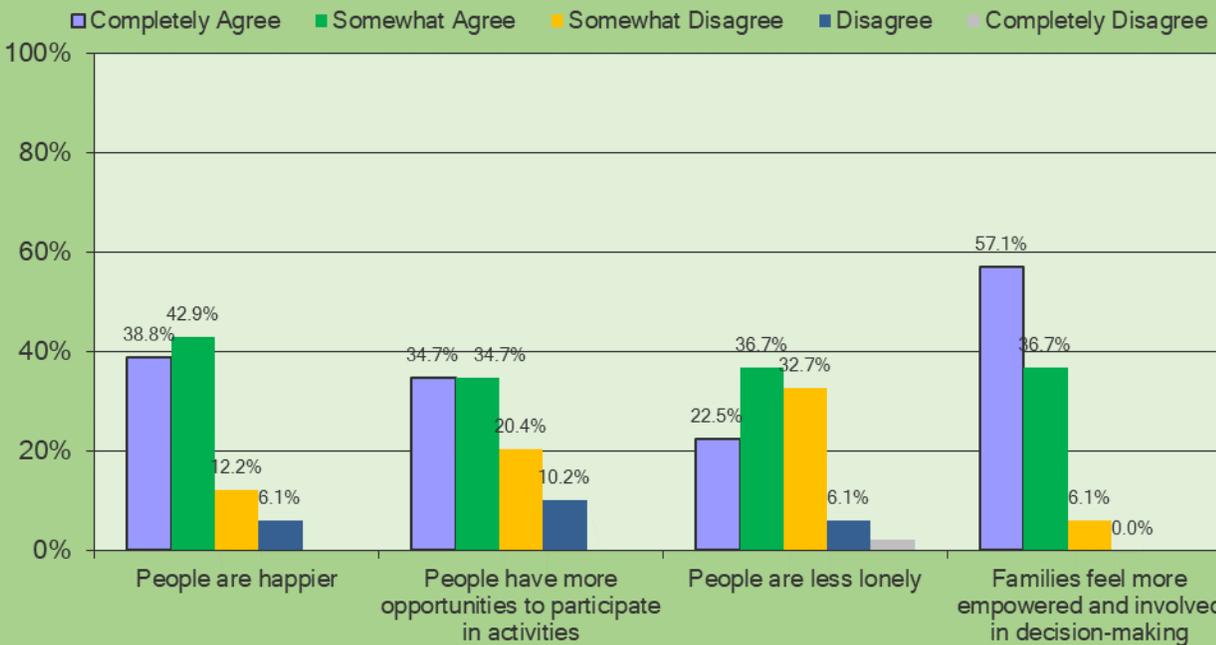
- Training materials for Support Brokers need to be clear and concise. PPL emails are often wordy and confusing. Language and labels used in training materials should be consistent. For example: Support Brokers should not be used interchangeably with other titles like Support Service Workers.
- Provide area office with service brokers who have received formal training.
- Organize the system and lessen the confusion. Colleagues (both SCs and management) I've spoken to about this all agree that present practices are convoluted and not very well organized or managed.
- I feel that my co-workers, managers and regional office are very supportive and we have lots of discussions, which is very helpful. It's always good for clients and families to engage and learn from each other if that's what they want. Some ASD and ID clients who do well in PDP reject traditional services because they don't want to be associated with "disabled" people, the other clients who DDS supports. For these clients too much pressure to interact with other PDP people and families can be a turn off. The Metro region, currently, has monthly leadership meetings that are not mandatory for clients. These are a good example of giving clients the choice to interact and learn from each other if they want. In these meetings the clients that do show up get a lot out of their discussions and interactions.
- Allocate far more money statewide. Encouraging Service Coordinators to help families to pursue this by ensuring it is not overwhelmingly time-consuming for them to do so. Reduce Caseloads.



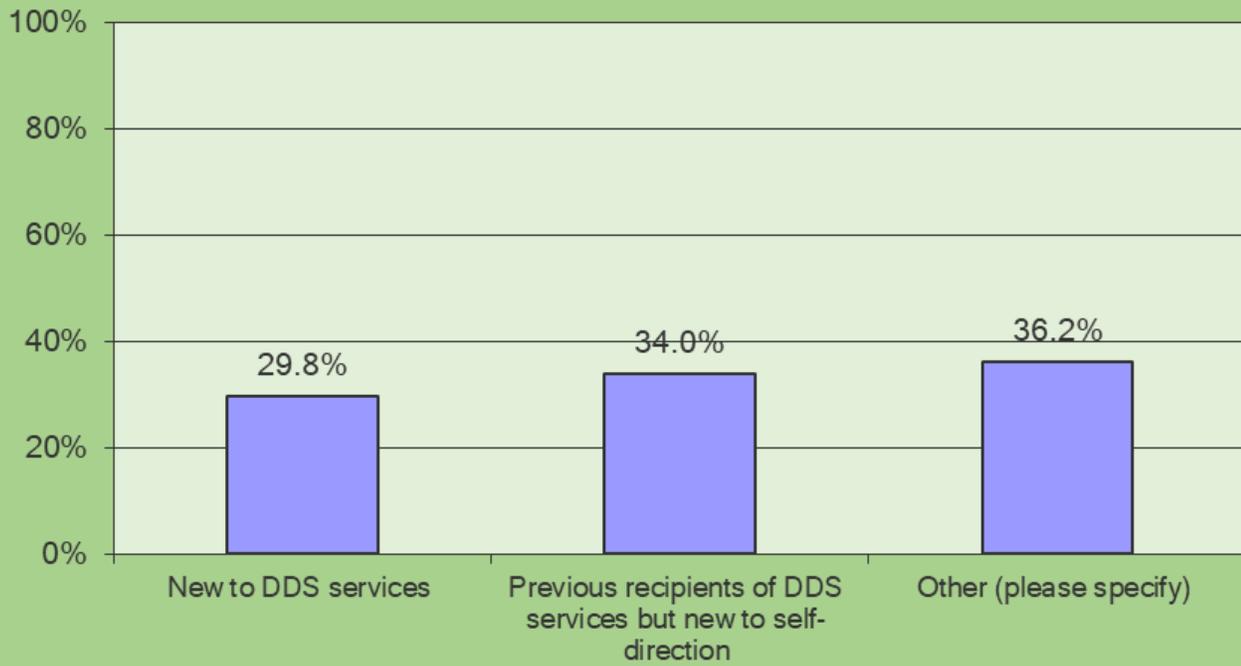
How much do you agree with each statement about the impact of self-direction?
(Chart 2 of 3) (N=49)



How much do you agree with each statement about the impact of self-direction?
(Chart 3 of 3) (N=49)

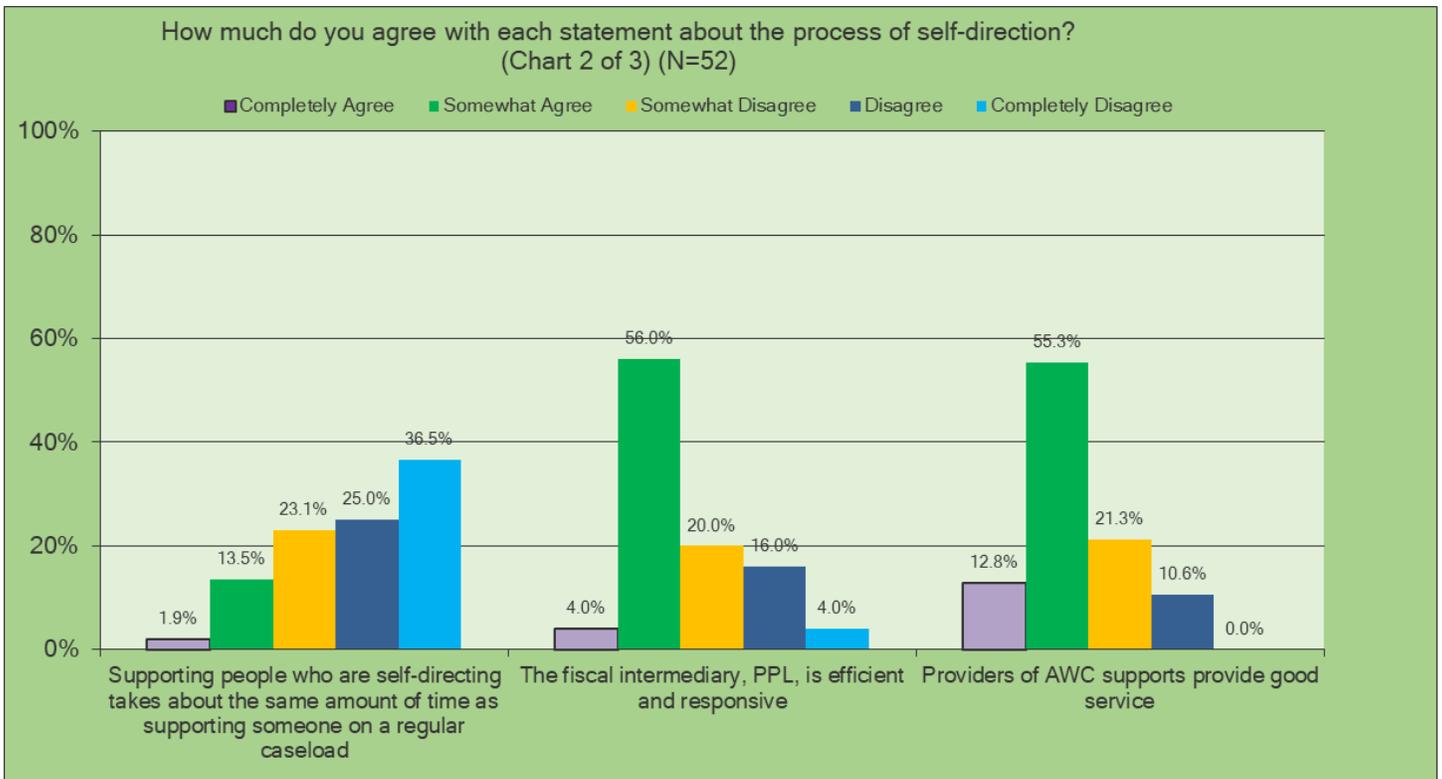
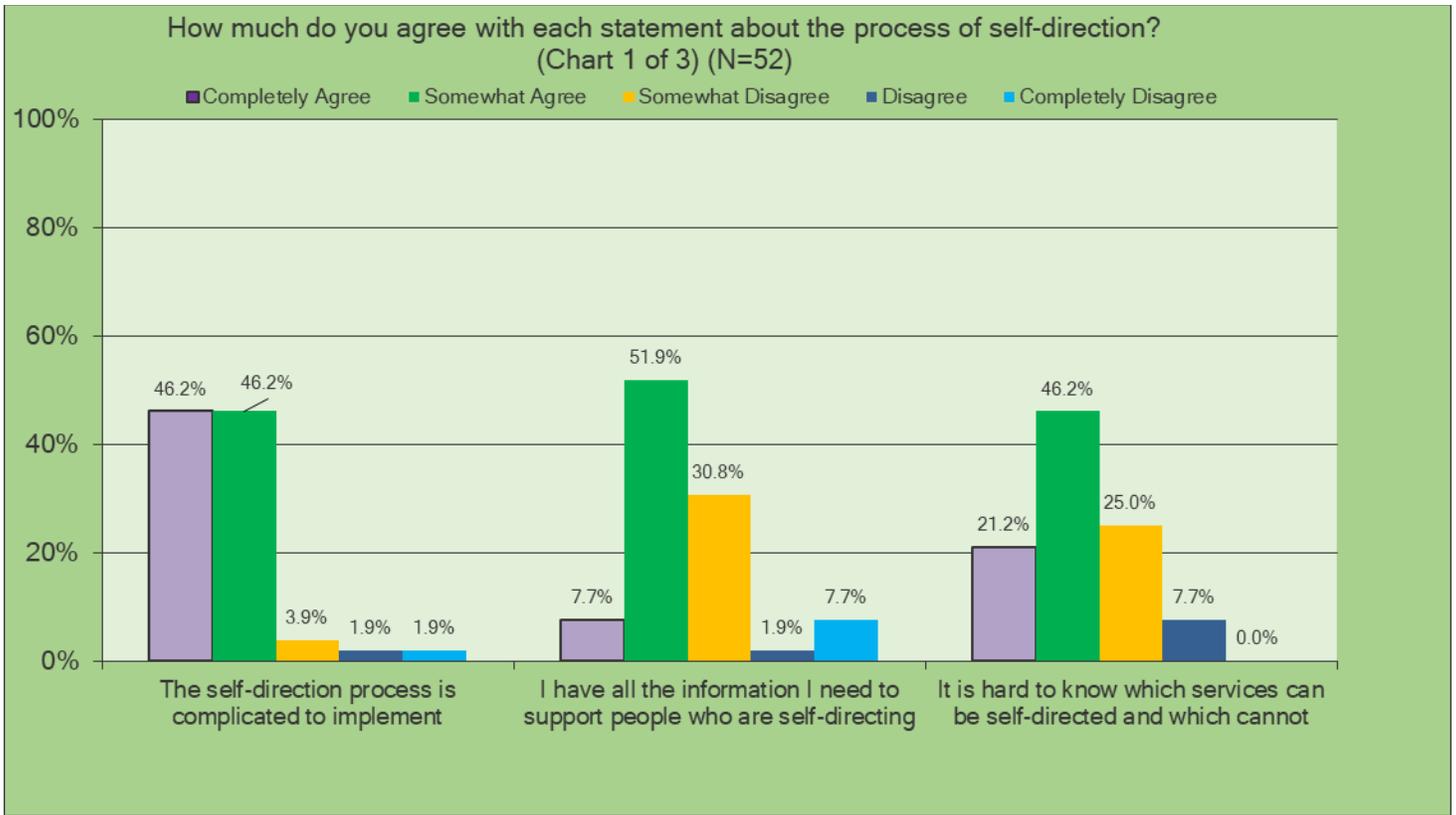


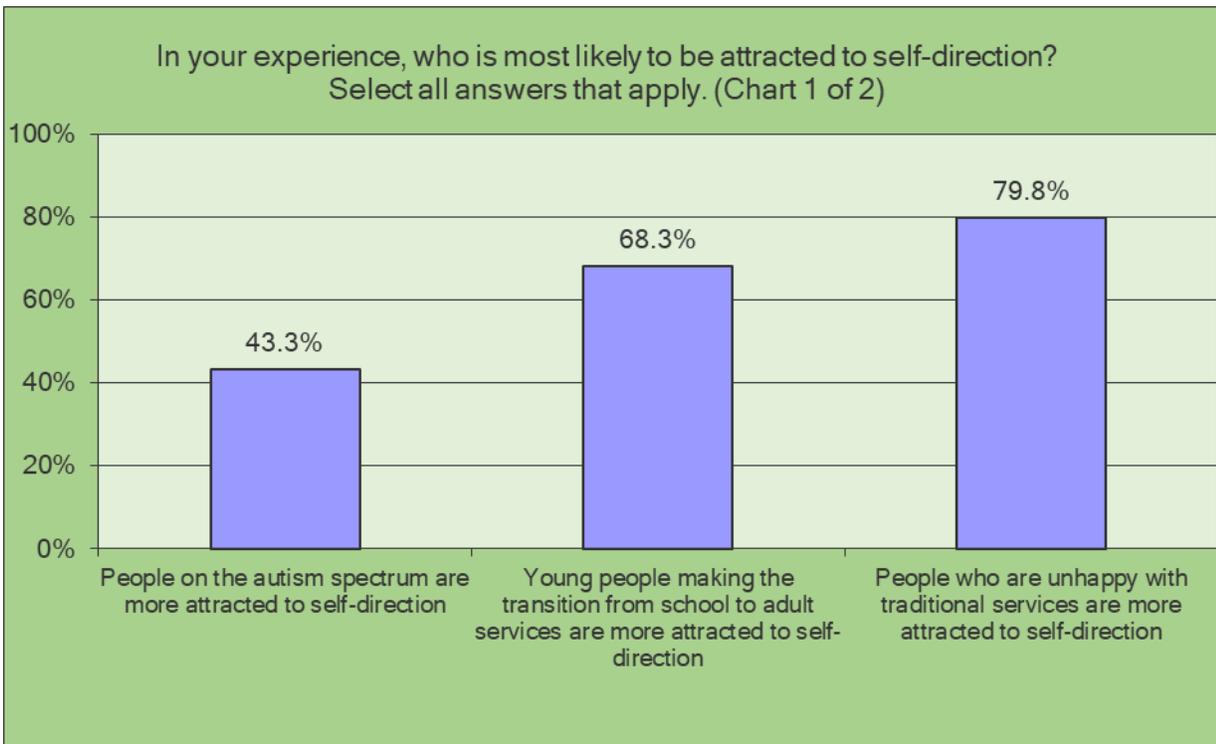
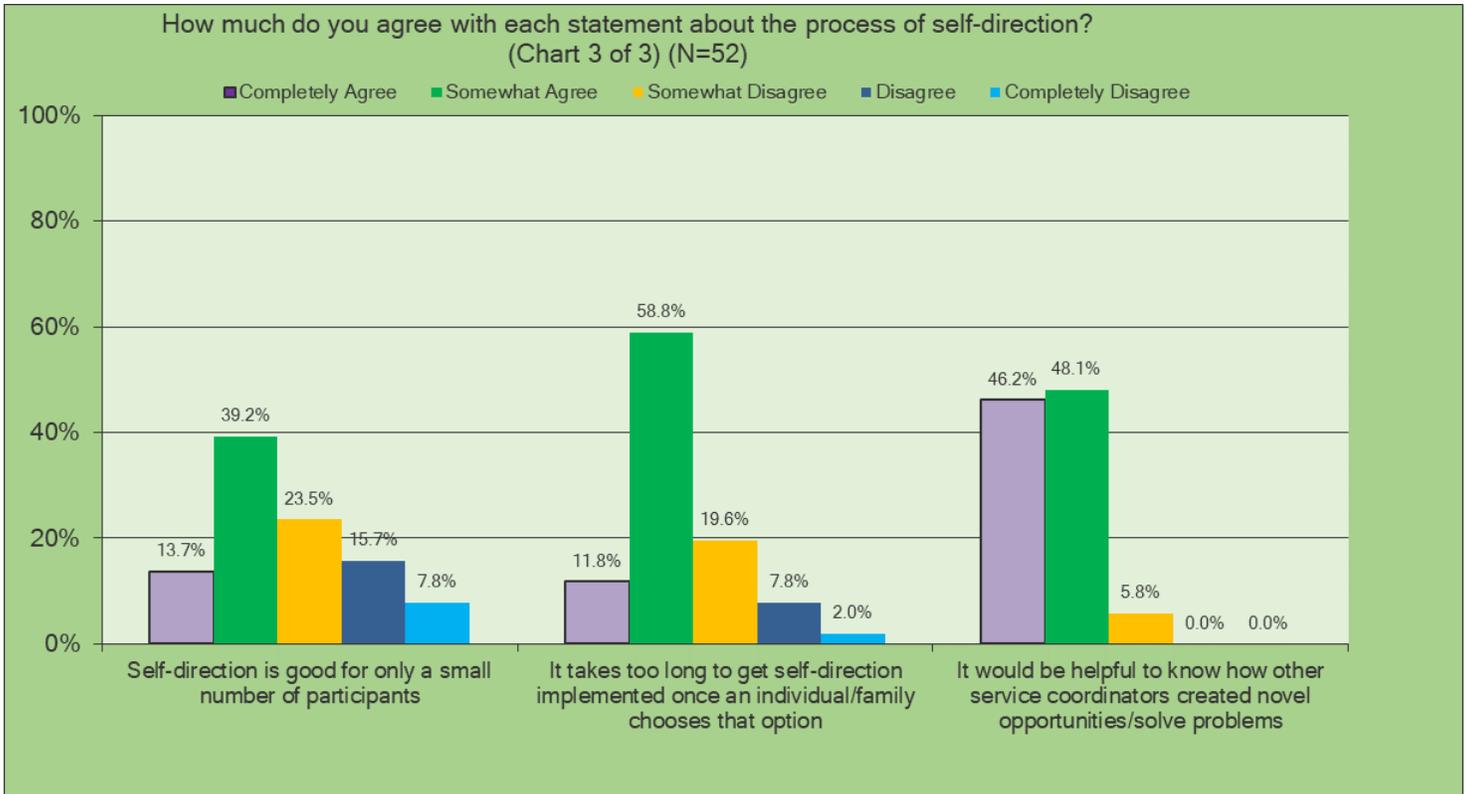
If you support people who self-direct, are they (N=47):

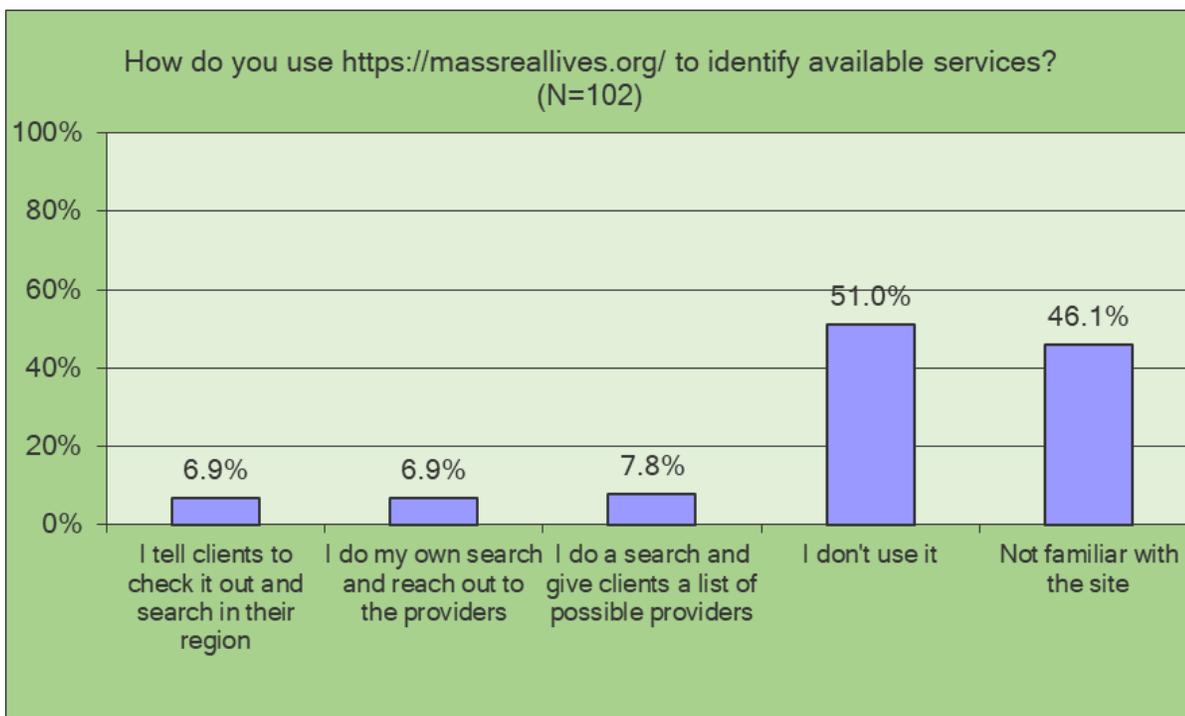
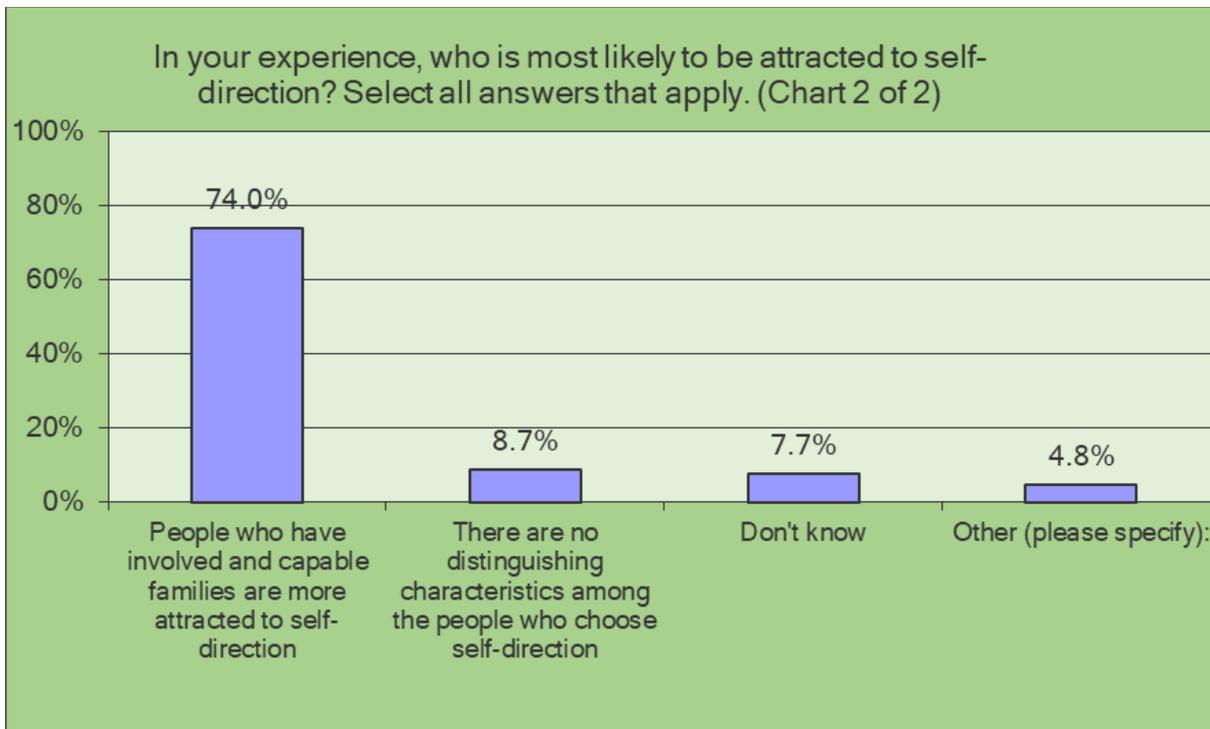


Other Responses:

- both
- Both are true.
- all of the above
- Current individuals doing self-direction
- I currently do not support any persons who self-direct
- they are both
- both
- Have been doing it since self-direction started
- both
- Both
- Both
- Both
- Both
- I have both ASD clients who are new to DDS and ID clients who have had DDS services in the past
- Both
- Some of both
- Previous DDS recipient of DDS services as well as previous recipient of self-direction
- Both

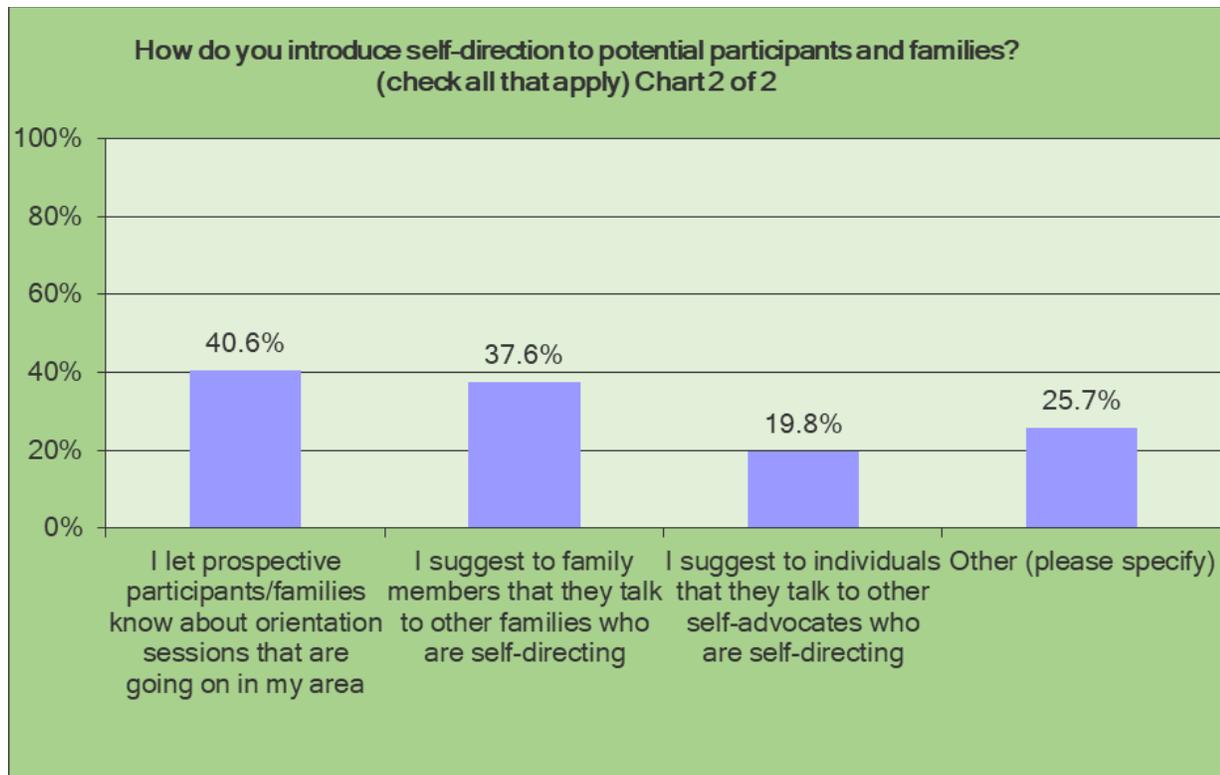






115 of the 117 respondents answered the question depicted in the graph below. Their responses indicate that they use at least one of these strategies to disseminate information on self-direction to potential participants.





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

- Have more local trainings for staff and families. I also think that Individuals currently engaged in PPL (including service providers), their Families & perspective families having a designated time to meet locally to socialize & brainstorm would be beneficial to building natural supports.
- More effort needs to be made educating and recruiting caregivers, as we are having a hard time hiring staff for support services.
- "Families/individuals do not have a choice of services when the individual is not provided with funding. One sure way of growing the program is to provide funding earmarked for the PDP. SCs, families and individuals would likely choose funded PDP supports/services over a mass health funded day program that isn't appropriate for the person. I would suspect that a large number of SCs would be willing to consider PDP services for at least one person on their caseload if he/she were given funding to develop a PDP supports/services for someone that they identified as appropriate.
- PDP services should always be presented as an option during Area Office planning meetings.
- The individual's team members should have regular/annual discussions as to whether or not PDP services would be better for the individual than the traditional services that the individual is currently receiving. Funding for current funded services would need to be transferable to PDP services. "
- The supports will expand with time as appropriate situations evolve
- Creating a database of providers, which identifies areas of strength specific to a certain catchment area.
- Make the whole thing less complicated - there are too many glitches with the PPL online service provider. Make the Service Coordinator delivery of Self Directed services uniform across all area offices.
- The conversation needs to start at a younger age, before traditional services are introduced.

- Self-direction should not be an additional voluntary task for workers who are already overwhelmed with excessive caseloads. Self-direction should be formally added as part of the job description of a service coordinator if this is the way of the future and a service we are trying to push. Each office should be provided with service brokers who are thoroughly and formally trained to provide this service. This role is extremely time consuming and should not be voluntary as it is then taking away from our time with the other individuals on our caseloads. It should also not lessen the caseload of someone VOLUNTEERING to do the job as that is not fair to all of the workers who have not volunteered as their caseloads will then increase.
- Again, there is no growth possible if no funding is available.
- Guide book for individuals who are self-directing so there are clear steps and guidance for the processes of self-directed support management. Something more in depth that individuals and families can read, or a "next steps" training after they go to the intro training. Outreach to schools and transition programs, as well as individuals currently receiving adult services.
- Clearer, simpler standards and operating regulations.
- Hire dedicated Support Brokers for each Area Office!
- Describe this option to all individuals turning 22
- Families who are interested in PDP are the families who are organized, educated, and motivated. Those are also the families who are financially more stable. The families who are interested in self-direction, but struggle with organization and motivation are more interested in AWC. However, AWC options are continually being trimmed. Recent moves to boost PDP have moved many families away from self-direction. Increasing options within AWC "WILL" increase the amount of people enrolling in self-directing services. PDP has more service options including ABA services but people in PDP are organized and receive ABA services through insurance due to the parents being educated and motivated keeping their children on their insurance. AWC enrolled folks are typically less organized and their children are on MassHealth which does not support ABA and neither does AWC. This is a perfect example of a support in abundance to families who don't require it and unavailable to the families who desperately need it.
- I think we have a great opportunity and a great product. The biggest challenge is that it is complex. PPL cannot possibly anticipate all needs or problems. They fix things when they arise but the "fix" does not always stick. This is very frustrating and time-consuming for Support Brokers.
- The ASD population is getting such great support from this program, and we are seeing success stories because of the flexibility and personal choice this program gives. Clients who would otherwise reject support because traditional services didn't fit their needs (due to higher intellectual functioning) or who don't like to be associated with "disabled" people are happily making use of this program to hire support workers. This in turn helps increase their independence, self-confidence, and social interactions. The ASD group has less funding so this is also a great program because it helps them get more support for less money, and make the most out of our resources. I wish more clients could be in PDP, but there are some difficulties. We can't post job descriptions on line w/o paying for the postings on job search websites. These are the sites that we find the most qualified candidates. Some clients can't pay out of pocket to post these jobs, even if they are going to be reimbursed later, so they are stuck waiting (sometimes for months) to get a worker. AWC is an option but it's very expensive and can cut the number of hours a client receives in half. For ASD folks this is very hard because many don't have enough funding to get AWC. This also means that they don't have enough funding for traditional services as well. I currently have 65 people on my caseload and 40 of them have ASD. Many with traditional services (or no services) would prefer PDP but I can't help them find workers. With that ASD service coordinators have very large caseloads and if we are going to be taking on more PDP clients we need to have a more manageable number of people on our case. Over the next few months I will be getting more clients on PDP so my PDP case will equal 16, but I will not lose any more clients to make up for the extra work. This will

make it hard for me to do my job properly, which is too bad because this is such a great program. Also we are still working on technical issues with the PPL website, however things are improving in that area, and I hope that trend continues. Otherwise I can't say enough good things about the program. I hope it can expand, but the state will need to think about how to help hire workers and case load issues if they want us to continue to do our jobs effectively.

- Create a website where all of the information, from general descriptions and success stories for people beginning to consider it as an option to tools and troubleshooting for people who are self-directing.
- Funding
- One problem in the Berkshires is access to the internet. Many of the southern rural towns do not have internet or families (and staff) cannot afford a computer and internet so self-direction is not an easy option. If staff cannot email or log in to PPL or fax there is a huge burden on the service coordinator or broker to manage things. More families would participate in those areas if the internet infrastructure was there and they had funding for the technology needed to run the program.
- more trainings
- Allocate far more money statewide. Encouraging Service Coordinators to help families to pursue this by ensuring it is not overwhelmingly time-consuming for them to do so. Reduce Caseloads.
- increase awareness

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

- I think individuals are empowered to tailor their supports to their needs & preference. I also feel Families feel they have more choice and control of the services they feel are most beneficial.
- Services and supports are truly individualized.
- Flexibility of service delivery
- It's a positive program for families who have extensive contacts within the community to assist them in providing adequate services to their loved one. It requires a high level of organization and time, and as such appears to discriminate against families who are less affluent and are required to dedicate disproportionate amount of their own time to work.
- empowerment
- Self-direction, if properly structure as a program provides a great benefit to those people who are not appropriate for whatever reason for the traditional dayhab/day program/employment model.
- There are less constraints in comparison to the traditional model. Individuals/ families can address issues in the moment and problem solve in the moment. There isn't a hierarchy that individuals and families have to adhere by, per se. If there is a change in someone's ability or vision of their services, those can be address quicker vs traditional models.
- I believe that people have a greater opportunity to find employment through self-direction than they might otherwise, although to date this has not yet occurred for either of my people, though that is their objective.
- flexibility of hours, ability to hire staff with targeted skillsets, ability to create highly individualized programming
- Families that are unhappy with traditional service methods seem to do well in self-direction.
- With more choices comes less frustration and less depression. Over all good health benefits.
- Individuals becoming stronger self-advocates.
- I believe it depends on the persons ability. Many times the decision is made based on parents and not what the person would benefit from.

- Ability to be flexible with services such as partial self-directed and traditional to ease individuals into the self-directed process
- This is an option that can be more financially viable as well.
- People have more self-confidence.
- Clients who don't fit into the old service model because they have a higher intellectual ability, "behaviors" that may be triggered by the setting or setup of traditional services, or who want to be more independent are very well serviced through this program.
- This option allows a man with very serious illness to remain living at home.
- More customized and individualized services.
- Networking and people are more connected with services.
- Families and individuals alike get to choose the services/supports that work best for optimal success; however, as the process is being streamlined with updated policies/procedures, some families/individuals feel less empowered due to a variety of stipulations. What folks can utilize the funds for are inconsistent.
- It can be a great option for people living in rural areas where they may be a long drive from a support agency. It can be a good transition from parent private-paid services as young adults transition into more independence.
- reach their full potential
- Allows thinking outside the box.

Have you seen change in terms of demand? Has outreach improved? Have you seen any other improvements in the system?

- No* (*this response was recorded 17 times and collapsed for this summary report)
- I am new support broker & need more time to evaluate
- I lack experience and training with my caseload presently.
- PDP is discussed more frequently at my Area Office. The Transition SC is more open to PDP (although her case load is too big to do start-up PDPs). The Autism SC is open to AWC as an option for people on her caseload with Autism.
- Yes
- I have not witnessed an upswing in people that want self-directed services
- I am new to self-direction but I am excited about the potential of the program to grow into more of what families need. I think currently we aren't there yet though
- I feel that more has been done to the turning 22 people
- In my experience most people who have been receiving traditional services do not want to change
- yes
- Outreach has definitely improved. There seems to be more interest from T22 families.
- I have experienced that families and individuals want to have more of a meaningful purpose and are looking for creative ways to do that. Families want to be able to choose from options and be presented with different base scenarios and then be able to branch into their own way of things. Improvements that I have noticed are making sure there is more oversight provided to what families are able to spend goods/and services, as this can potentially be a crutch where the system is being taken advantage.
- The logistics of implementation of Self Directed services make me very hesitant to recommend it to individuals for the following reasons: 1) it is complicated and takes a long time for people to be approved. 2) the logistics of implementation in my area office does not make sense to me as the SC must be the intermediary between the family and the PPL Contract manager on a weekly basis 3) Service Coordinators

are not properly trained in advance of offering and implementing this option making the whole process inefficient and unprofessional.

- Caseloads are too high for service coordinators to effectively provide outreach services. I think improvements will not be achievable until caseloads are manageable.
- some change in demand, the improvements have not been rolled out in a way that has been transparent, so it has made things more difficult than necessary, and families have had difficulty managing the changes. Outreach could continue to improve but in order to do so, we would need more support brokers able to take on the work. This will only truly be able to flourish if we have the time to dedicate to properly building these programs.
- From my vantage point (conversations with colleagues involved; vendor community; etc.), have seen very little increase in interest. Outreach, which frankly seems more like a biased ideological sales & marketing approach, has definitely increased.
- No. Outreach is limited and infrequent. I feel supervisors and service coordinators ought to be educated on self-direction on a frequent, reoccurring, and regular basis. By and large, I don't think we feel as a group that we can speak with confidence about some of the details and successes of self-direction.
- Demand for self-direction seems to be growing on a year to year basis.
- Our Regional Self Direction Manager is a HUGE asset! Always willing to lend a hand and be supportive! She does a lot of outreach and assists the Area Offices with Out Reach as well. Having a direct line to Eric and John at PPL helps when dealing with tough issues.
- More people have heard about the option for self-direction while in high school in our office
- I have seen initial interest in the program but ultimately I see families converting back to traditional service models
- Demand is increasing in the Turning 22 group. Transition Coordinators are having to do more PPL start ups which can be time consuming. some processes in PPL website have improved but enrollment process is still very complicated and cumbersome especially if a family does not have an identified person from the beginning
- PPL is improving, but there are still issues. Outreach and education in our area is great. I think that a lot of people are getting to know more about the program. I see a lot of demand among the ASD clients, we can't meet the current demand.
- No. Some individuals on my caseload have moved from self-direction and/or AWC to traditional services. Outreach from my region and AO has improved significantly.
- I have seen some improvement, providing information to families.
- I have seen changes since I first started with the department. Outreach has improved with monthly/quarterly support broker meetings and trainings. Policies/procedures have been developed to streamline how self-direction can be functionally utilized throughout the fiscal year, which is helpful but confusing as implementation is not consistent for all folks involved in Self-Direction
- I have seen more word of mouth from family to family.
- yes
- Program is eliminating some of the ability to be creative.
- A little

Is there anything else you would like to add?

- I am new support broker & need more time to evaluate

- "Finding and maintaining staff is very difficult for both of my PDP individuals. Some type of internet resource tool that is easily accessed/used would be helpful for participants and support brokers...with various info/ideas.
- The content and amount of PDP emails can be overwhelming and time consuming to read/comprehend. PDP and involved AO Management staff need to be supportive of Support Brokers. Support Broker Supervisors need to be knowledgeable about and committed to the PDP program, and willing to team up with Support Brokers. Support Brokers need to feel empowered and supported.
- The new PDP webportal enhancements are user friendly and helpful. "
- PPL is TERRIBLE
- If the Commonwealth assigned each Region some dedicated Support Brokers instead of expecting Service Coordinators to do this work that requires a completely different skill set and mindset, I think the program would grow faster. As it stands now there is disincentive for SCs to take on self-direction as it increases the work load and requires a completely different set of skills and a different kind of case management. In addition the lack of clarity about the ISP document for self-directed participants and the fact that some of it is in HCSIS and some of it is not, also creates added work. Overall, the choice and control offered by self-directed services seems to be mostly philosophical not actually realized. The codes, the portal work, the planning, the documentation and the overall bureaucratic structure that makes self-direction more complicated than traditional service delivery rather than less complicated causes aversion to and avoidance of the whole mess. Sadly the whole program seems like yet one more great idea that was poorly thought out and executed with little or no thought to how to operationalize this in the field.
- As more people are using the service, more restrictions, rules, codes and caps can feel overwhelming. Concerned that people can't choose to give employees sick or vacation days when if they work for a vendor - they would receive those benefits. Especially for individuals who are hiring full time employees who have worked with them for longer periods of time and depend on the money to pay their bills. Should not have to offer it but it should be an option even if someone has fewer than 11 employees.
- It is my understanding that in some area offices only certain SC's are assigned individuals in self-directed services. I presume that those Service coordinators are well trained in Self Direction because that is the main part of their job. In my case, with 4% of my caseload in Self Directed services, I am not well versed in the process, and feel that I must be asking more questions of our contracts manager or regional support manager than providing answers. If I am asked a question of someone being supported in Self Direction, I am rarely able to provide even basic answers. Although I like the concept of Self Direction a LOT, I am not enamored of its implementation - because it is complicated, time-consuming, and because I need way more training. I feel that its implementation is currently out of my league due to a lack of training.
- The Department has not provided adequate training to our region nor have they taken the appropriate steps to implement this new service.
- Word of mouth has always been the best selling point for a product or a service. Thus far, in my area, the word has not been very good. In it's present state, this ideologically driven service is rife for the abuse of tax-payer dollars (i.e. \$1,500.00 + for a service dog that really isn't a service dog at all but a companion? Really? A mutt from a local animal shelter wasn't good enough for this family. When do the tax-payers' interests and good old common sense take hold?).
- We are having difficulty recruiting workers for our individuals. Most job posting sites require payment upfront and not all of our individuals and/or their families can afford the added cost.
- In order for this program to be implemented with integrity the Department needs to hire and train dedicated Support Brokers. They rolled out an ideology with no way to ensure the integrity of a program.

There were no real rules in the beginning or consistency. If this model is going to be successful DDS really does need to treat this more seriously and put the funds into it that it needs to operate.

- Families are ambivalent about committing to something when they don't know the final allocation. They also don't realize that the money is final, it doesn't change and within a few years it doesn't go very far.
- Self-Direction should be offered and explained to everyone.
- Again this is such a great program.
- Caseload numbers are high despite with eligible ASD only folks (there is currently not a cap); additionally, self-direction is supposed to count for 2 for 1 theoretically but that is not the case realistically.
- It's great service model
- I strongly advocate for Self-Direction because I liked the creative planning piece. But there appears to be new restrictions that may impact the ability to 'think outside the box.'

Considerations

The time self-direction takes may discourage Service Coordinators from promoting the model. It might be worth considering ways to support individuals and families through mentoring from experienced individuals and families to change the time demand on Service Coordinators.

Finding ways to make self-direction more accessible to anyone interested might be accomplished by promoting targeted training/mentoring, focusing outreach in more diverse communities/populations, mentoring, and perhaps a gradual move toward self-direction or Agency with Choice for individuals and families. Service Coordinators can start slowly rather than an all-or-nothing approach.

As noted in several of the comments, more training for Service Coordinators, families, and individuals would be beneficial to the growth of the self-direction program.

Funding is an issue that many Service Coordinators discussed as a need to expand the program (funds available to people who want to self-direct their services) and to help reduce caseloads for Service Coordinators so they have the time to support families who self-direct.

Several Service Coordinators commented on issues with PPL, the fiscal management service.

The website is not being used to its potential, with over half of respondents reporting that they do not use it. Service Coordinators who are supporting self-direction reported using the website to locate agencies that support self-direction just a bit more than those who are not supporting self-direction participants. Respondents suggested there are opportunities to enhance the visibility of Self Direction, for example to "Create a website where all of the information, from general descriptions and success stories for people beginning to consider it as an option to tools and troubleshooting for people who are self-directing."

MA Real Lives Evaluation

For internal review. DDS Quality Assurance Evaluation

Real Lives Participant Directed Program Survey Results August 2018

Prepared for:

Massachusetts Department of Developmental
Disabilities Services

Prepared by:

HUMAN SERVICES RESEARCH INSTITUTE
August 13, 2018

Background

The following data were collected using a survey that was mailed out to 568 individuals who are participating in the Participant Directed Program. Participants were given the option of completing the paper survey or using a provided link to SurveyMonkey to complete the survey online. HSRI received 195 valid surveys between April 30, 2018 and July 23, 2018. Survey respondents were not identifiable in the surveys; however, they did provide their zip codes to allow for reviewing findings by region. Regional analyses are not included in this report; however, they may be available in the final report for Year 2 of the Real Lives Evaluation.

Summary of Findings

Respondents to this survey are using the Participant Directed Program, an option for self-direction in Massachusetts. About 96% of respondents fall within the DDS service population ages of 18-65. Only 4% were over age 65. Almost half (48%) of respondents live at home with their family; 27% live in their own home or apartment while 16% live in a group home and 3% with a foster family or in shared living; and a small percentage (6%) live in other residence types.

People found out about the self-direction option from a variety of sources. 71% of respondents said their DDS worker told them about self-directing; 11% said a staff person from their agency; 12% said at their ISP meeting. Other ways people heard about self-direction were from family members, at a self-advocacy event, from a friend or at their school. There are also comments under this question in the *Results by Question* section.

More people have been self-directing for more than 4 years (50%) than those who have been self-directing for less than 4 years (43%). 7% of participants were not sure how long they had been self-directing. Participants were asked if they were receiving traditional services from DDS before they started self-directing: 55% said they were; 28% said no; and 17% were not sure.

The majority of respondents participating in PDP (92%) said they will continue to self-direct in the future and 88% said they would recommend self-direction to others. 97% of respondents know who their service coordinator/support broker is, and 91% said it is easy to get in contact with their service coordinator/support broker. 76% of respondents indicated that they get all the help they need from their support broker/service coordinator. When asked to say what additional help they needed, respondents gave the following answers: “More money in the budget to go out in the community. More money to buy clothes. More time at job so I am not alone” and “help with hiring staff.” Overall, 95% of respondents said they have had a good experience with their support broker/service coordinator.

Being involved in PDP means that participants use PPL as a fiscal management service. Respondents were asked questions about their experiences with PPL. Participants said that PPL always (54%) or very often (23%) processes their employees’ timesheets correctly; PPL always (59%) or very often (18%) process their employees’ timesheets on time; PPL always (65%) or very often (14%) pays their employees accurately; and always (58%) or very often

(19%) pays their employees on time. For those questions, there was a range of 17% to 20% of respondents who responded that they did not know. Respondents also answered the question “If your employee’s timesheet is denied, delayed or pending payment, does PPL tell you right away?” About 50% fell into the always or very often categories, 8% said sometimes, 13% said not very often, and 28% said they do not talk to PPL, the support worker they hired does this. Almost half (48%) of participants said they always feel comfortable calling PPL if they have a complaint or concern about their services while 10% said they sometimes feel comfortable, 7% said not very often and 30% said they do not talk to PPL, the support worker they hired does this.

Respondents said that PPL staff always (43%), very often (14%), and sometimes (11%) responded to their questions in a timely and professional manner. For 44% of participants, PPL’s instructions always or very often helped them to enroll in PDP; 16% said sometimes; 8% said not very often and 33% said the support worker they hired deals with this. More than half (53%) of respondents said that the information they receive from PPL staff is always or very often helpful; 14% said sometimes and 28% said they don’t know, the support worker they hired does this.

When asked if they got all the information they needed about self-direction, 62% of respondents said they got all of the information they needed in the beginning, while 27% said they got some information but could have used more, and 11% said they still have questions they need answered. More than three quarters (77%) of respondents said that they know who to contact if they have questions.

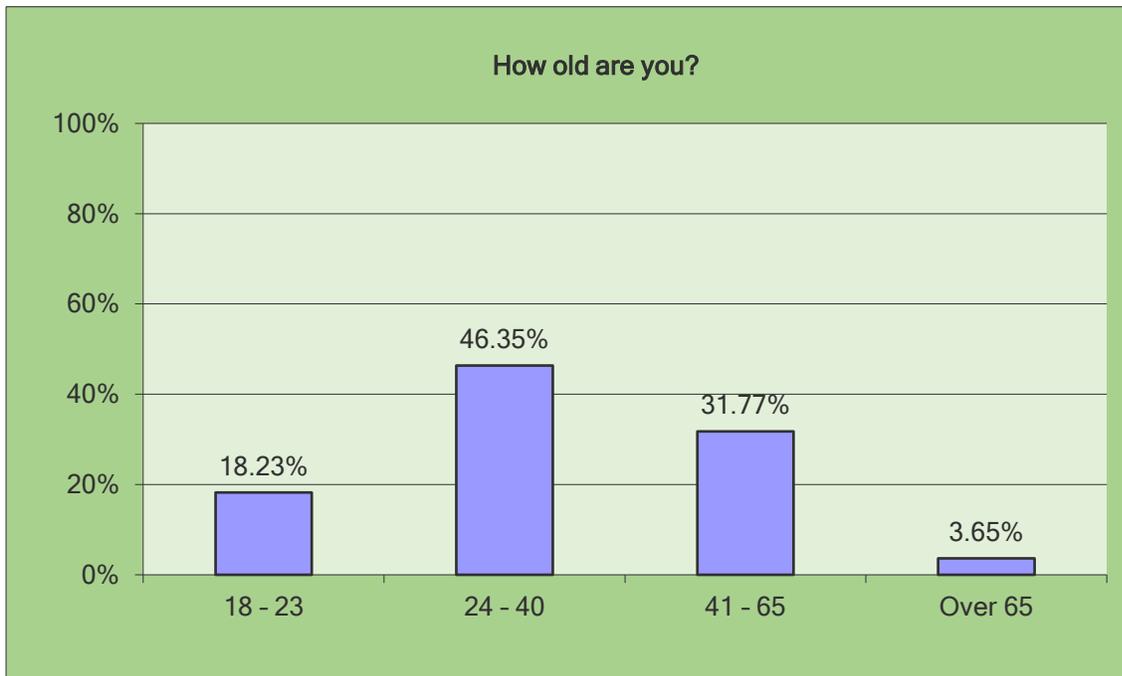
Almost all (92%) of respondents stated that the people they hire do what they want them to do. When asked what is better in their life since self-directing, respondents provided many examples. Around two thirds of respondents said that they are learning new things (61%) and that they are making more choices in their lives (71%). More than half (53%) said they feel better about themselves and 55% said they are more independent. People said they have more friends, their health is better, and they have jobs. One person left the comment “I’m an individual person who needs a specialized individualized day. This self-directed program has changed my life for the best!”

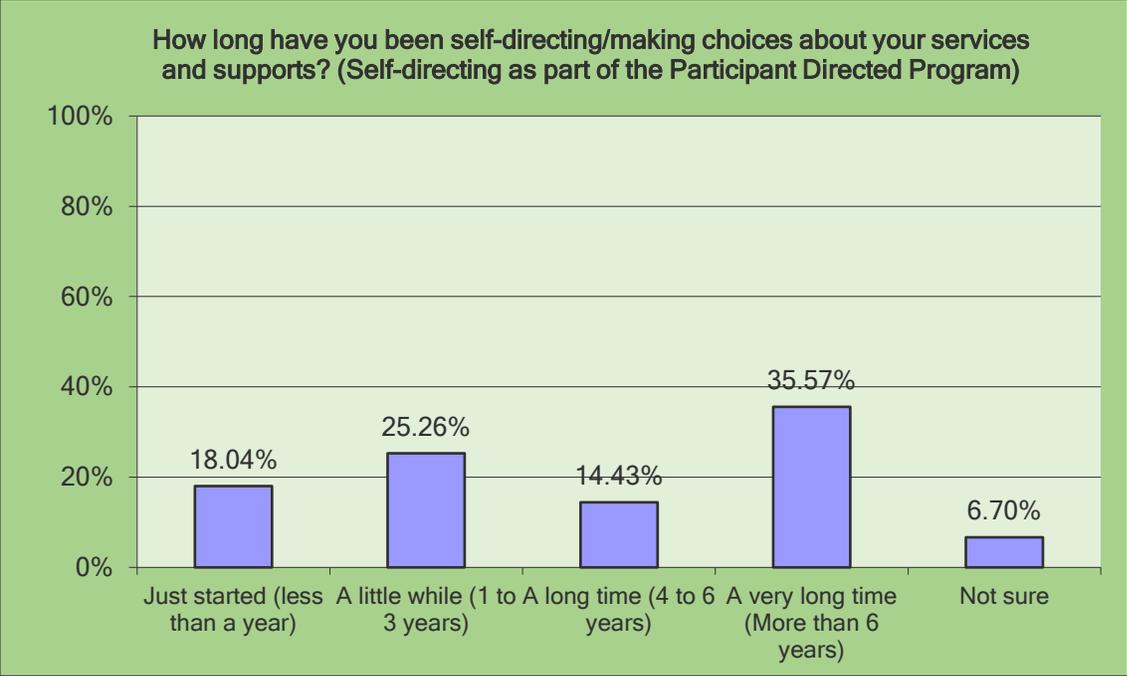
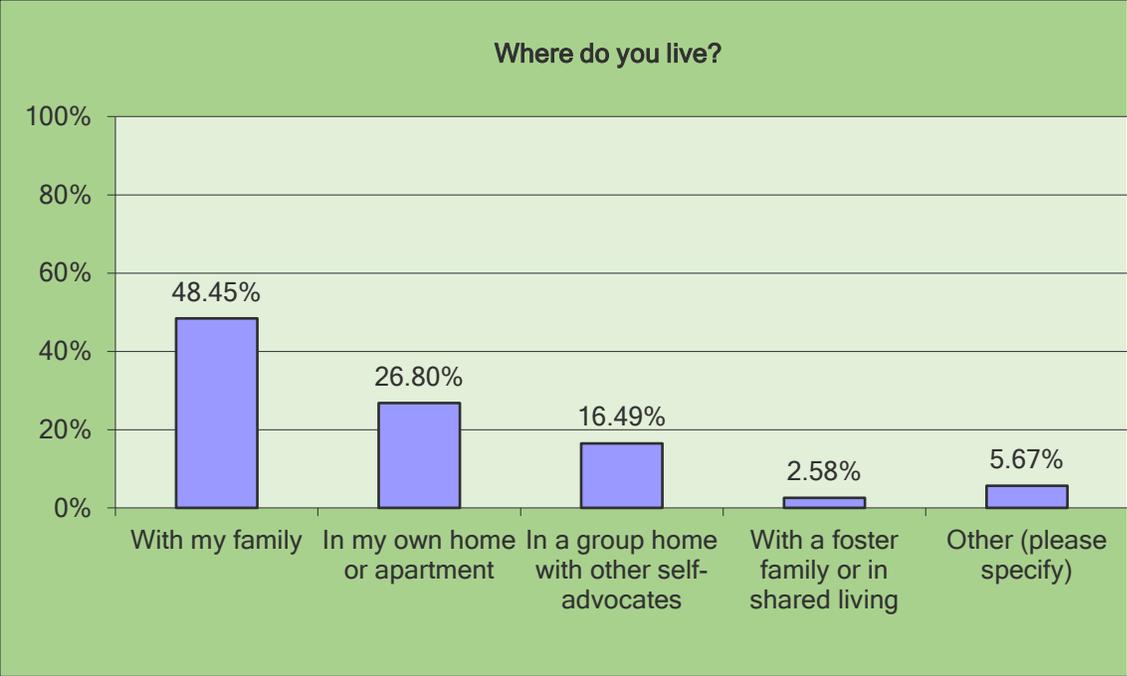
Respondents also discussed what hasn’t changed or what they still want. Those responses are listed below, in the *Results by Question* section.

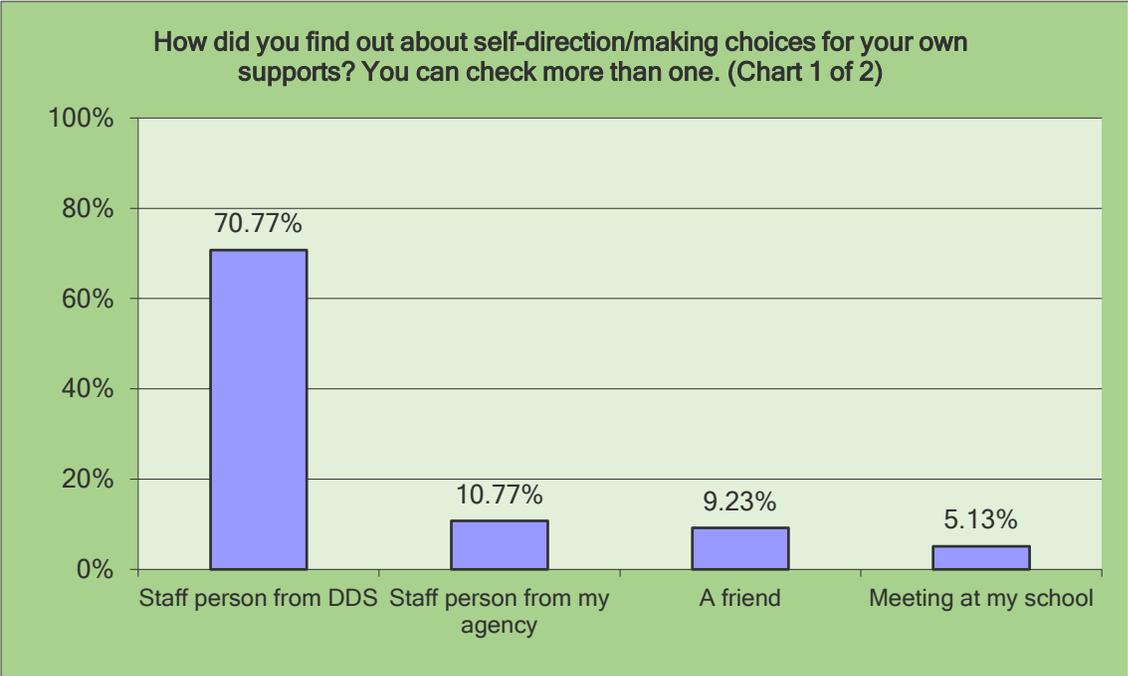
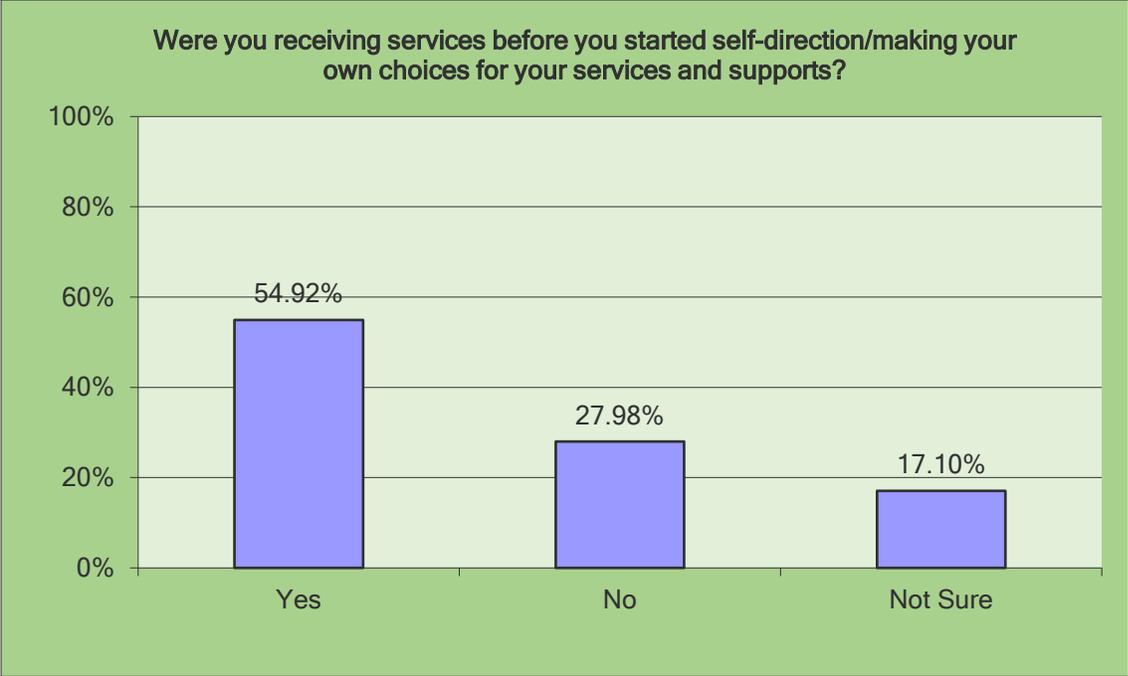
Participants were asked if they had any problems since they started self-directing. 56% of respondents said that they have not had any problems and 40% of respondents said that they have had problems, but someone has helped resolve them. Of those who reported having had problems, 40% noted that the process is complicated and 17% said they still have questions about the process. More than a third (37%) said that it is hard to find and keep good staff. One third of respondents said there is not enough money in their budget for them to do what they want. 23% said it takes a long time to make a change in their services and 12% said it is hard being the boss. Respondents also wrote in answers, which will be listed below the chart in the *Results by Question* section. Here is a sample of some comments: “DDS does not support my work, my social life, or my choices. They do not work with my vision,” “DDS personnel are interjecting their person opinions, without justification, into the choices made,” and “guidelines changed this year with little to no notice and I left the program because of the changes.”

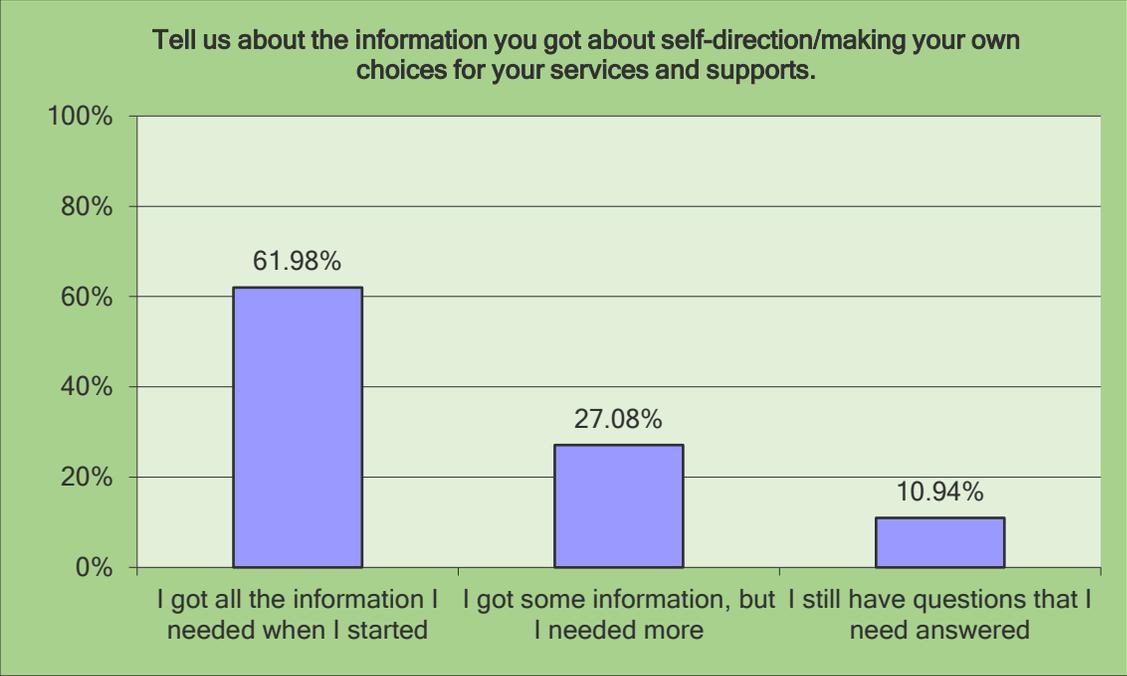
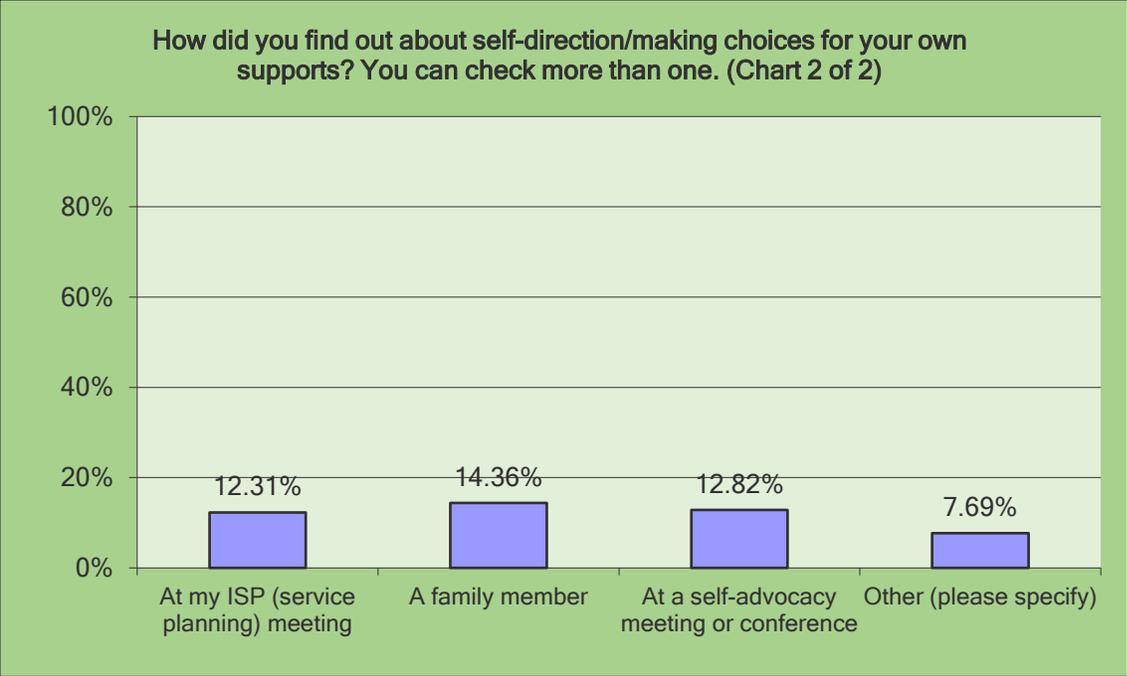
Results by Question

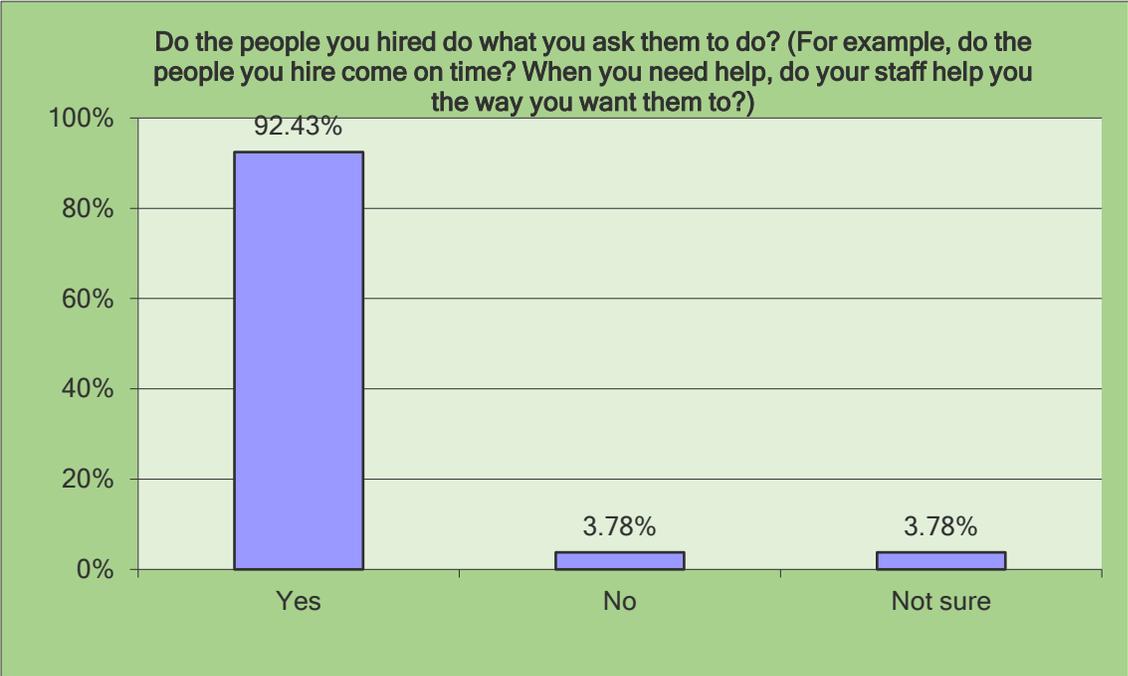
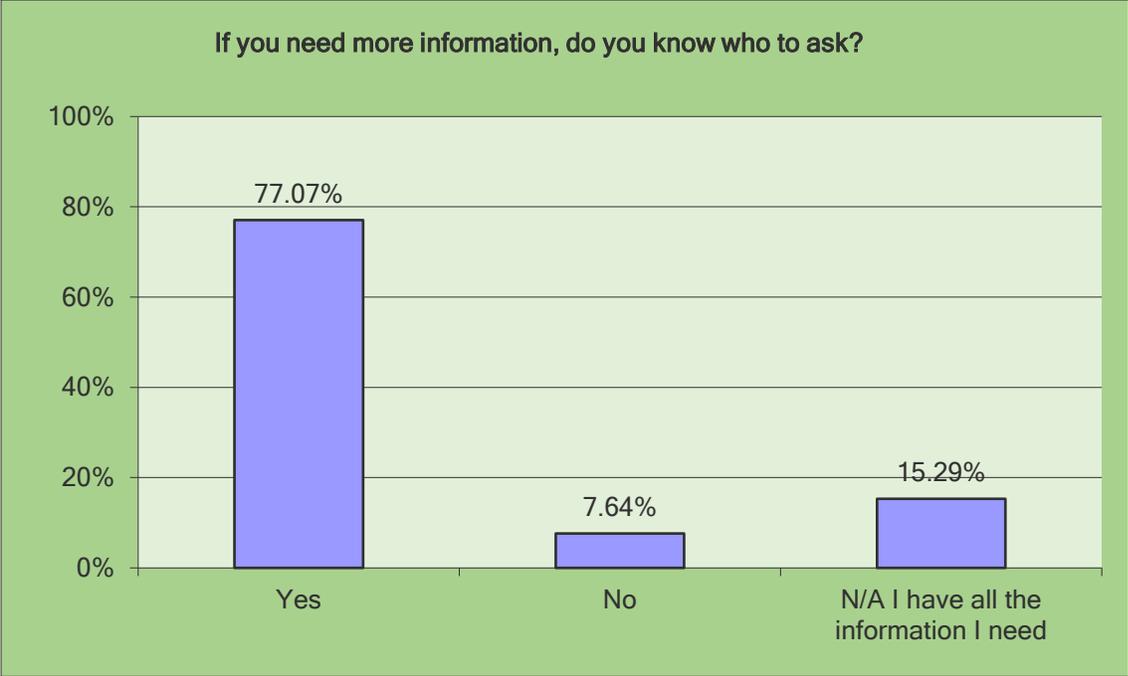
Detailed results and graphs for each question on the survey are presented below.

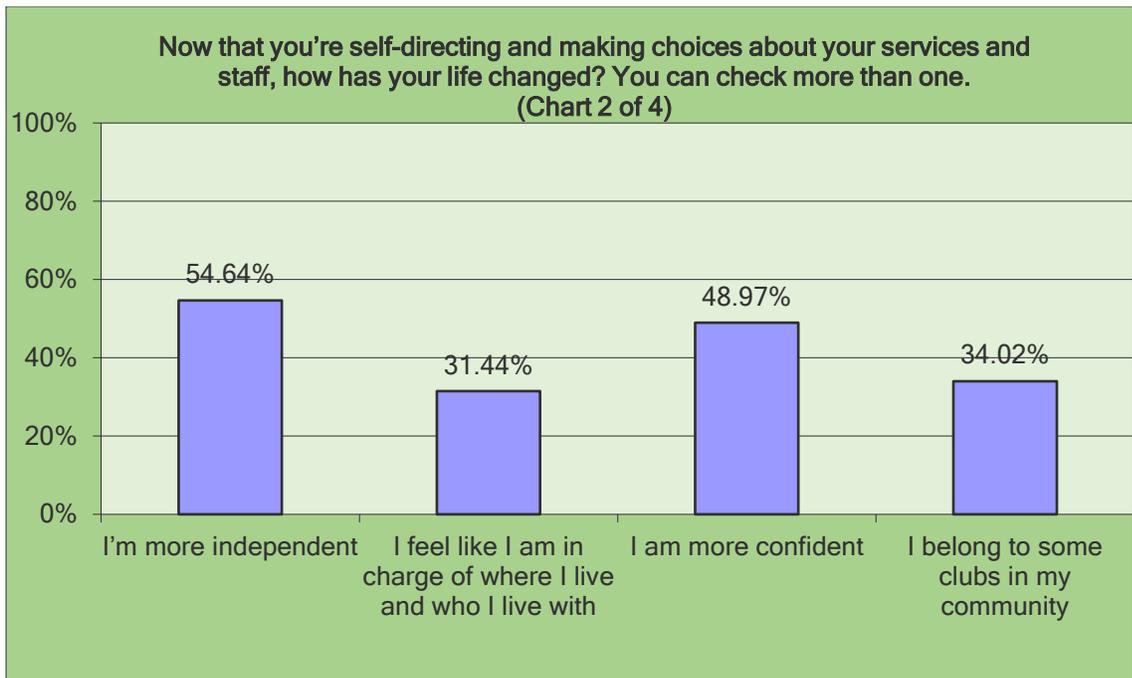
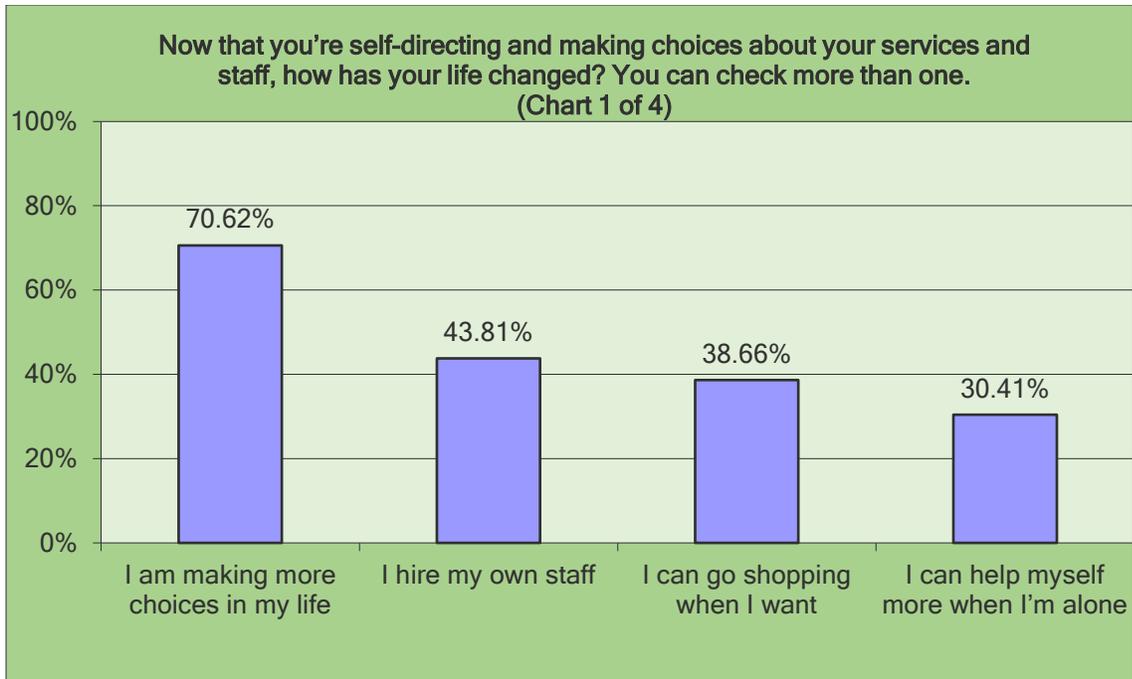


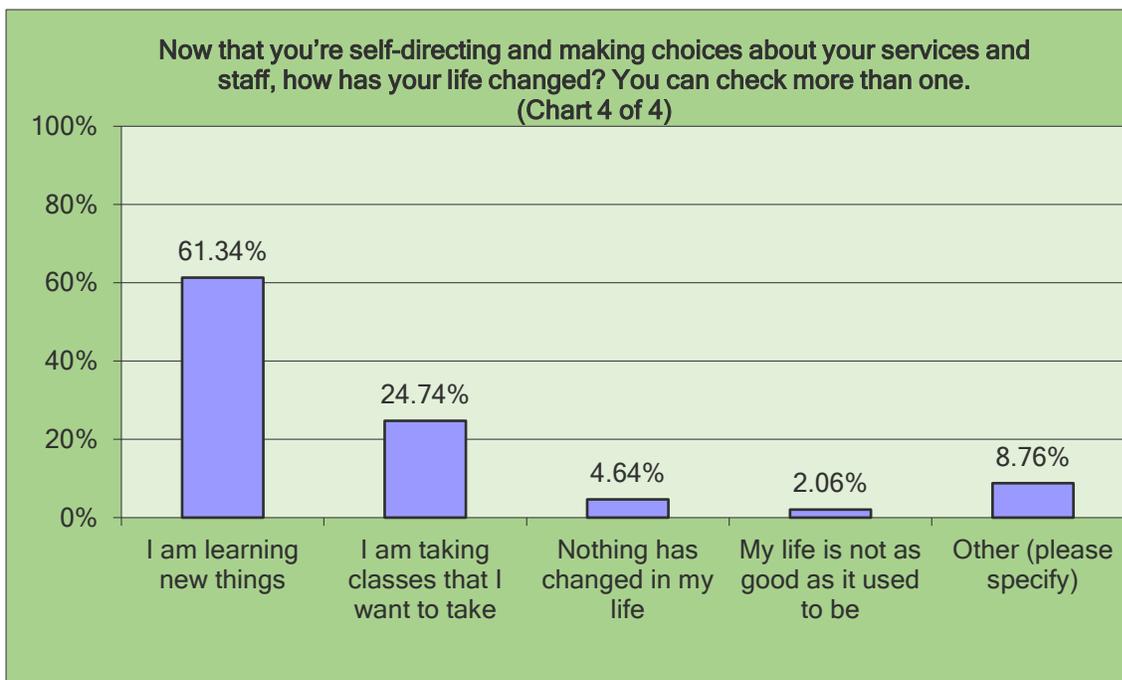
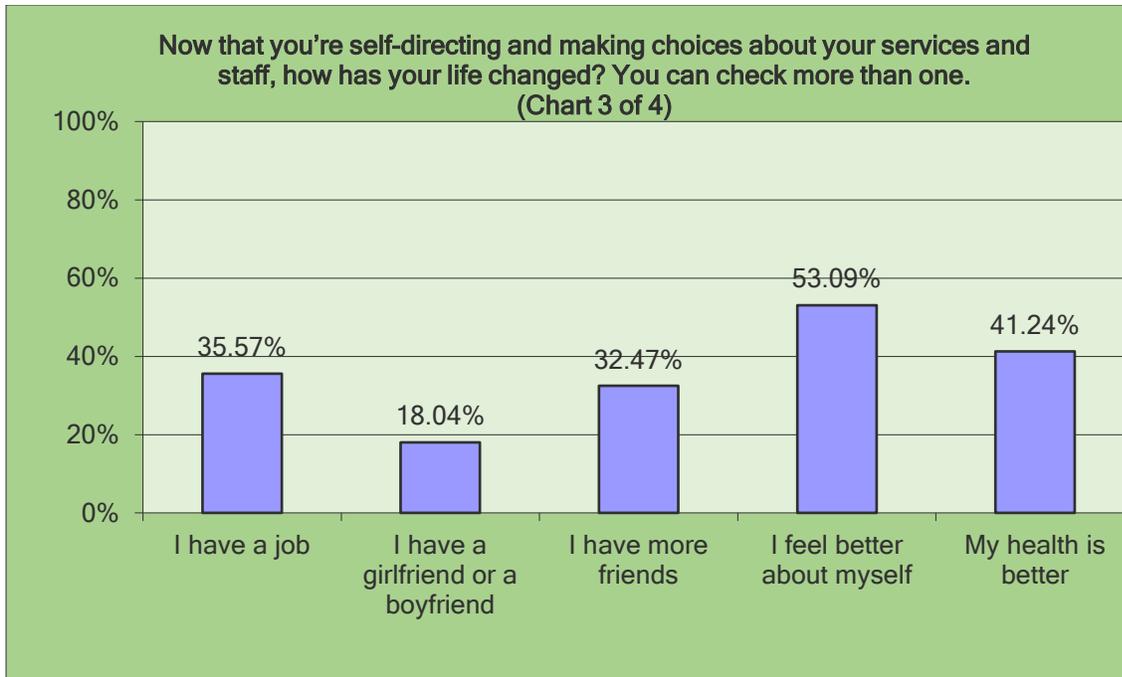












Other responses (as quoted from survey respondents):

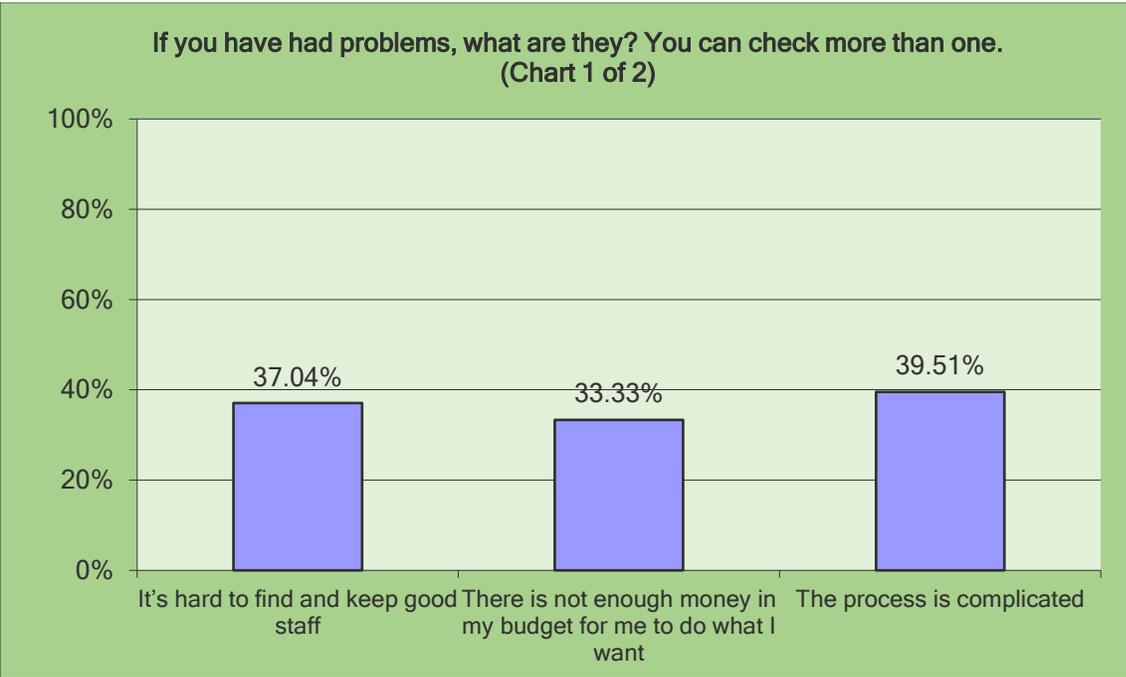
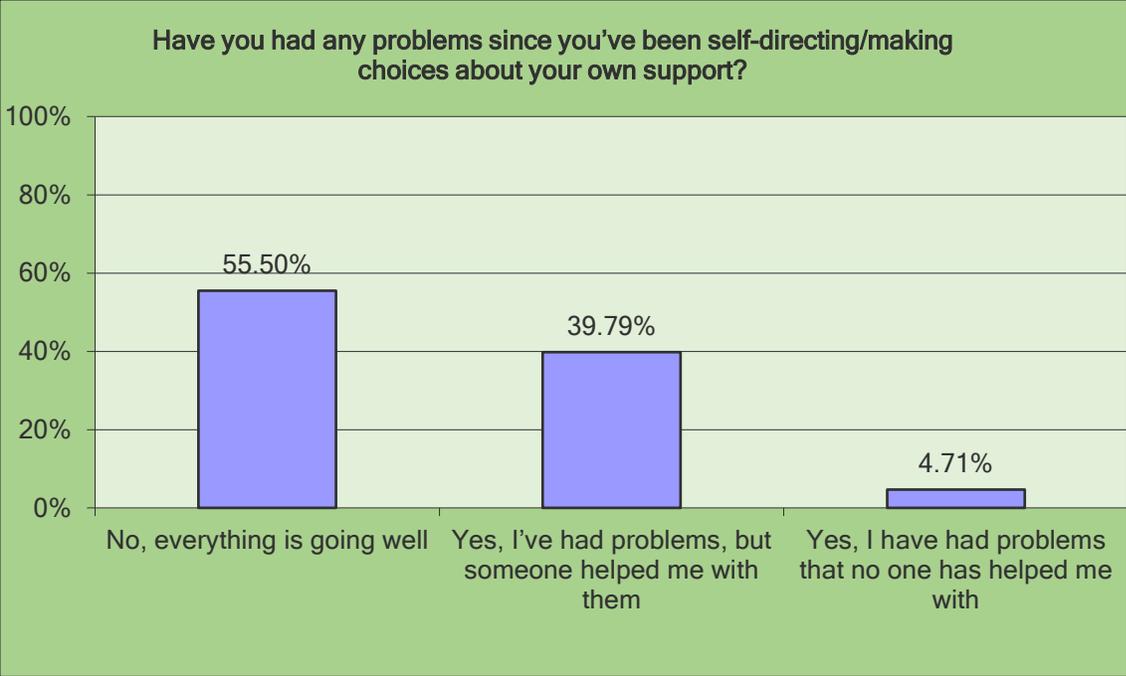
- I don't like it here because I don't like my house
- much happier
- mother passed away. Father is in a facility for dementia
- living situation is perfect. everyone is very caring

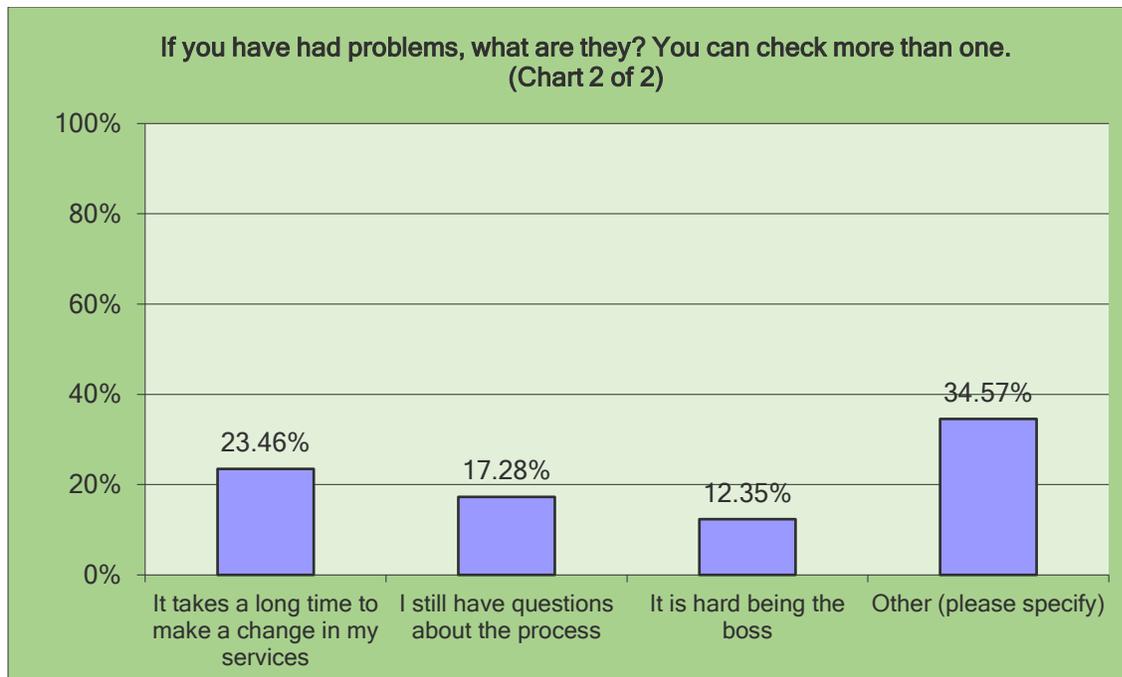
- I feel less anxious and happier
- I'm an individual person who needs a specialized individualized day. this self directed program has changed my life for the best!
- I would like to live on my own, but i know i need help
- my life is more
- my family helps me make choices that benefit my health and happiness
- when my son was at school
- I have nieces
- I am able to adjust to new people and new activities
- when certain people are with me here, I would like to cancel my therapy.
- I get to visit many other places
- Always self directed
- I'm getting older and need more help with cleaning and hygiene.

Are there things in your life that haven't changed or that you still want? (as quoted from survey respondents):

- I want to meet friends and go out more.
- I would like more friends and a job with dogs
- I want to learn how to cook and stay independently at home. someone that is good with dogs
- Having additional hours would be a plus. Currently have on average 11/2 hours per week. Being able to exercise or get out 2 or 3 times a week would be better
- more social activities to get involved in the community
- the only thing that has changed is I don't have a job coach
- take driving lessons when my baby is old enough to go to daycare
- would like paid employment
- More flexibility, less restrictions, especially for severe individuals being helped by family members. Our lives changed after receiving in-home support for many years. More restrictions now due to real lives bill. Not Good.
- To travel more, to shop without staff, to get a new job, to take the ride more
- ability to take regular art class, more social activities in the community
- difficulty in finding qualified support staff
- I want to go to Berkshire Hills Music Academy
- I want to belong to a club and need friends and maybe learn how to drive
- I would like to get a job
- would like to lose weight
- I want to be able to confidently drive on the highway/ in the city
- I wanted to change about myself is and get to know each other people know about of boyfriends
- things will always change
- more cooking. camp
- Bring my daddy back from heaven
- live on my own
- well we been thinking about apartment living
- social life has not changed much and don't drive

- allow travel and hotel expenses
- I would like to be able to get more hours so that I can go out more because when I am out in the community and keeping as busy as I can, I feel a lot better of myself and I get less anxiety when I am out.
- that could help if the program could make easy
- I still feel like taken advantage. I want more control of my own budget. Budget person tells me what I am going to do rather than help me or support what I want.
- Not always capable of making decisions parent and guardian make them after we have talked.
- transportation options are very limited in the PDP program. Too many restrictions on funds that are available.
- I want a girlfriend. I was a car someday.
- It is difficult to find people to work with me (Lee) and train then (BCBA).
- More opportunities to socialize with people like me: severely disabled/intellectually disabled
- Yes, I want job training (have applied to Mass Rehab)
- In the process of learning skills that will help in the future - read signs (traffic), learning money skills
- We have had the same budget amount for 3 years with no increase and I need more help with cleaning and hygiene.
- I am working on becoming more independent.
- I would like more opportunities to make friends. More weekend activities offered by the ARC and Family Support Centers
- I would like to travel more but it is too expensive.
- It's hard to make friends living alone.
- Job and my own house
- I still want a girlfriend. I want to get married.
- I would like to see if I can get some money to pay for taking a class online.
- I want to live alone or group home
- still not getting paid for work
- I would like to explore the possibility of dating. I am still single and would like to have a relationship with someone and eventually marry and have a family.
- yes, I am still working on making social connections and independence
- I would love to have funds to pay for my college classes
- My family still helps me when I ask

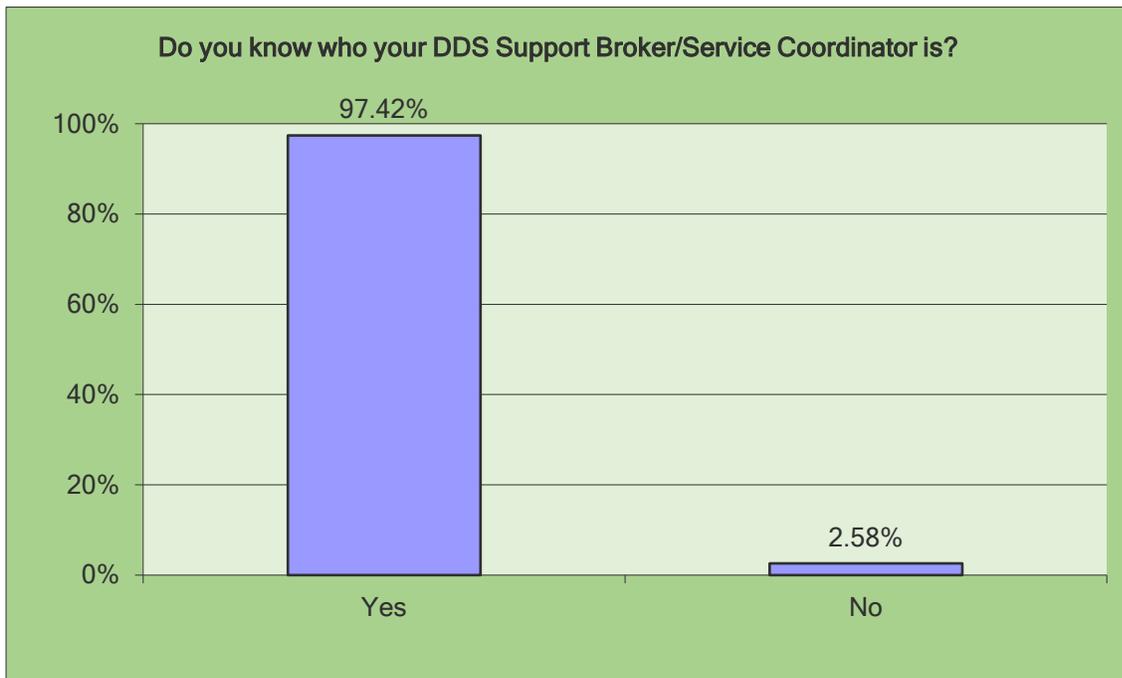


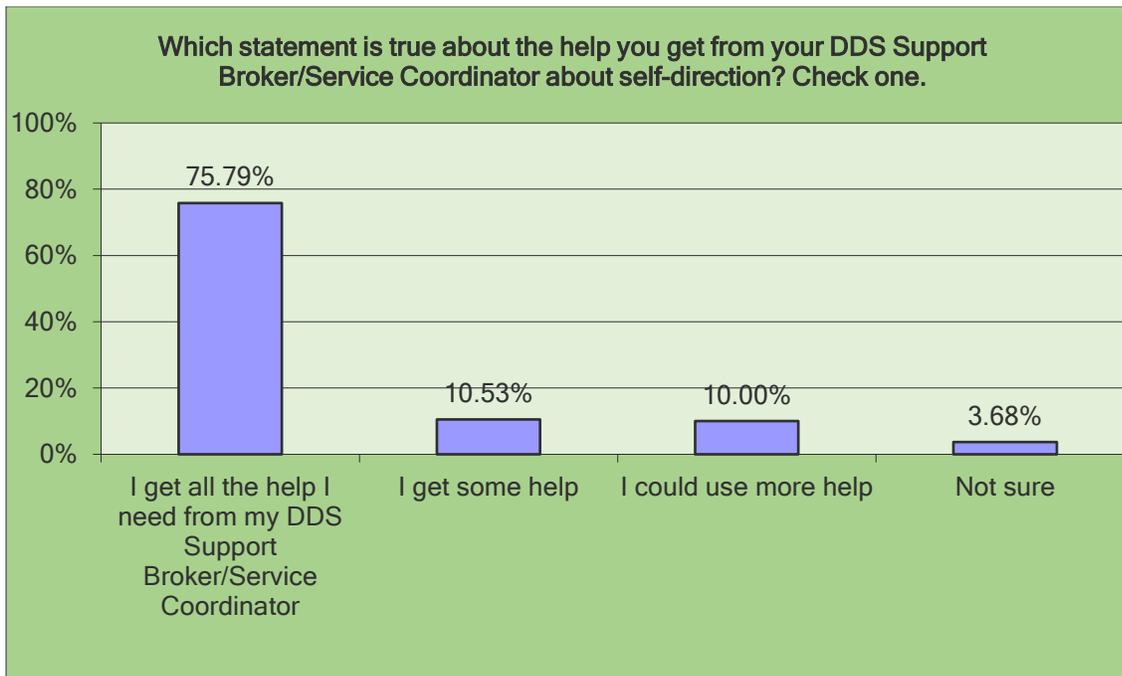
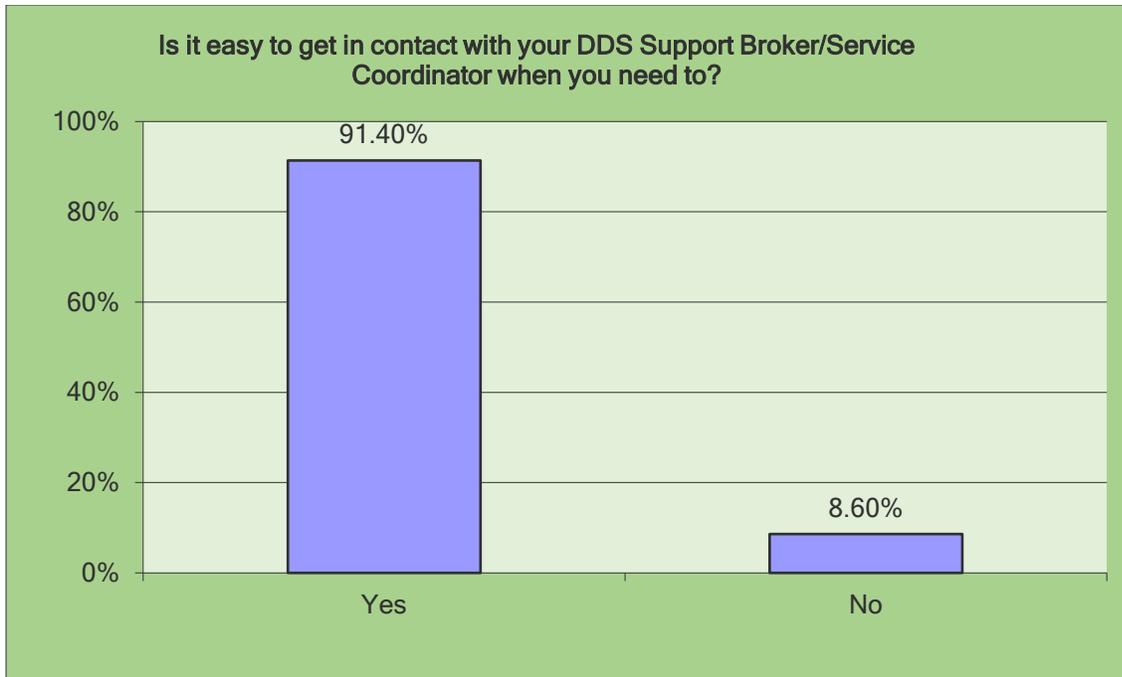


Other responses (as quoted from survey respondents):

- a few ppl issues
- DDS does not support my work, my social life, or my choices. They do not work with my vision
- PPL tech needs to be upgraded
- Hiring new staff is a long process due to all the paperwork. It takes forever to get someone approved
- it's hard changing homes, moved recently with family
- payment problems, but resolved
- I should be getting services from DDS Holyoke only not DDS North Hampton
- I'm told to use the money in my budget when I want to do more or use more services which then uses up my budget sooner; so then I can't go
- finding knowledgeable staff and relief staff for coverage when needed
- did not get enough hands on help with hiring people through public partnerships when I first started. After a few months however DDS provided someone else to support me and now we are good
- I've often felt unsatisfied/ discouraged with the quality of life
- knowing what I can use my allotment of fun for
- I am subject to my Autism and change can be hard
- need more funding
- behavior problems/bad moods
- I had to fire people. I don't want to upset people, not enough communication; people don't want to hear when I need change; I feel ignored by DDS when I don't like something. Not listening to people with special needs to make change.
- DDS personnel are interjecting their person opinions, without justification, into the choices made

- employer/employee paperwork processed with DDS February, 2018 employee started March, 2018. Employee still not paid as of June 14, 2018 due to failure of DDS to follow through. All of this documented.
- waiting for reimbursement all the time
- PPL is not reliable and does not communicate
- I wish they will keep give me the money is good to go out to lunch and \$15.00 is good to go to the movie but you take that away I wish that you give it back to me and you not going to give it back and it is not fair but I will do it myself I love it but I do have it. You guy and girl need too give my staff the gas card to her because if she don't have it and she need it to go place with me.
- social isolation
- ppl related
- On the provider application, there should be a medical information page for their doctor to fill out. If they take medications that would interfere with care for a special needs person. Or if they have any history of mental illness.
- The hardest thing is getting backup staff when someone cancels
- guidelines changed this year with little to no notice and I left the program because of the changes
- The process to get reimbursed for transportation requires filling forms for each leg of the journey even if its the same location every time





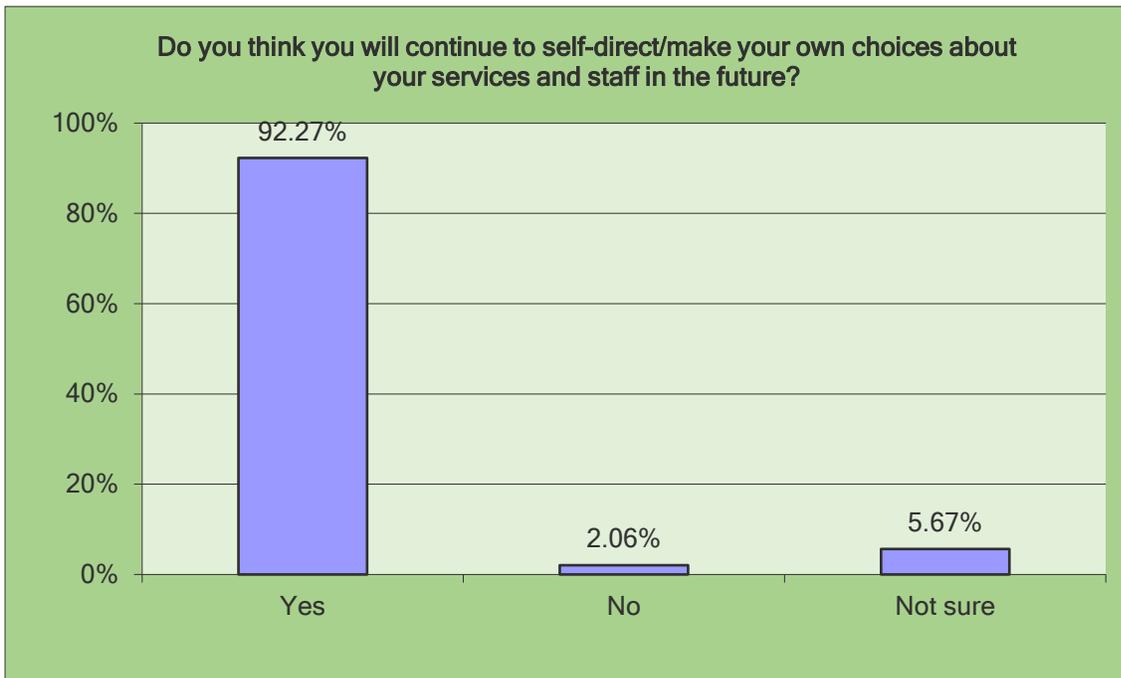
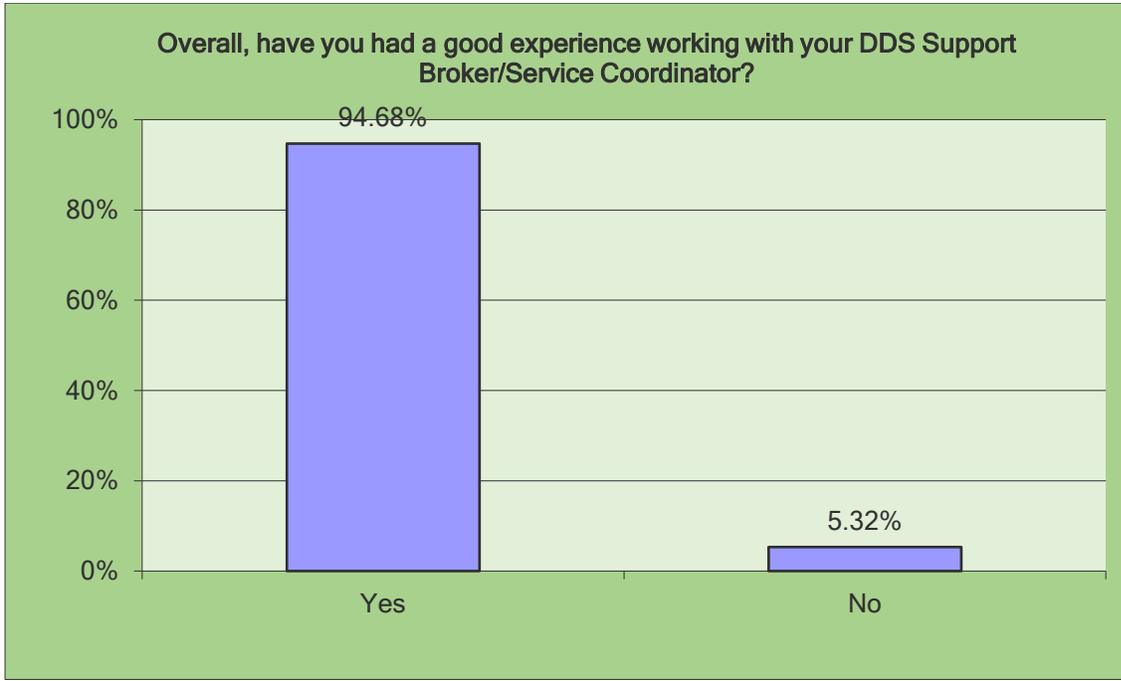
If you need more help, what kind of help do you need? (as quoted from survey respondents):

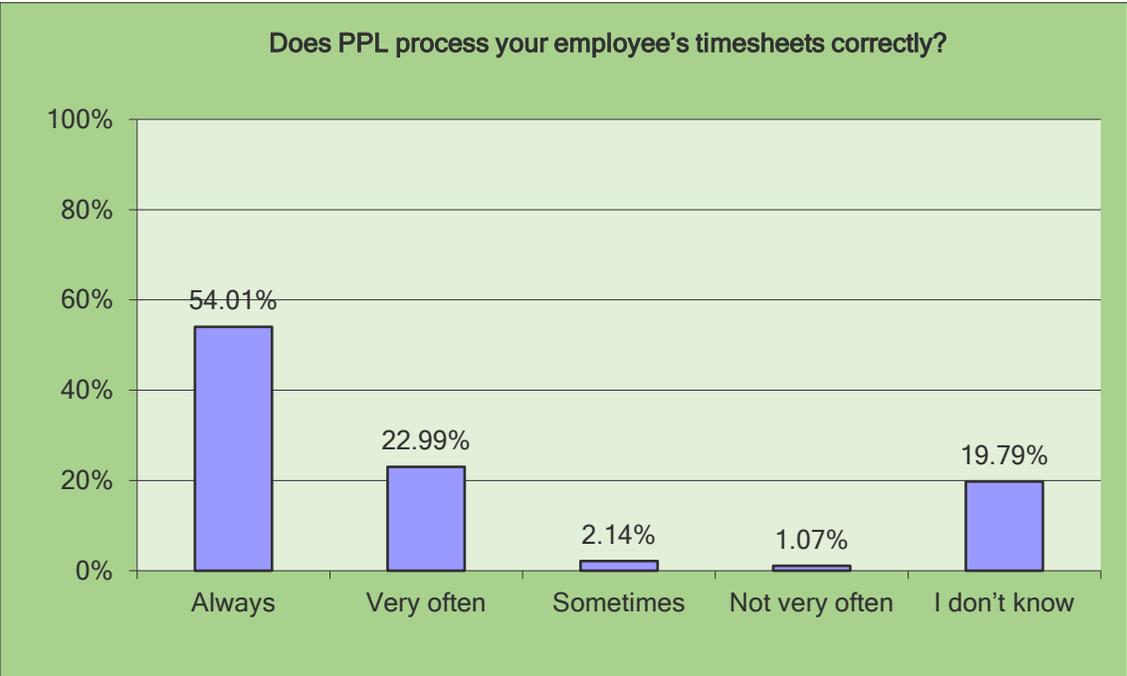
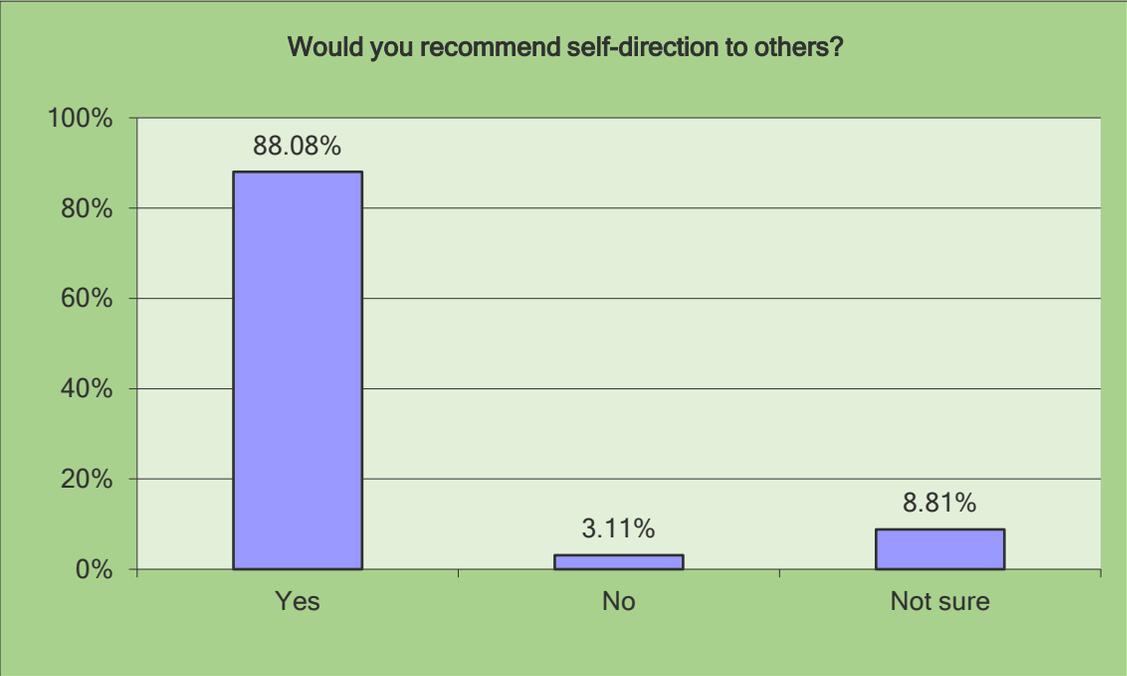
- more money in the budget to go out in the community. More money to buy clothes. More time at job so I am not alone
- I need to go out and do something. i cant stay home all the time

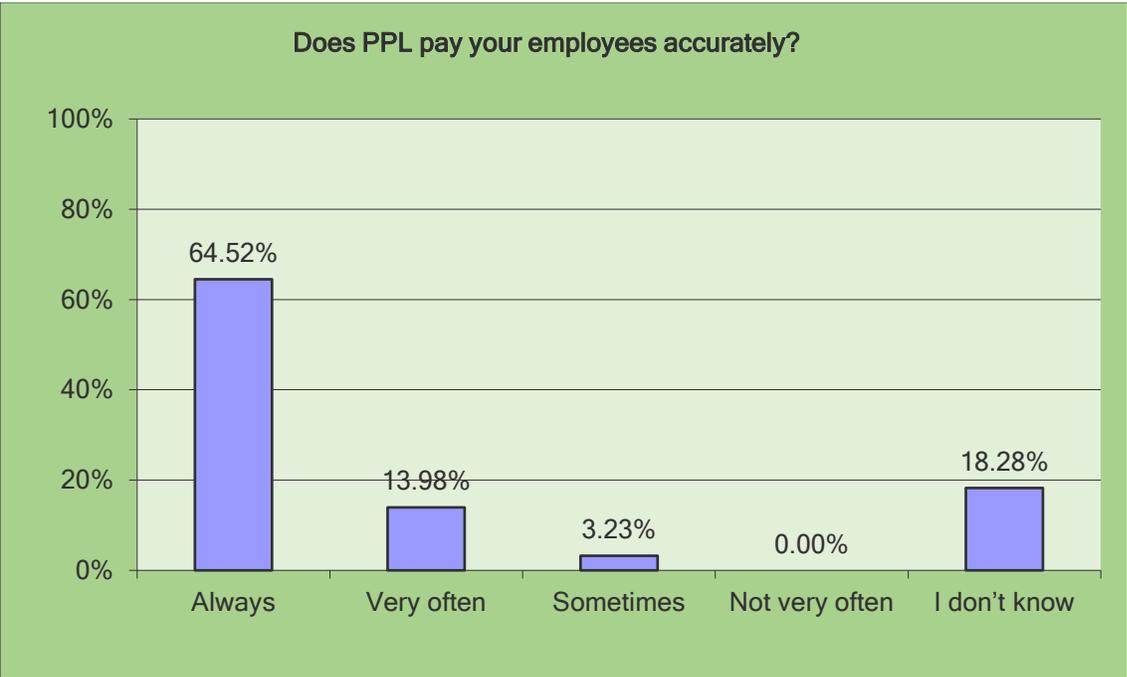
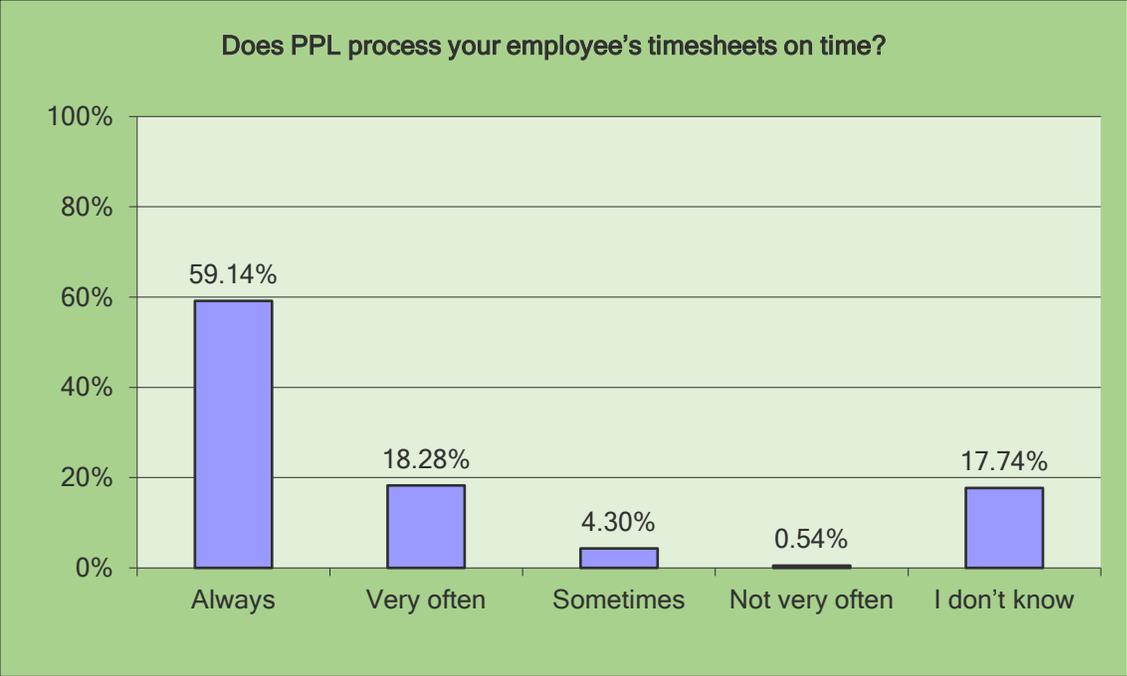
- I've called my dds coordinator several times because I don't know how or who I'm supposed to pay for TILL - springboard events but he never calls back or replies to my emails. I don't know who else to call
- more staff
- We need our service coordinator to respond more quickly with solutions. Right now they are bogged down going through receipts
- our coordinator needs to go through his supervisor and it takes too long to get any answers!!
- our service coordinator changes- our precious coordinator transferred- we miss her!
- hiring staff
- (name) helps out but it should be someone out of the DDS Holyoke office
- need an increase in my budget to get more services that I need
- my current service coordinator is (name) is wonderful. if we had her help from the start, many difficulties could have been avoided
- go shopping for food, iron clothes, room
- (name) and (name) take care of all my questions all supported and monitored by my mom
- more help at doing things
- I have to find resources myself
- help with paperwork when hiring new help
- to get socially involved
- I have the best DDS support broker/service coordinator
- understand how this work and simplified paper work
- I sit down explain things; do things too big. Too many people involved. I don't want so many people who don't help and the ones that help me are not DDS or broker or coordinator and can't help.
- support broker/service coordinator seems to always be working against my wishes, and goals. SB/SC always find a way to restrict my choices.
- answers and questions
- clarification as to what is covered in my budget keeps changing
- DDS does not promptly return calls or e-mail DDS does not follow through. DDS does not solve problems
- help processing paperwork
- Need help increasing budget for cleaning and hygiene - help with services.
- My support broker doesn't respond to my requests for information. I believe that is because she is too busy.
- finding adequate staff of support systems
- Help finding additional money to help pay rent, staff training.
- She provides the necessary help, but the process itself is overly cumbersome and time consuming for DDS coordinator and for families. It's a real disincentive to self-direct.
- Going more places to get some things if and when I need them.
- help with correct billing
- I am an individual who uses The Ride to get to and from work everyday and other places on occasions. While The Ride is very beneficial for me as I am legally blind and therefore do not drive, it is also very expensive to take as the fare is high both for going to work and for coming home. As a result, I end up having to put as much as \$100 into my Ride account since I do not have enough money in my budget to cover transportation for a period of time. This makes it difficult for me as I also need money for other things such as grocery shopping and

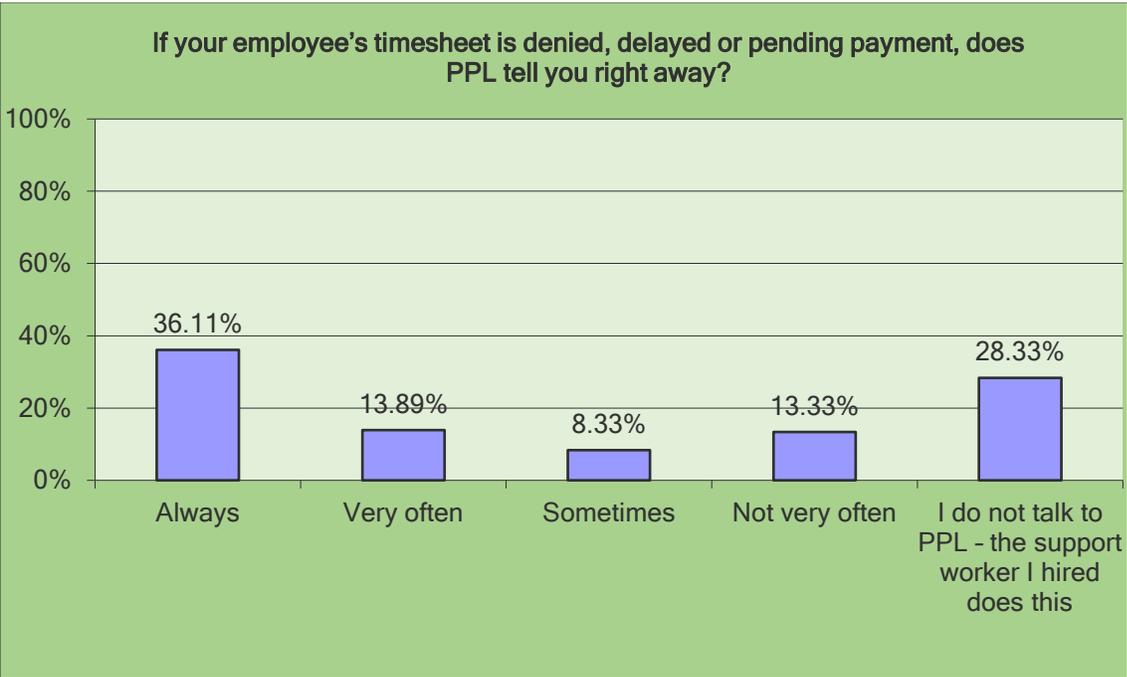
rent. If DDS added more money to my Ride account, I would be able to afford buying more groceries and paying my rent every month.

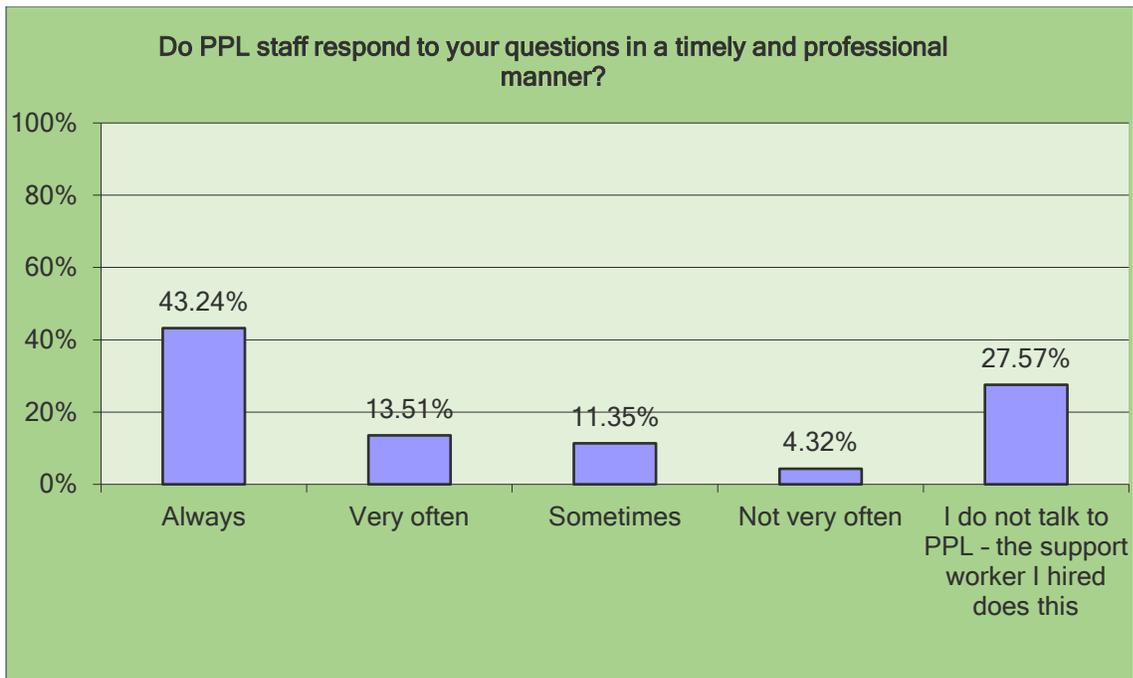
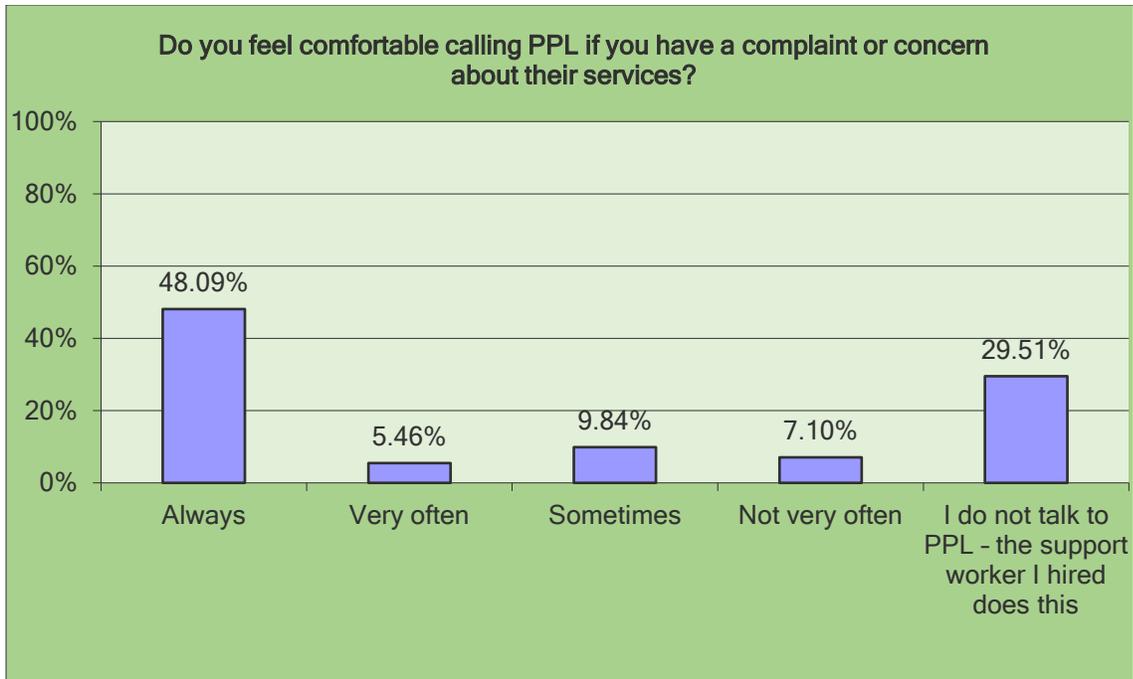
- consistency and submitting invoices quickly
- communication is excellent with my DDS provider

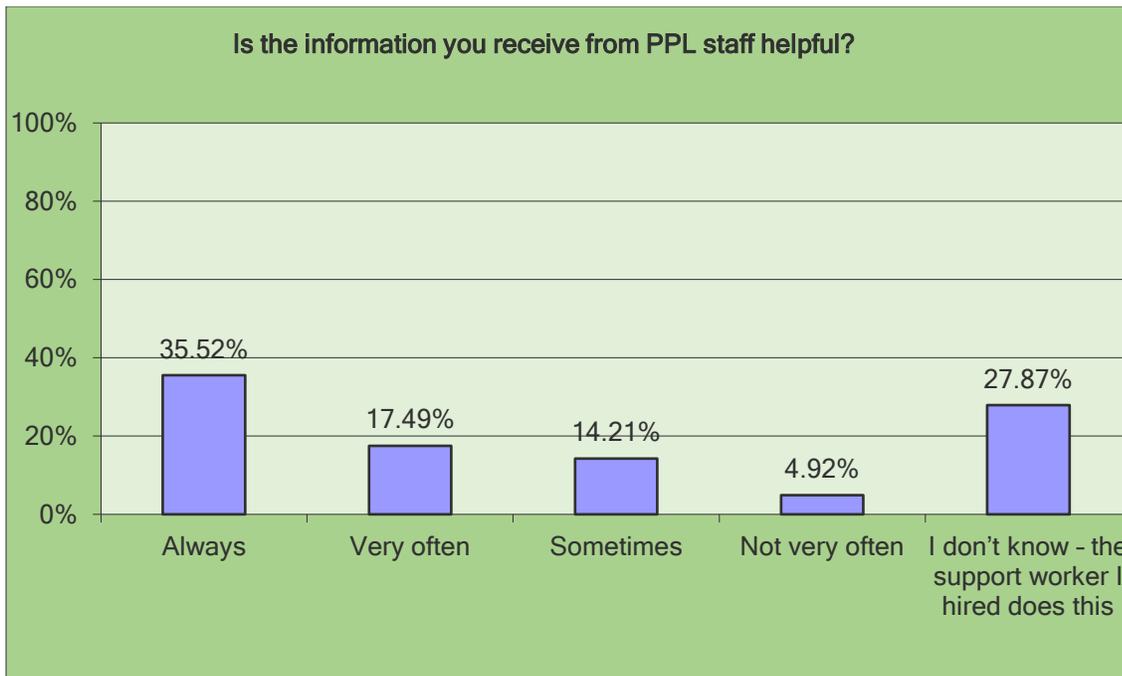
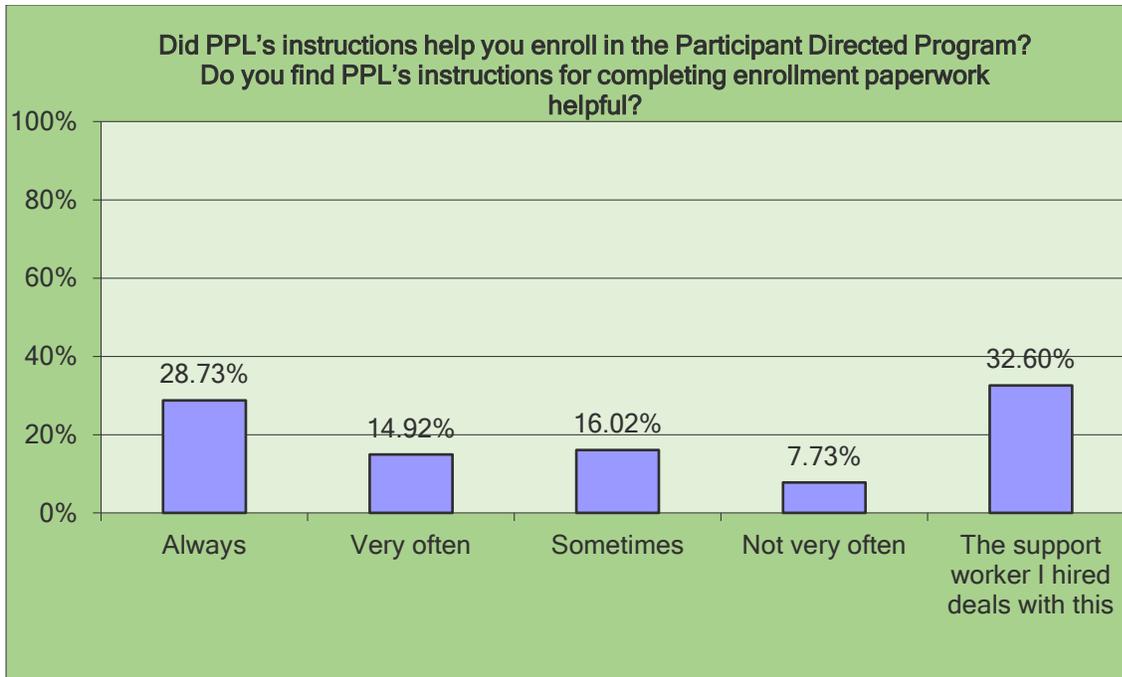


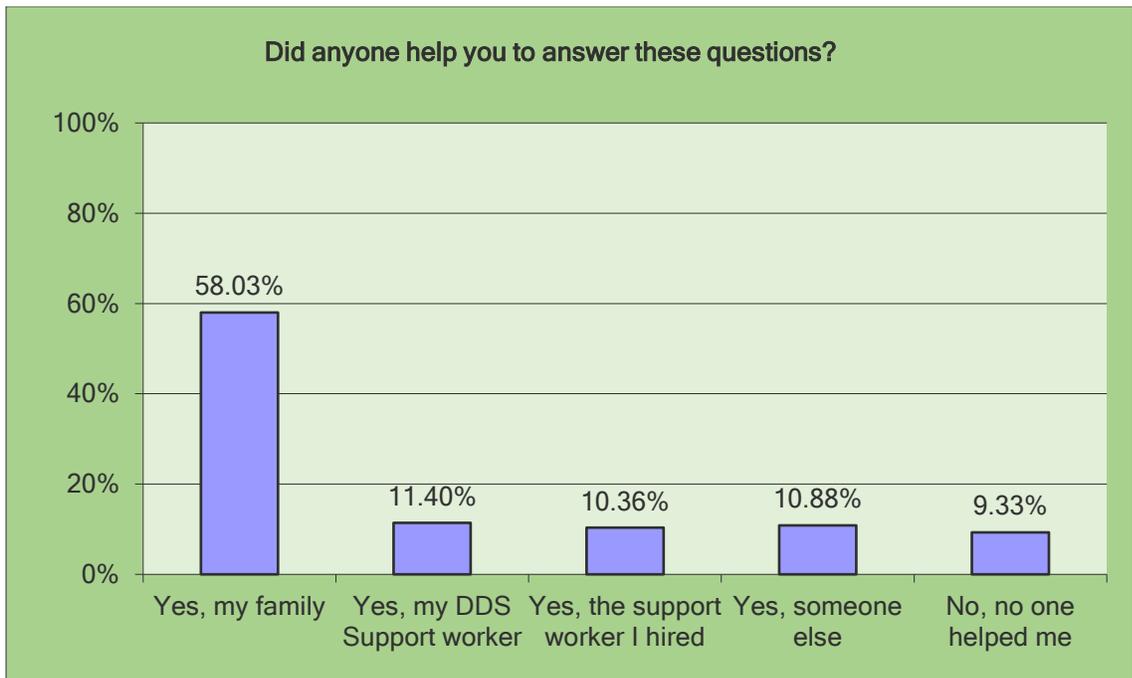
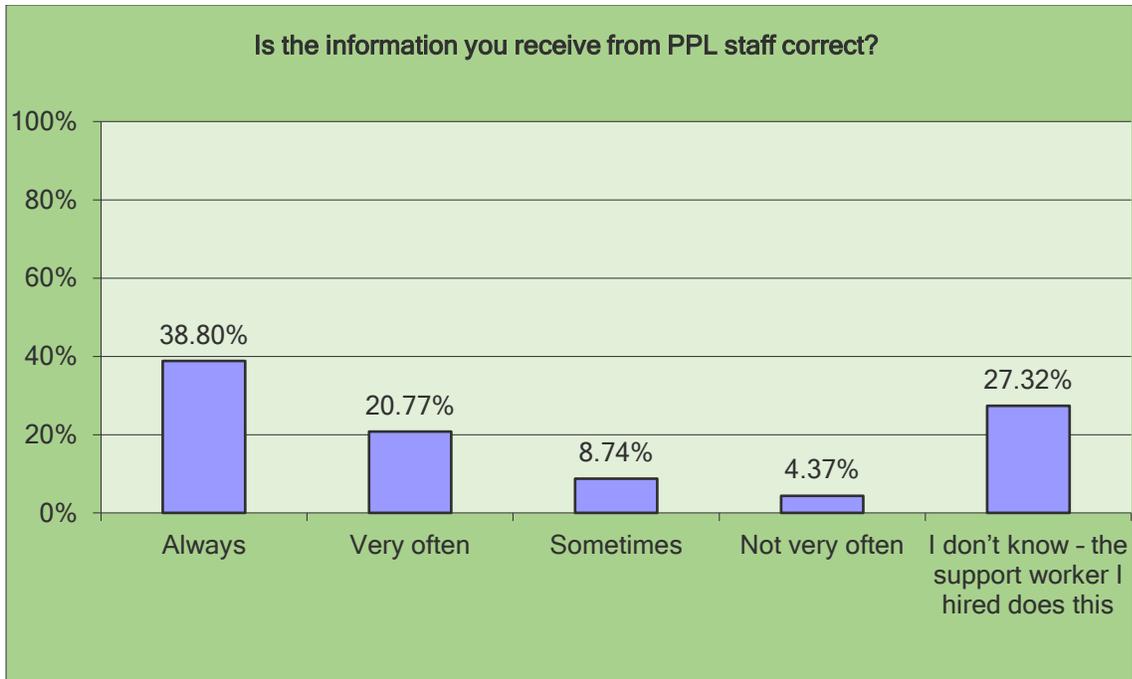












Is there anything else you would like to tell us?

- we are all very grateful to have this to self directed program option. Thank you
- self-direction is the very best option. Highly recommend it to others

- Since PPL has come into my life, my housekeeping skills have improved. I have great social skills and arrive on time daily for my job
- I am (name's) mother and I filled out this survey overall I am very pleased with self directed program. DDS has been very helpful going through this journey PPL staff is always very professional when I call them
- overall the participant directed model has worked well. People need to understand the level of commitment yo make it work. PPL tech needs to be upgraded and processing time for new staff needs to be a shorter timeframe. Three plus weeks is not acceptable.
- we have no contact with PPL. This is an amazing option allowing "me to work a job". It was just very complicated to get the services. During the initial DDS transition at age 22. I mean very difficult
- biggest challenge is having a pool of people who would potentially work for you. It would be great if DDS could provide this service
- once I let my best buddy job coach go for lousy job. My dds supporter told me I had to go on another program but i don't remember which one. I've called my DDS supporter several times and sent emails. I also called his supervisor and left a message for over a month now and neither one has responded. I feel isolated and alone
- I want to do more under self direction but there is not enough things to do to stay busy
- Thank you for ppl and dds for supporting my independence and growth, someday i hope to be on my own
- This survey is being filled out by is mother. (name) is not capable of managing this program. We have him make the choices for his day and give us as many direction as he can. His volunteer work tasks are all activities he enjoys
- I would like to see more about housing and how this can be figured out with a profile like my sons. he eventually needs a place to call home beyond living with us
- We- as a family taking complete care of a severe individual- had a much easier task before the real lives bill was passed. It did not give us more dignity or freedom but added to our already heavy burden. Family support should be significant help- considering it saves the state so much money for an individual with severe needs. the real lives bill should be for someone that can speak for themselves. A different bill should be proposed for family support that does not come with so many strings attached. families are unpaid caregivers that save the state money. our daughter is severe enough to be placed as priority. our lives should be made easier not harder
- We appreciate the flexibility that he self directed program allows us to have in terms of hiring own staff and setting up an individualized budget.
- self direct has been a life savor for (name) We hope to get more hours. Standard programs in our area do not work for her. She is to easy to ignore and let sit unattended.

- we love designing my sons day ourselves. he feels more confident going off every morning to his job sites,art class, etc.
- I would like to play music as a job like other professionals do for money. I would like to be in Path Light In Greenfield
- I enjoy making my own decisions and self direction services. the only area of need is receiving more money to help me get necessary services.
- this funding helps pay for my rent. I wouldn't be able to live here, right near a T stop if it wasn't for this money. I live in a location that I can be independent. I don't have staff. My parents help me with things I need help with
- thanks so much for everything so far
- I am looking for an apartment to live in and maybe I need roommates too to have fun with them

Appendix G: Agency with Choice Participant Survey Report

MA Real Lives Evaluation

For internal review. DDS Quality Assurance Evaluation

Real Lives Agency with Choice Survey Results July 2018

Prepared for:

Massachusetts Department of Developmental
Disabilities Services

Prepared by:

HUMAN SERVICES RESEARCH INSTITUTE
July 24, 2018

Background

The following data were collected using a survey that was mailed out to 440 individuals who are participating in Agency with Choice. Participants were given the option of completing the paper survey or using a provided link to SurveyMonkey to complete the survey online. HSRI received 126 valid surveys between April 13, 2018 and July 7, 2018. Survey respondents were not identifiable in the surveys; however, they did provide their zip codes to allow for reviewing findings by region.

Summary of Findings

Respondents to this survey are participating in Agency with Choice, an option for self-direction in Massachusetts. 96% of respondents fall within the DDS service population ages of 18-65. Only 4% were over age 65. About 71% of respondents live at home with their family. 18.3% live in their own home or apartment and 6.4% live with a foster family or in shared living and a very small percent (4.8%) live in group homes or other residence types. More people have been self-directing for more than 4 years (46%) than those who have been self-directing for less than 4 years (43%).

The majority of respondents (65%) learned about self-direction from a staff person at DDS; 23% learned from a staff person at their agency, 15% of respondents said a family member told them about self-direction, 13% said their ISP meeting, 7% at a meeting at school and 9% learned about self-direction at a self-advocacy meeting. Respondents answered questions about the information they received when they started self-directing their services. More than half of respondents (61%) said they received all the information they needed; 29% said they received some information but needed more; and 10% said they still have questions they need answered. Almost three quarters (74%) of respondents said they know who to ask if they have questions, 10% said they do not know, and 16% answered that this was not applicable because they have all the information they need.

Prior to self-directing, 59% of respondents reported receiving traditional DDS services, 27% said they were not receiving services, and 14% did not know if they were receiving services. People reported feeling like they are making choices about their services and supports all the time (61%); some of the time (36%); not much of the time (2%), and 1% of respondents said they didn't know. Some of the things people said have changed in their life since they are self-directing are: making more choices in their life (71%); they hire their own staff (47%);

they can go shopping when they want (38%); they are more independent (46%); and 46% said they feel better about themselves. A complete picture of their responses is in the *Results by Question* section.

When asked if they will continue to self-direct in the future, 93% said yes, 2% said no, 5% said they are not sure, and 88% of respondents said they would recommend self-direction to others.

Participants were asked if they have had problems since they have been self-directing. More than half (54%) said they had not had problems and everything is going well; 43% said they have had problems but someone has helped them with the problem, and a small percentage (3%) said they have had problems that no one has helped them with. Participants reported that it is hard to find good staff (61%); there is not enough money in their budget for them to do what they want (34%); the process is complicated (27%); it takes a long time to make a change in their services (23%). Smaller percentages of respondents reported that they are having problems with the agency they are working with (5%); they still have questions about the process (13%); it is hard being the boss (11%); and 25% of respondents listed other problems (listed in the *Results by Question* section).

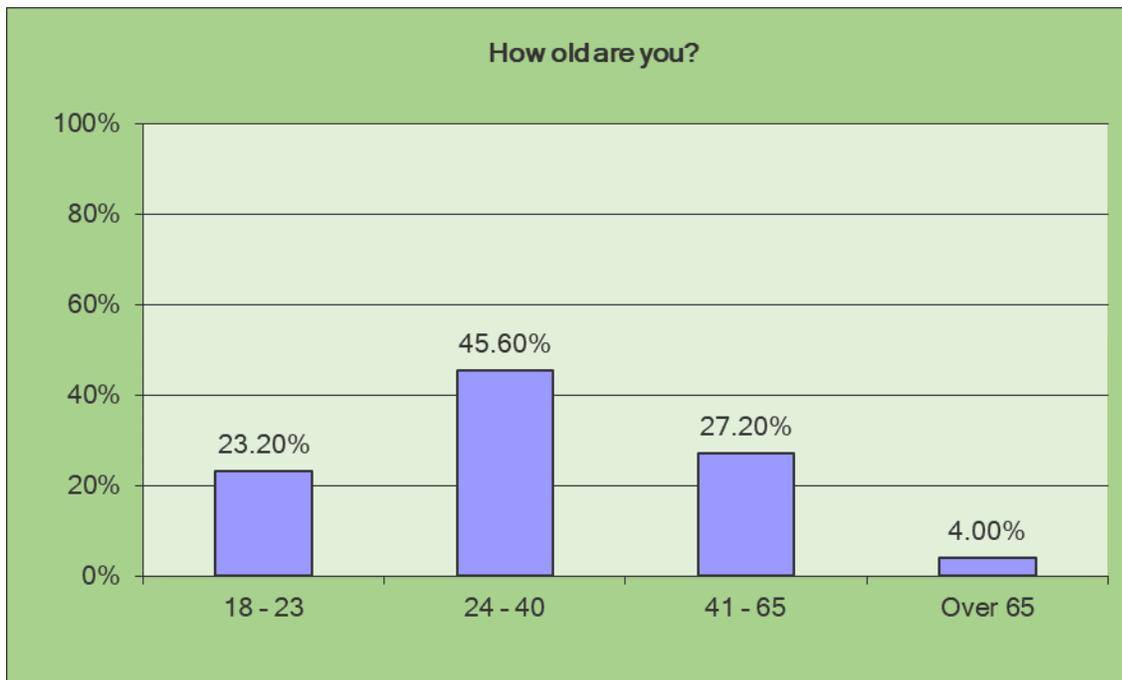
Most of the participants know who to contact in the agency they are working with (95%), and 93% reported it was easy to get in touch with the agency. In terms of what type of help participants receive from the agency, respondents said they got help: choosing their staff, paying staff, tracking timesheets, sharing information about their budget, interviewing staff, becoming involved in their community, making decisions about what they did during the day, managing staff schedules, planning for emergencies, and some listed other answers to this question which are listed in the *Results by Question* section.

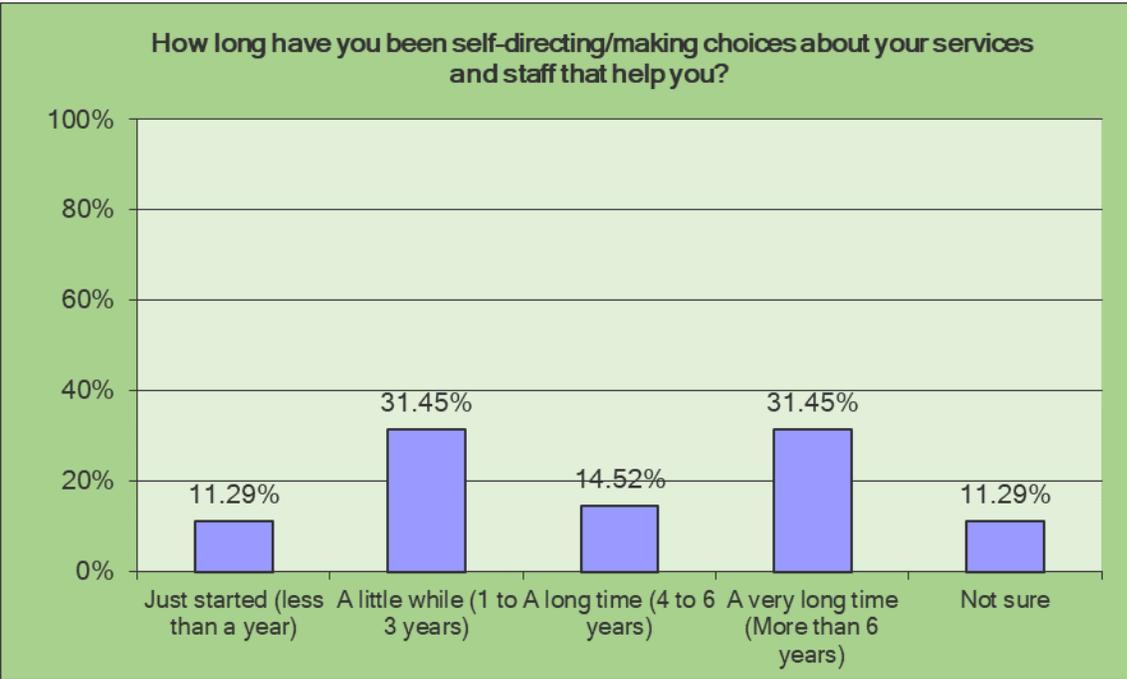
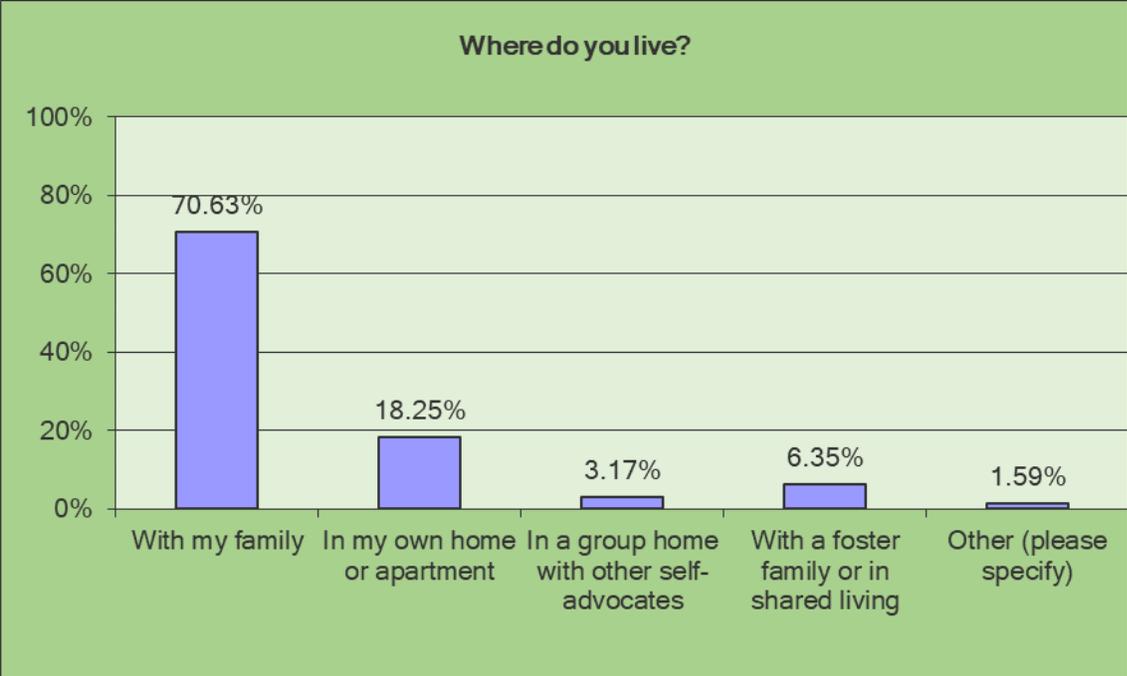
62% of respondents said they get all the help they need from their agency with choice, 18% said they get some help, 17% said they could use more help. A follow-up question asked what kind of help they need. A sample of their answers are: “advocating for transportation funds,” “It would be great help if agency with choice would have people trained to step in to help especially during helper absenteeism. DDS providing enough \$ for families to develop a structure to assist with absenteeism,” “need the agency to speed up the process of hiring the individual that I get.” Others talked about budgets, better trained staff, needing a job, etc. When asked if they have had an overall good experience working with the agency, 97% responded they have.

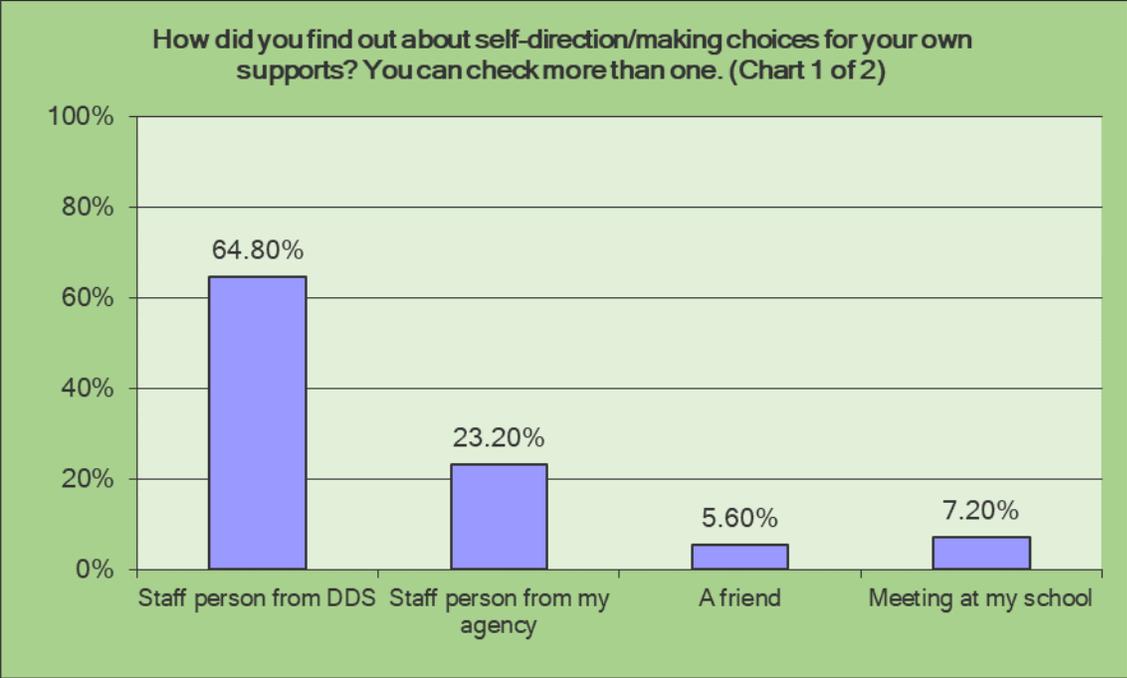
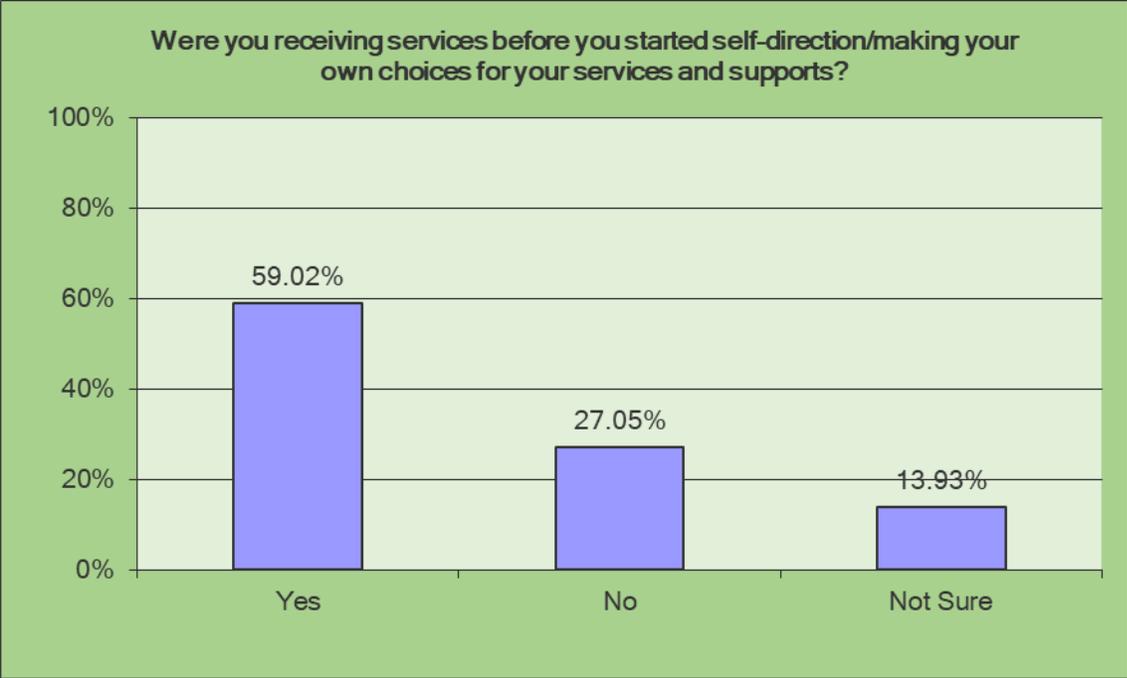
Most respondents (93%) know who their DDS Support Broker/Service Coordinator is, 96% said it is easy to get in touch with that person if they need to, and 95% reported having had a good experience working with their DDS Support Broker/Service Coordinator. When asked about the help they get from their support broker/service coordinator about self-direction, 63% said they get all the help they need; 22% said they get some help; 12% said they could use more help; and 4% said they weren't sure. The follow-up question asked what kind of help they needed and responses ranged from help with making good decisions to a Service Coordinator who has more knowledge about AWC/self-direction. The entire list is included below, in the *Results by Question* section.

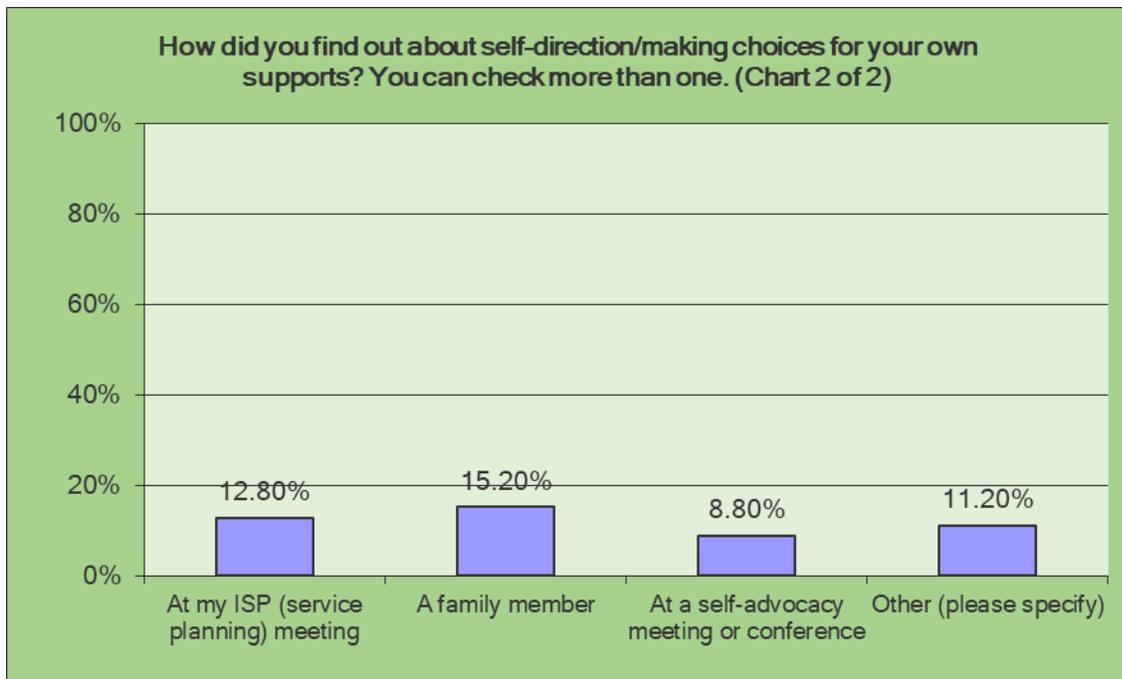
Results by Question

Detailed results and graphs for each question on the survey are presented below.



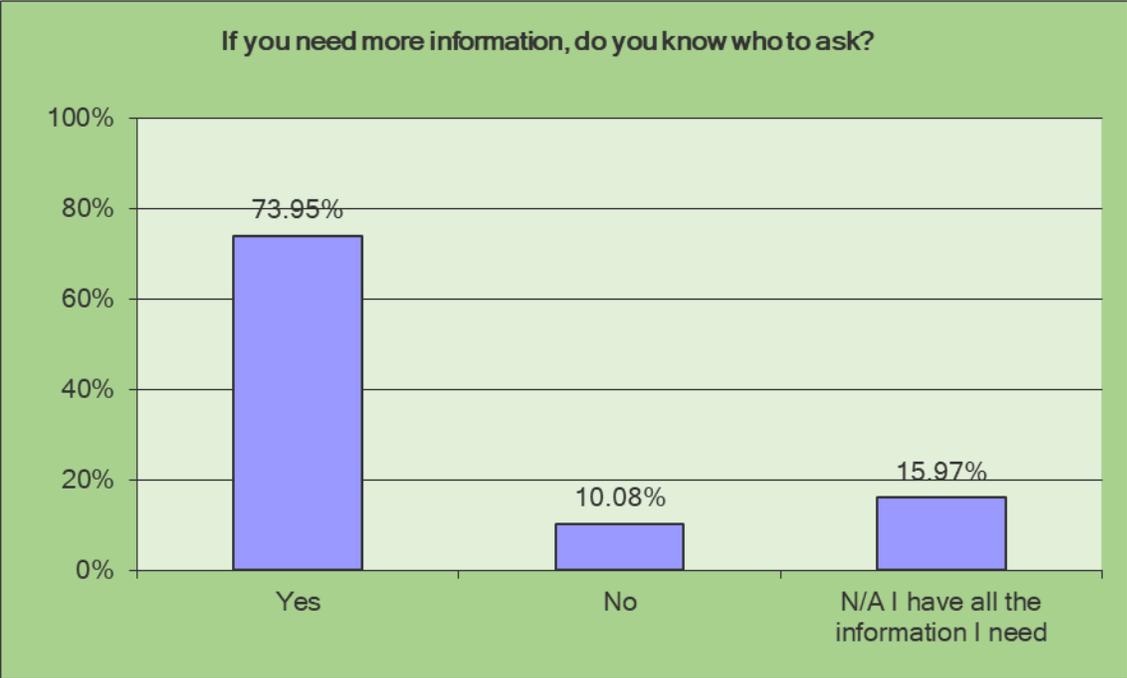
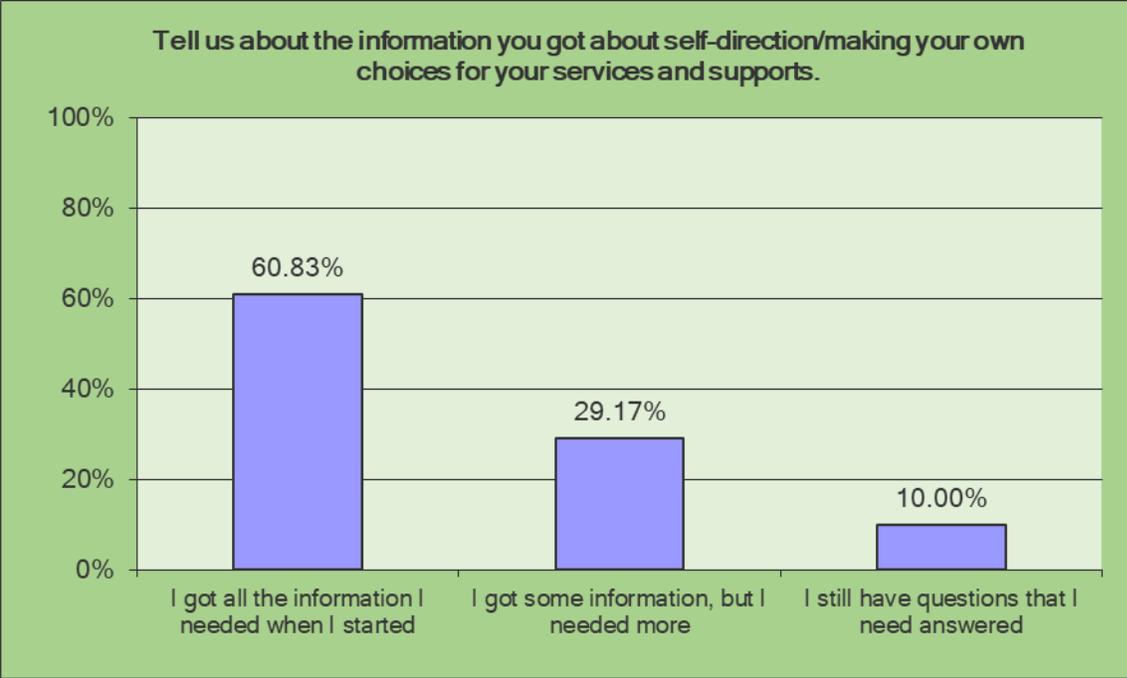


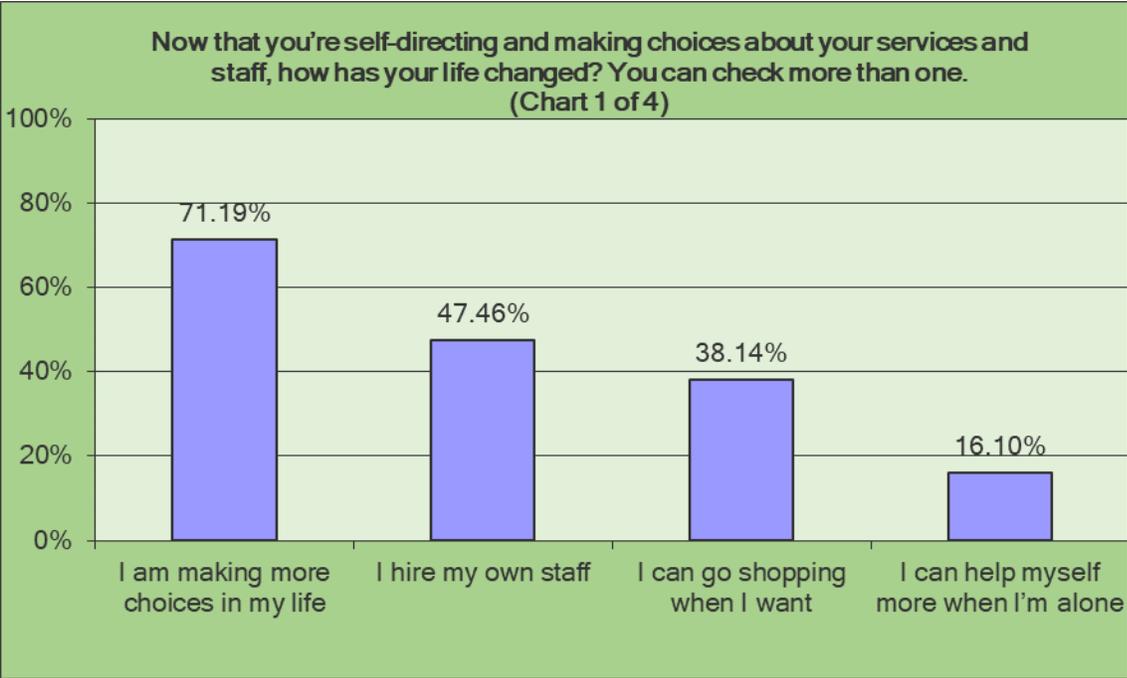
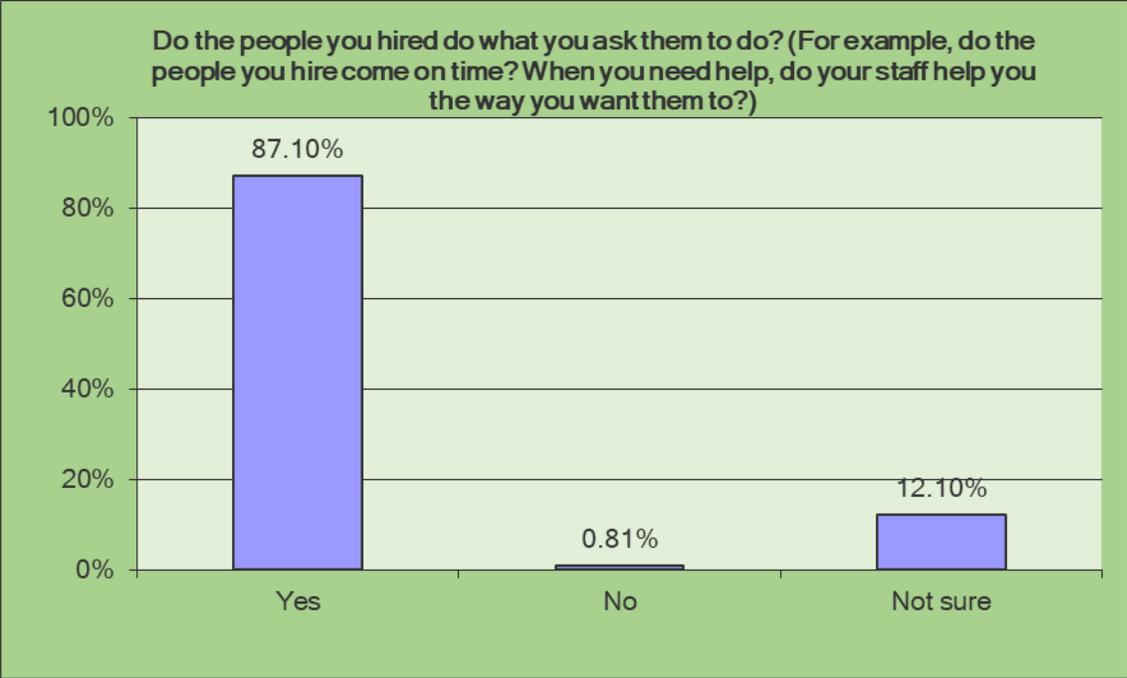


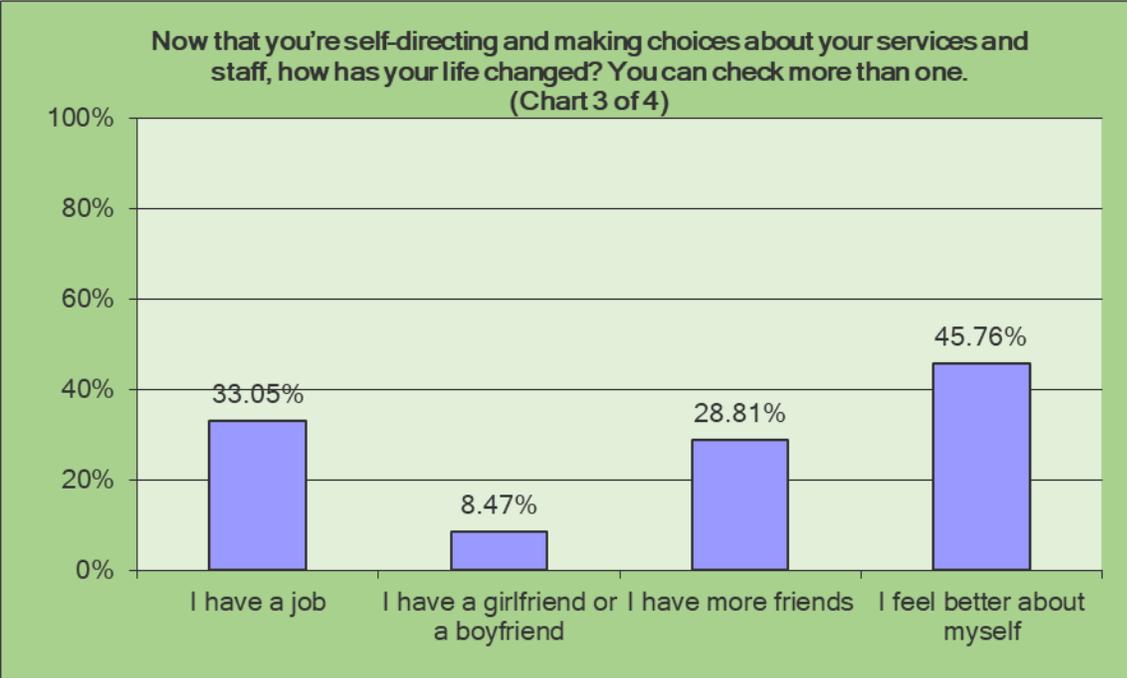
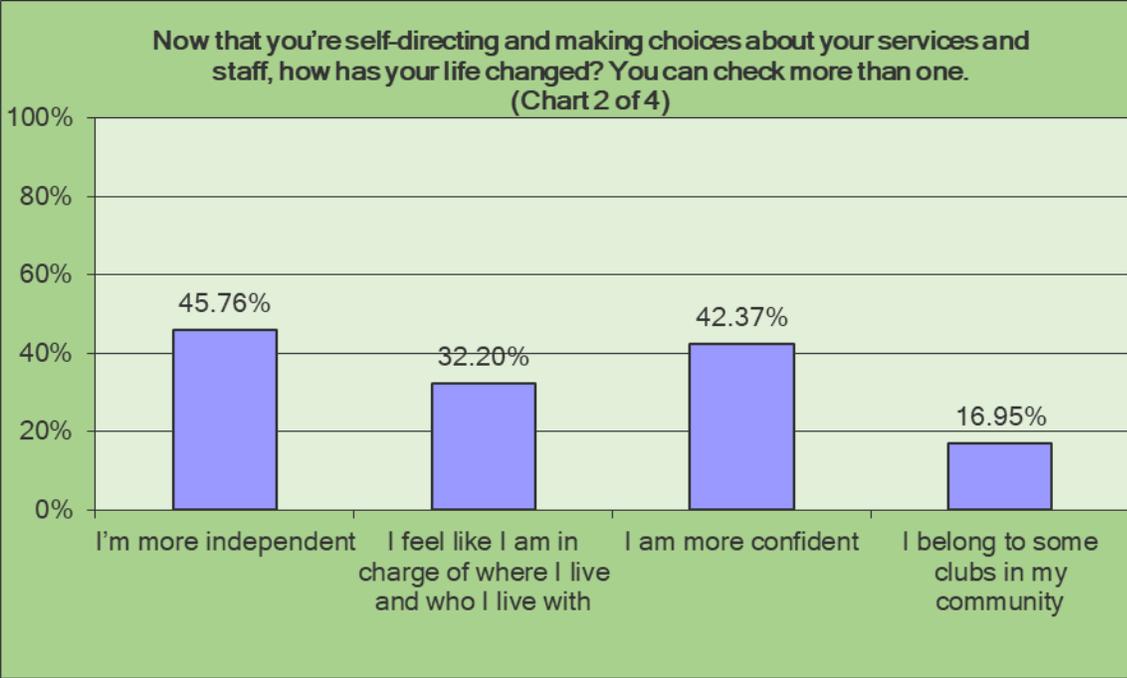


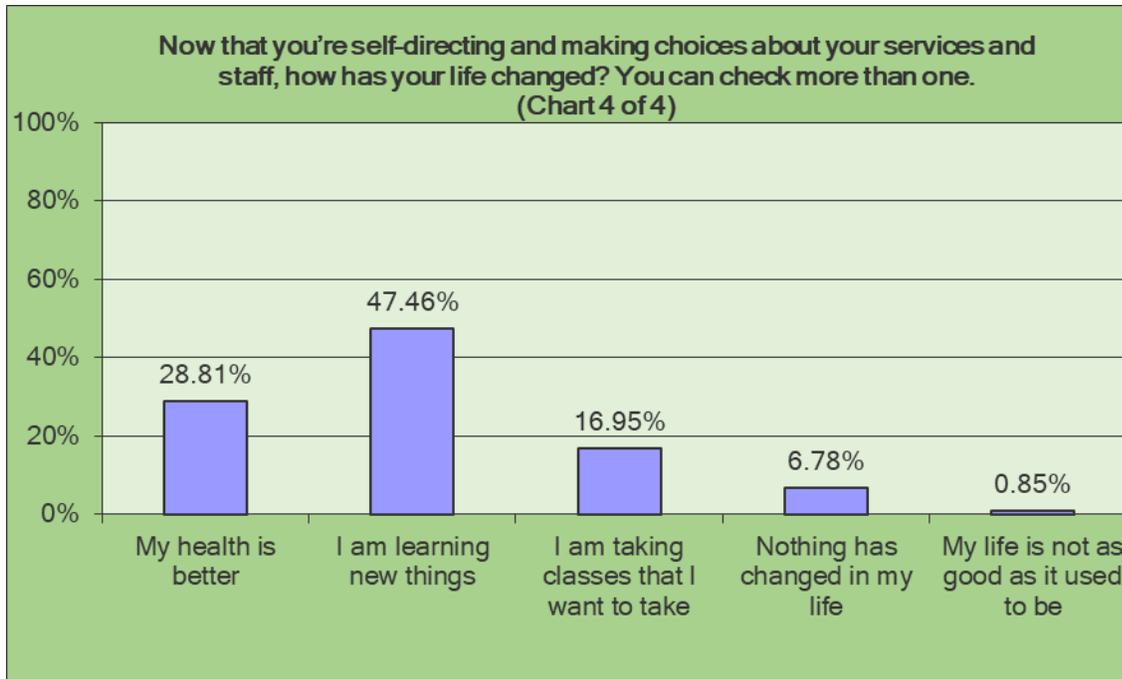
Other responses:

- Started in 1992 before introduced to others
- agency head
- mcs
- not sure
- staff
- Massachusetts Families Organizing For Change
- mom presented desired plan to DDS When my son turned 22 years old.
- no one
- seven hills
- DDS Training
- father
- none
- advocated for years for quality choices
- letter







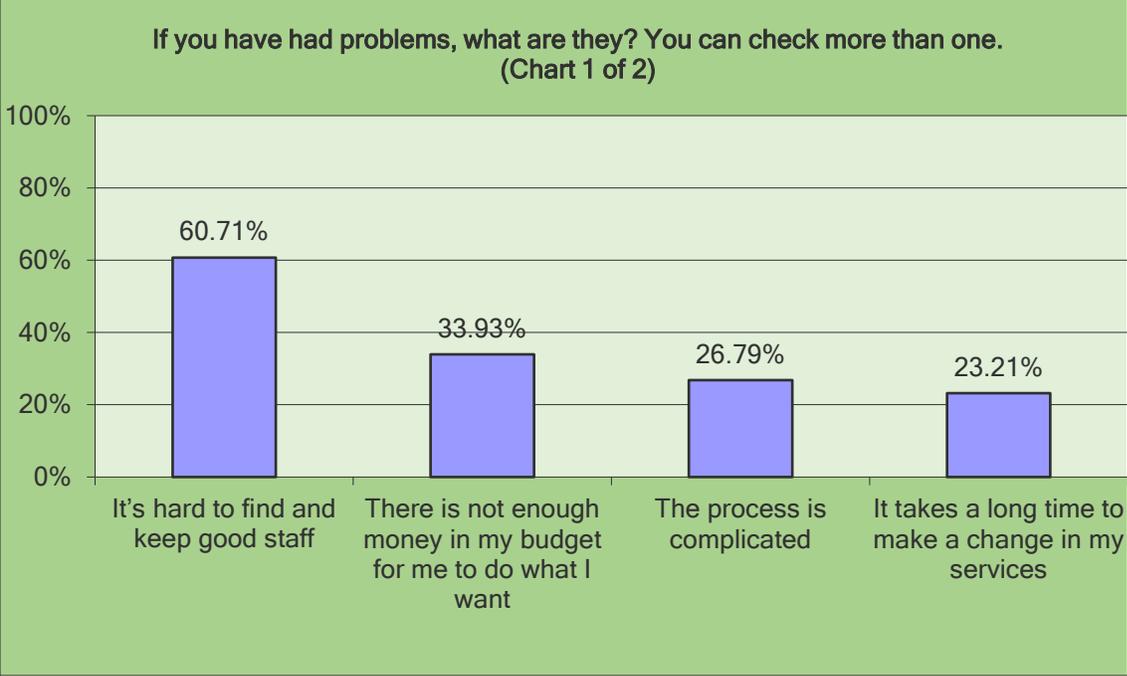
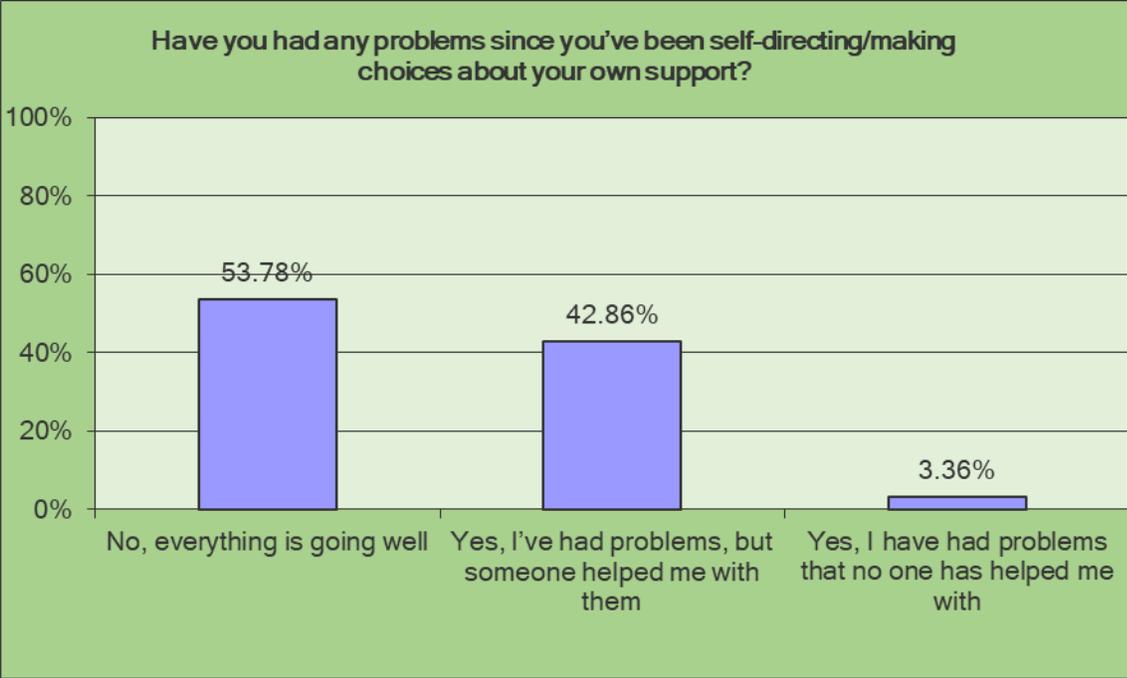


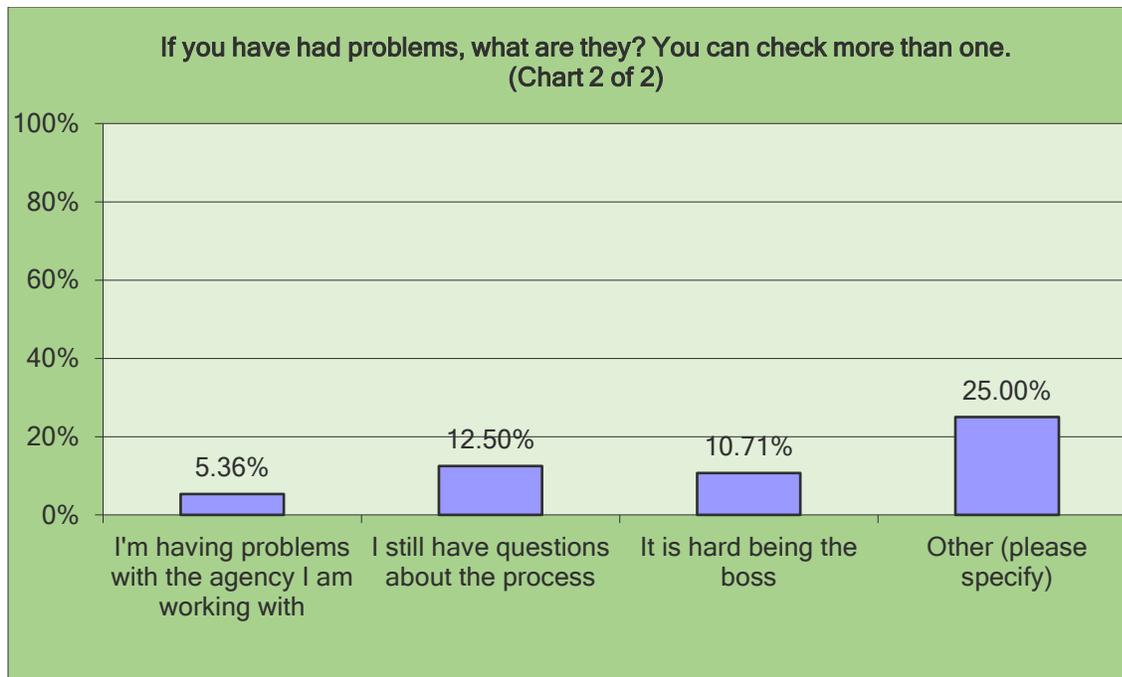
Respondents were asked if there are things in their life that haven't changed or they still want, their responses are here:

- I would like to work 6 more hours a week
- better job, license
- to stay away for vacation and staff can help or, place (ineligible)
- would like a mentor that is willing to stay out a little later in the evening
- hard to keep workers
- more friends- girlfriend
- n/a
- I want to continue to receive the level of support as my needs continue to increase.
- options for supported living in a home other than a group home. In other words my own home but staffed and a roommate or two. Planning for next stage as participants parents age
- Continue to get more independent
- not sure
- Access to appropriate social activities and meeting a peer group to socialize with.
Transportation remains a challenge
- He is now at a program instead of school. Structured day
- To meet other clients and do things
- Physical, reading and writing
- I am more independent- less harmful to myself

- Does not know what he wants, prefers that others make decisions he can choose from, too anxious to own all the responsibility for/of choice
- I got a job and I still want to find another job in a theater company
- not at this time. simplify the process. too complicated. more budget
- I can go to Alabama to learn SAB civil rights
- I want to try some classes, I'm still too anxious
- staff
- I want more self directed services so I can be connected and involved in my community and engage in more social activities
- I wish to be fully independent and no longer need services especially H.M.E.A
- transportation is most difficult.
- more work
- It would be nice to get more help in assistive technology.
- No, I have pretty set up program for now.
- More \$ to make a transition to a "hybrid" shared living model. my son would not fit well into a traditional shared living model. He is more than ready to live without his mom. (please see earlier note)
- Staffing has always been a big problem
- no change, i still want my own house
- no
- Not sure now
- Above (roommate) would like a job coach but I don't have enough in my staffing budget from DSS
- I do Agency with Choice 2 days a week, I need to know I have access to more staff if I change to full time I live in a rural area.
- I want to get a job, I want my own apartment in the future.
- name is delayed about 18 months old, legally blind, my husband and I take care of all of her needs
- my angry outbursts, my behaviors
- I still wanna live on my own in my own apartment
- yes. I want a girlfriend and to be a firefighter
- i want a new girl friend
- maybe more support if we are at the hospital more in the future
- finding quality staff is a challenge I need 1:1 support with many activities
- I still need a job
- still having an interest in weather/auto mechanics
- to be more independent and to go more places by myself or with me and just staff alone!

- planning 24/7 services which takes time and more funding
- I would like more overnight coverage so I don't have to sleep at my parent's house on the weekends.
- I need a guardian to make choices for me since I am incapable of doing that for myself. Although my guardian informs me of my choices this will remain the same for the rest of my life.

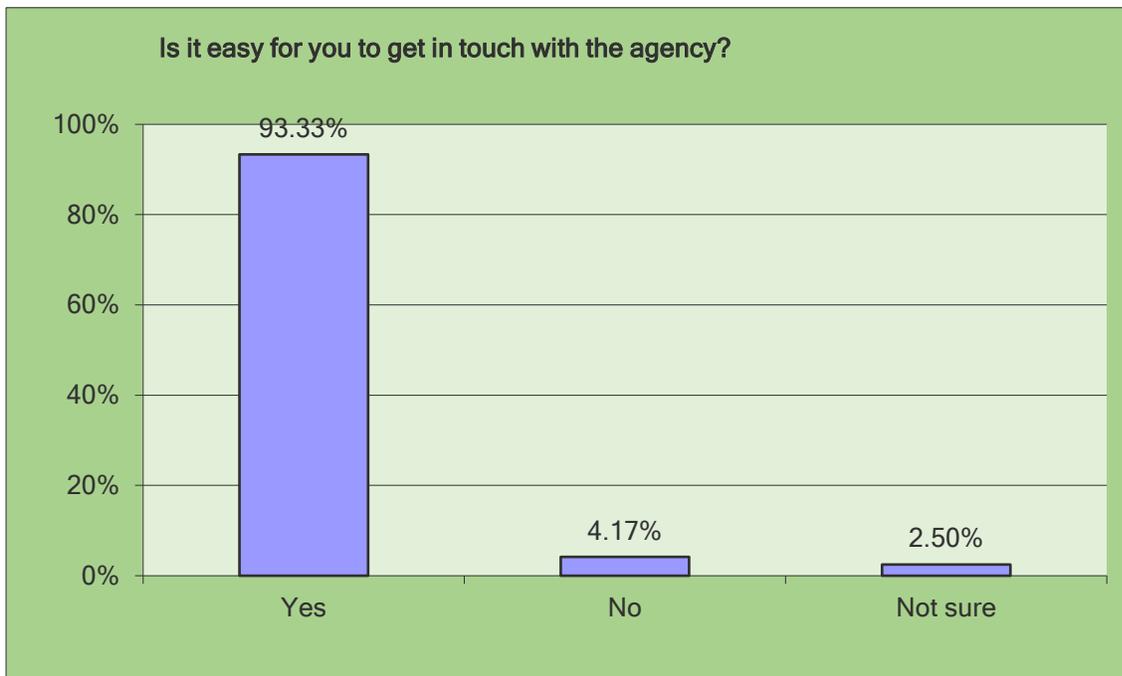
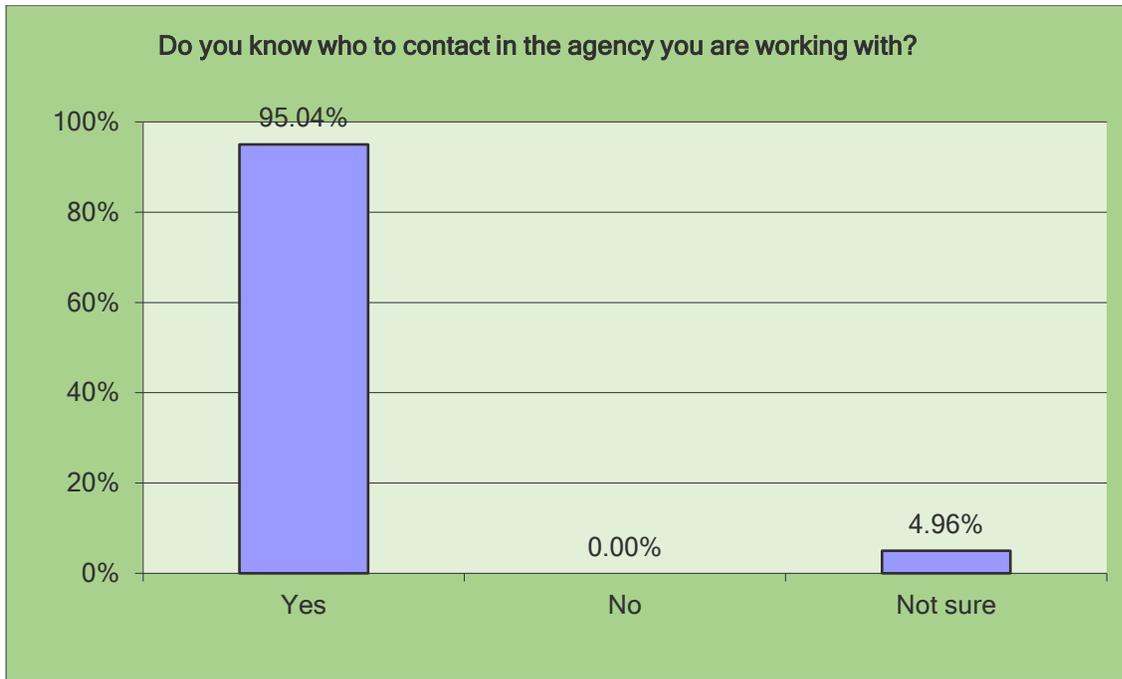


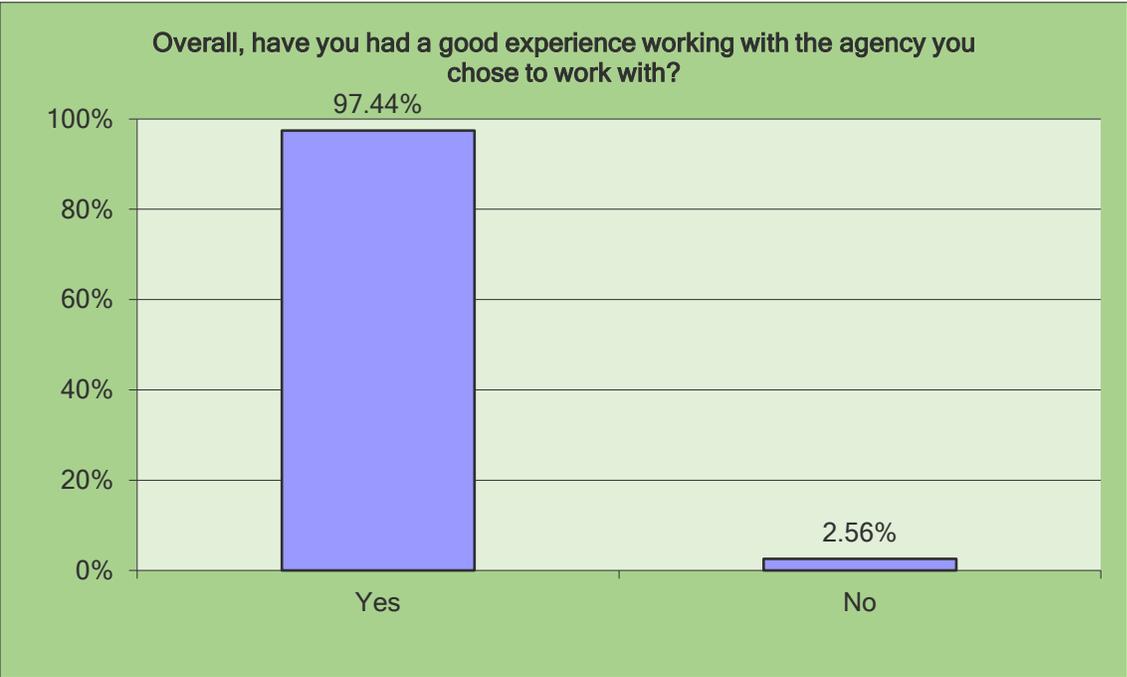
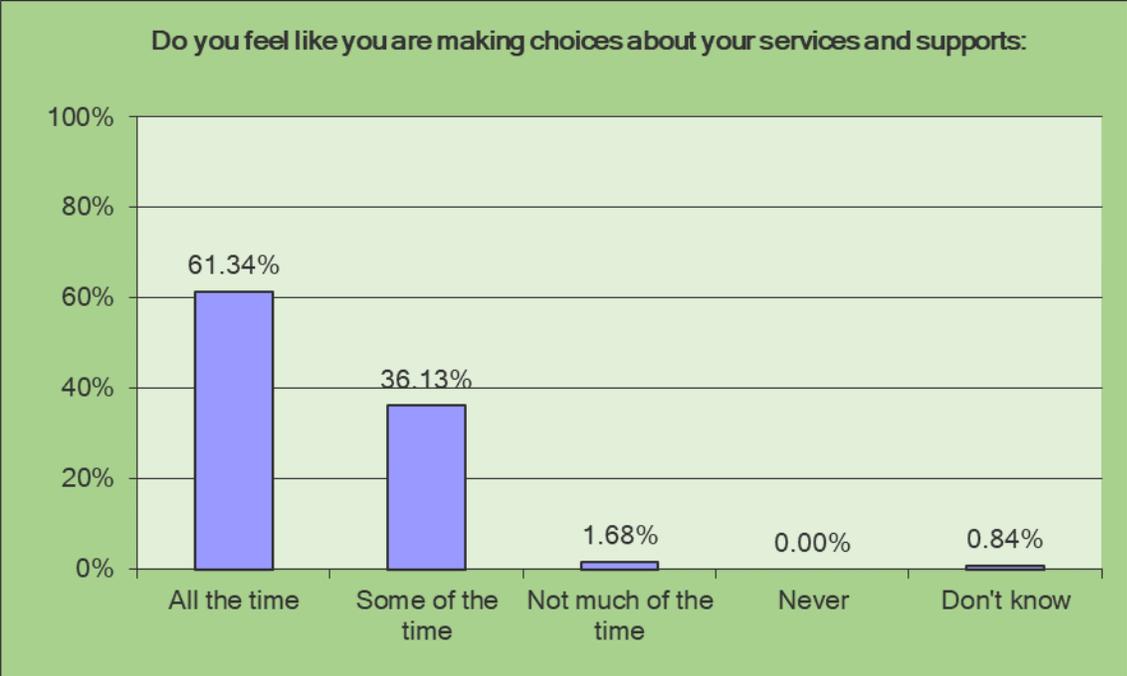


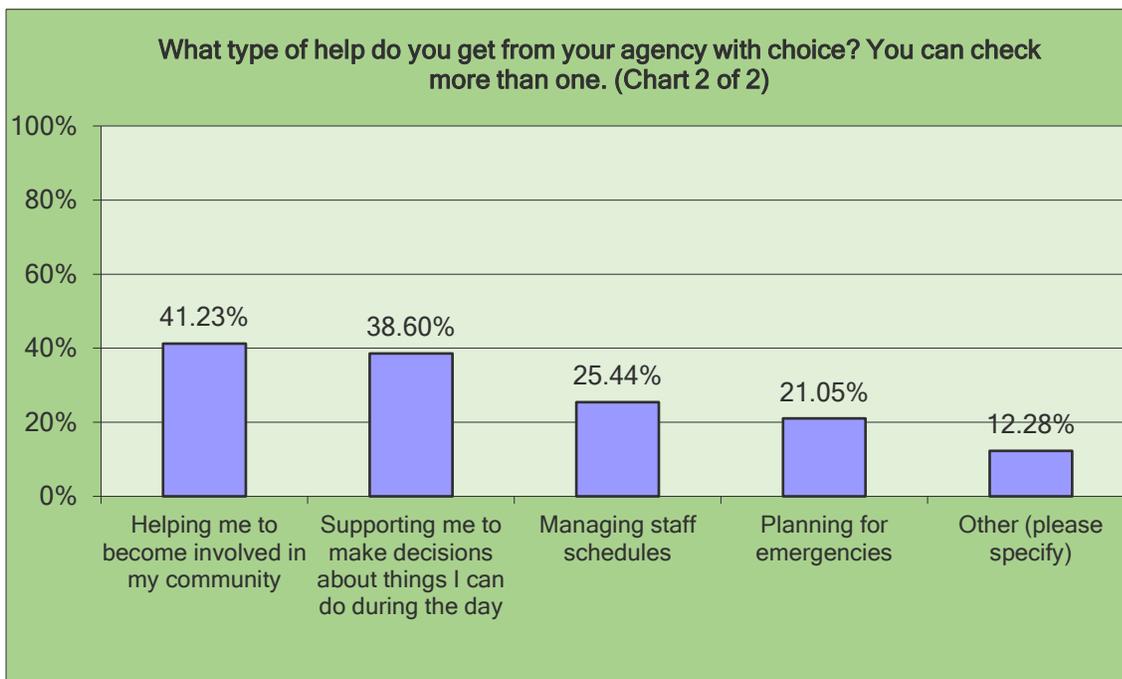
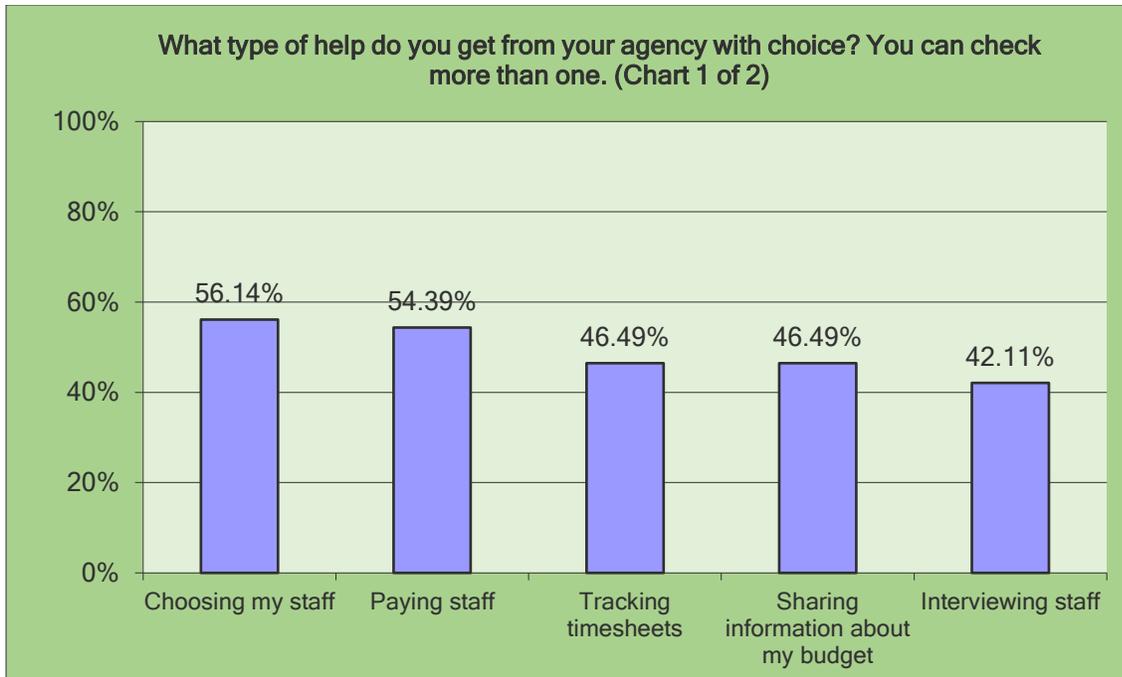
Other responses:

- not enough transportation money
- communication is hard for me due sensory issues, OCD, PTSD
- budget concerns were addressed
- i have had great people but they left. Now introduced to two more and I feel good about the choices
- There is not enough money in the budget to give the staff a raise even though they have worked for us for many years
- My parent helps
- New DDS service coordinator- not much help
- finding appropriate services
- Being the boss is hard, I've never been the boss before
- Some staff do not listen and do what I want. They do what they want and talk back
- As legal guardian, I need to hire, interview, train, and monitor/ supervise. It is a lot of work. When helpers don't show up or have vacation all the work is on the parent. Some of the rules are applicable to group homes and don't work well in real homes.
- Staff have been excellent - but pay does not encourage staff to stay long term. It is an issue with human services in general . Agency I have is definitely one of the best. We found this agency through my brother, when he changed agencies and was happy
- We changed agencies several years ago and that has made all the difference - much better !!

- We were one of the first families so there are things I would have done differently like having 24/7 coverage from the beginning, so I could live independently from my parents.



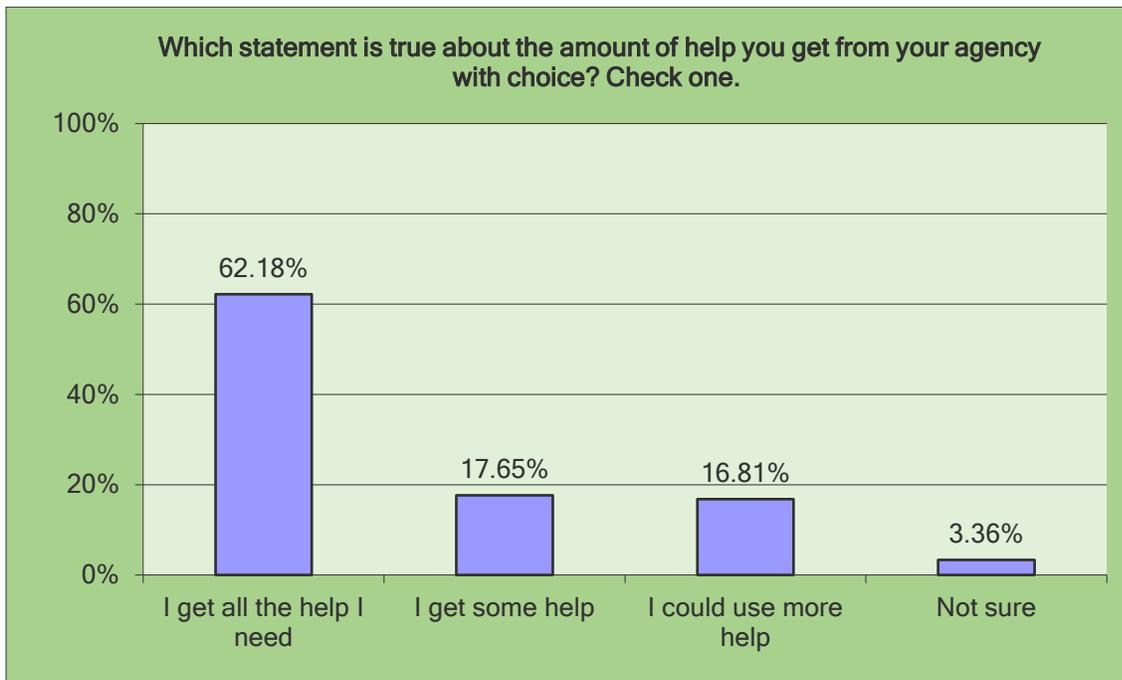




Other responses:

- couldn't find hospital to be treated after i get to Faulkner hospital ER, other couple weeks went by (ineligible)
- Problem is lack of staff to take her out
- continues to inform me of resources that may be helpful

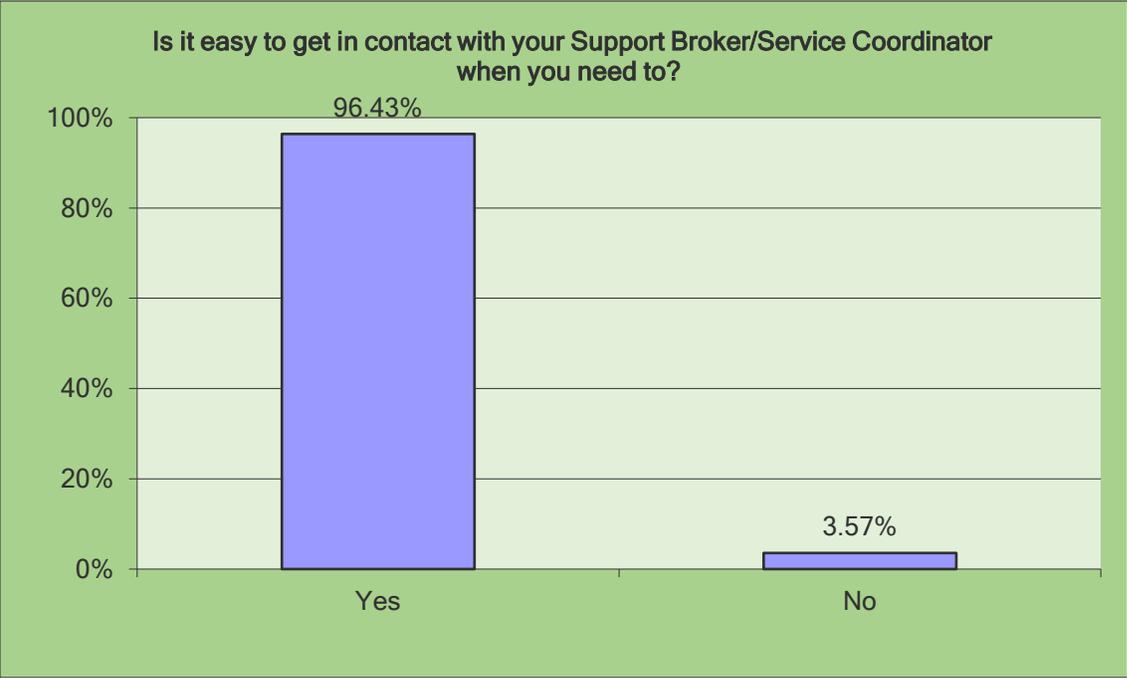
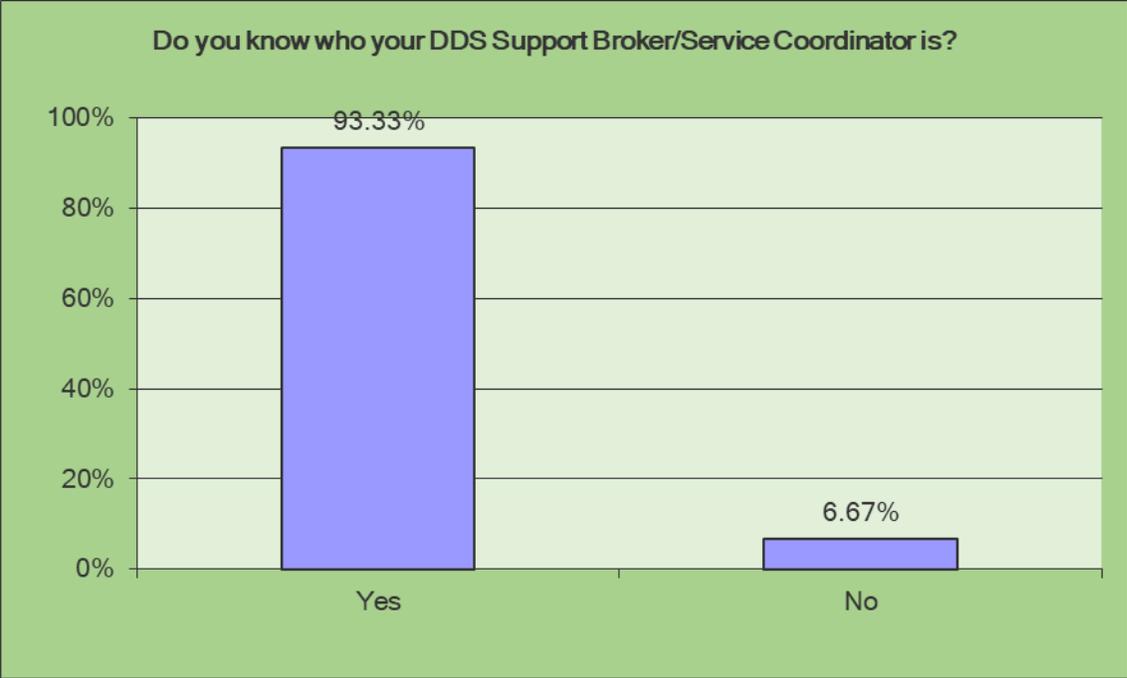
- incapable of large decisions. we help him
- Leaving me alone so I don't feel like i'm under a microscope
- My parents do everything listed above except paying staff
- life skills, shopping, cooking, cleaning
- Keeping informed about my life
- Helping me with my anxiety and learning about safety in the community
- very flexible
- planning activities at home and having several things planned depending on medical status
- agency staff are very helpful
- My sister is allowed to be part of my staff
- Understanding the budget categories is not easy.

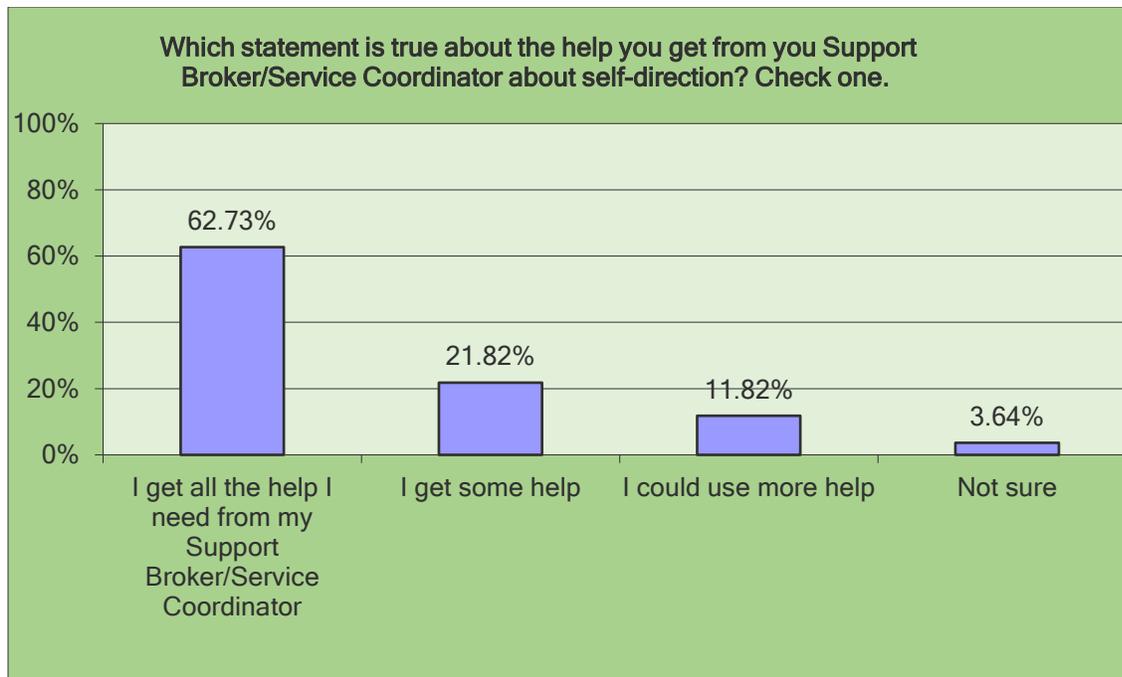


Responses to If you need more help, what kind of help do you need?

- advocating for transportation funds
- a miracle
- If I don't feel good can DDS provide respite for weekends or other holidays to be away from home.
- need a day program with staff
- the amount doesn't cover a full year of services
- How to change budget requirements- have more say on what I spend budget on

- They don't do much- basically process payroll and interview staff they make me find myself, help to find staff, help with community involvement, community opportunities, enrichment/leisure things
- Finding appropriate services to improve my social life, work life
- did all the work myself except for paying staff
- finding a job
- share budget information , support make decision
- Staffing for respite, etc.
- Having staff and getting someone to fill in when regular staff is unavailable. More support on where I am at with my budget, answer funding questions, help me more with planning activities and letting me know what needs to be done
- help finalizing transportation. More communication
- i could use more time for my staff to teach me life skills
- to make sure that they hire good staff that treat me with respect and not "bully". I have asked 2 staff men to be changed. I have had good women
- transportation
- more updated budget numbers.
- It would be great help if agency with choice would have people trained to step in to help especially during helper absenteeism. DDS providing enough \$ for families to develop a structure to assist with absenteeism.
- with staffing. i have 2 people working for me but if anyone of them needs time off, i have no one to help me and the agency doesn't have extra people to cover.
- getting more staff and better trained
- need the agency to speed up the process of hiring the individual that I get.
- access to more staff and backup staff
- more hours
- making good decisions
- would like to start working at Market Basket, DD, McDonald's or out of the program jobs.
- I need more help buying clothing
- "1. Emergency staff sharing services when regular staff could not make the shift.
- 2. staff training"

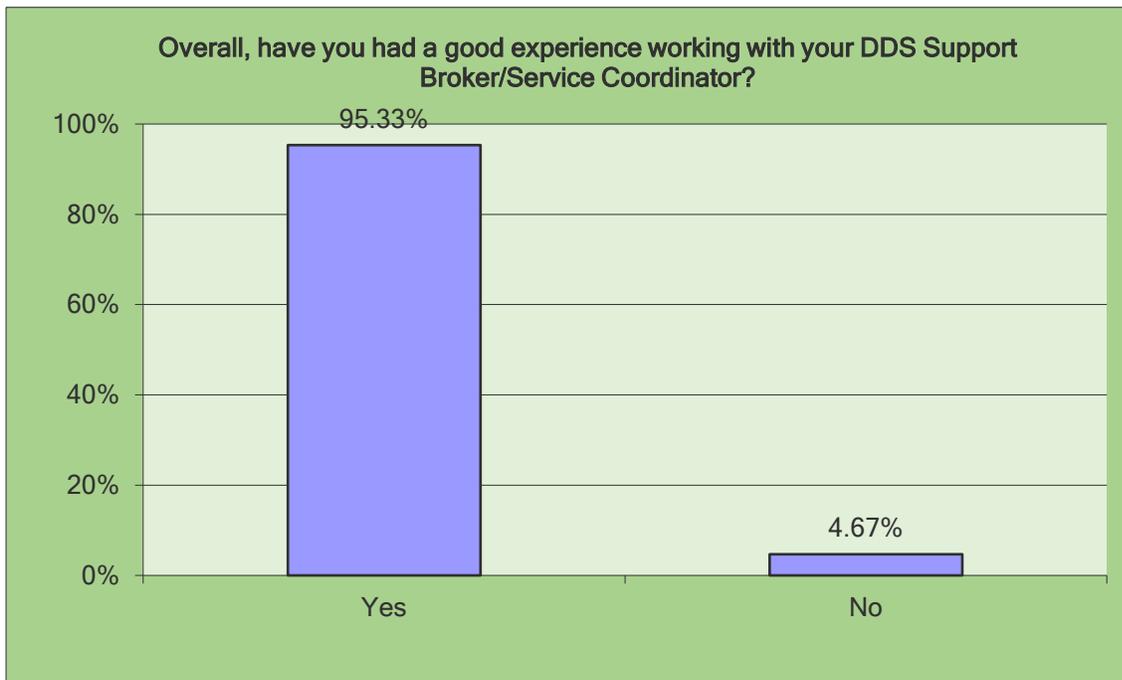


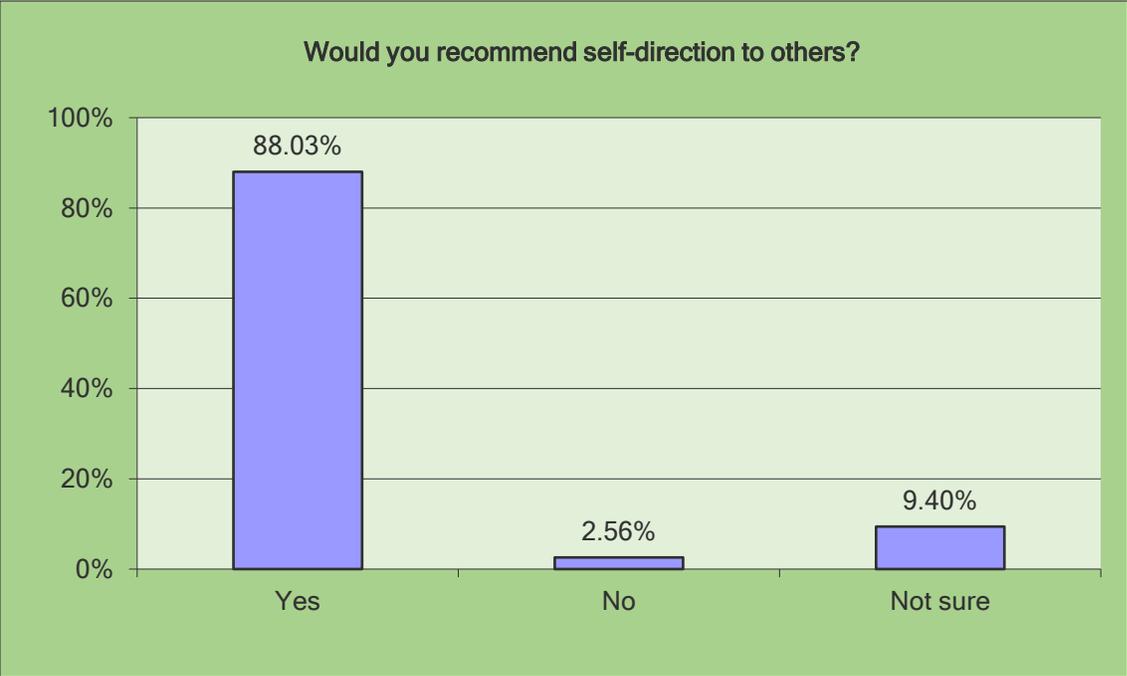
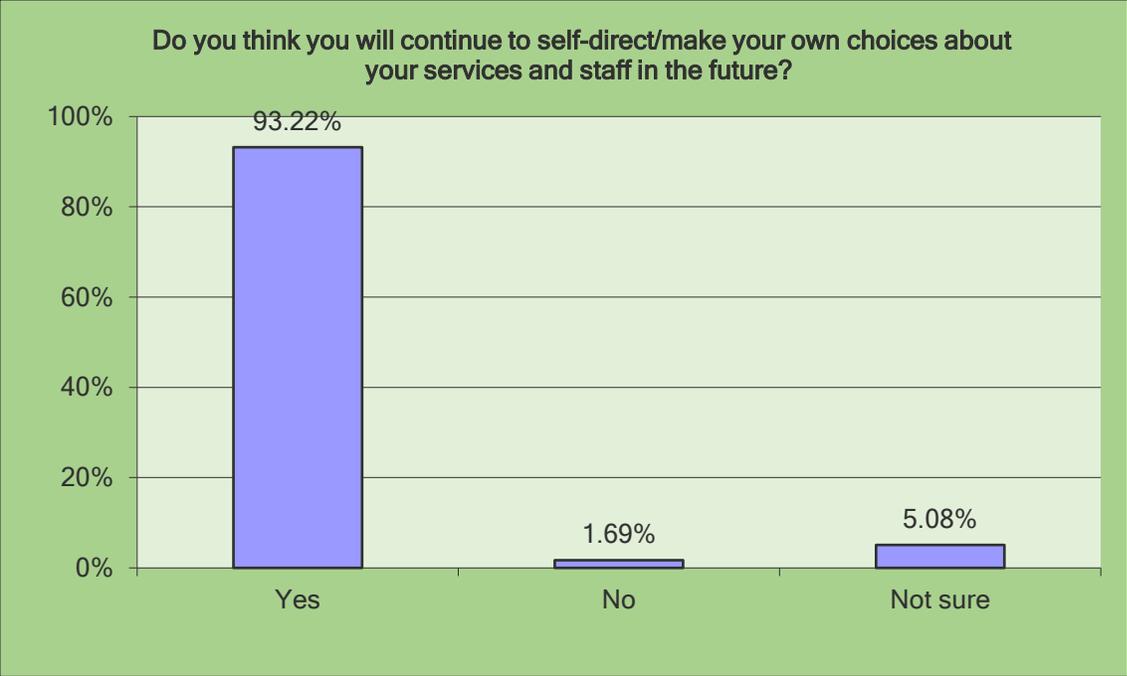


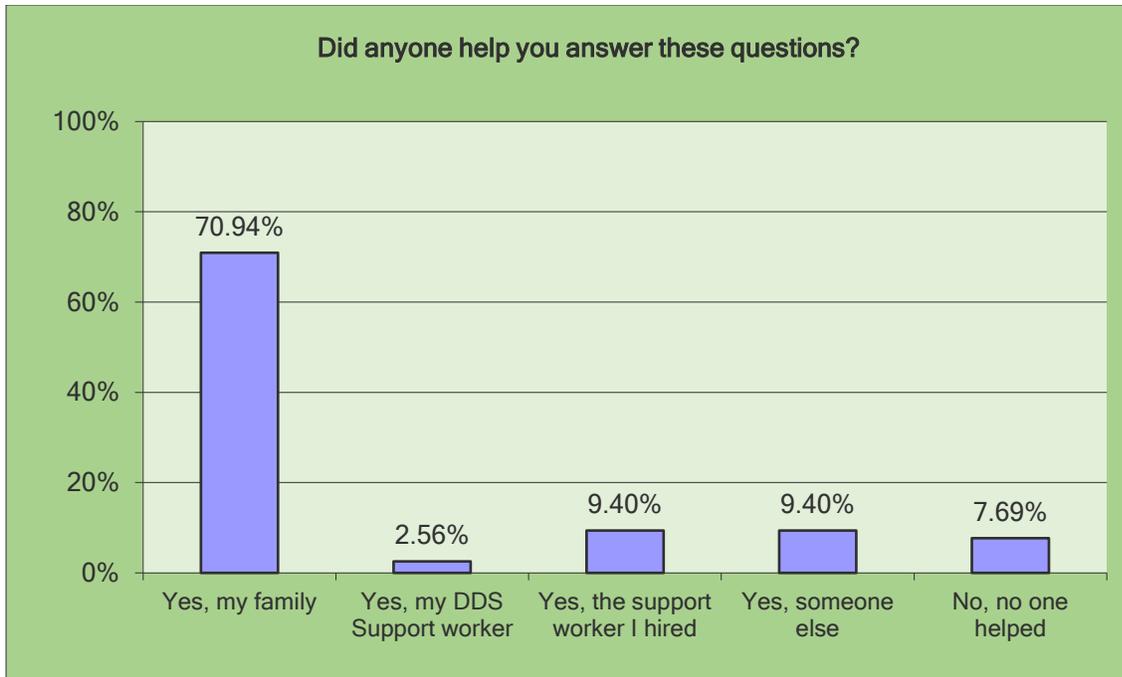
Responses to If you need more help from your Support Broker/Service Coordinator, what kind of help do you need?

- I been punish from transportation (bus service) to go to program. No one helps and says its not their responsibility because we don't pay them
- need help with a good day program
- making changes
- Reached out to service coordinator in Nov 2017 with request. (ineligible) It is now April 2018 and she never check back. Only see her 1x a year for annual ISP with no follow through and she has all my info yest still asks the same questions every time. Very disappointing!
- need help in acting classes. (illegible)
- The arc
- staffing fore respite, etc.
- Pretty much the same as in question 17a. I don't hear much from my coordinator unless I call or contact her.
- Have not seen or heard from other than 1 ISP meeting. No follow up from that
- more money for more hours so my staff can help me with life skills
- Help with absenteeism, help with crisis (behavioral problems) In general DDS and community supports are non- existent when there are problems. Families have to go through it alone.
- really need for them to help supply a person for when somebody takes vacation or is sick or needs to take time off to take care of their personal situations.
- just getting a job

- motivational help, more choices on things to do during my day.
- Better communication, Quicker email, phone call replies
- Need them to get back to me quicker
- A service coordinator who has more knowledge about AWC/Self-direction
- making good decisions
- I would like my coordinator/case manager to get me a different day program.
- our agency is helpful, not sure I would call DDS staff support broker- haven't experienced that kind of help from anyone at DDS
- staff training program, staff hiring
- suggestions on activities and other potential services
- Not sure exactly what things she can help with.







Is there anything else you would like to tell us?

- Note from a family member: As long as families have to pay upfront for transportation costs - this will prohibit many individuals from participation in the Agency with Choice model. DDS should be more proactive and provide more information to families about self-direction options before people transition to adult services. Waiting until there is a problem with services and sharing self-direction information with a couple families at a time does not provide everyone with the same opportunity to self-direct. Agency with Choice is an awesome way to provide individuals with an opportunity for a person centered and real life in the community.
- It's good to be in charge of my life and have support i need.
- I was one of the first self directed clients through our agency. At first they wanted to keep me in "Group" approach. Very unhappy with that option. I'm happy to make my own choices about what I want to do
- I am very thankful for support and help from dhs and my family
- ineligible
- Self direction for my son age 22 diagnosis of autism would not be possible. Both parents juggle schedule (working) and time is limited. Fidelity hurtles majority of paperwork and staffing. Day program is excellent an dds was extremely helpful with placement.

- "I want DDS as office for this service has to be more responsible not to watch how many hours of respite I get and I have to be alone but help me from morning to night.
- I have a question about: My dad, he is not my guardian and he can't be my respite care , what make such sense since I still use them a lot! Do any lawful person have to be on my side to provide advocacy. "
- I love self directed services
- mom answered all questions. I am non verbal.
- I filled this out for my son who has no language. Many of the questions are too vague to be helpful. #5 could actually require 2 different answers.
- Agency advocates dictates to me- how to spend my money-won't allow me to move any budgeted money from April to June. Emergencies and hiring process takes too long, weeks!
- Mother's response- (name), age 51, broad spectrum autism, does not like to answer questions, but is very happy with people inc, - so am I, we could make even better use of opportunities, if (name) would open up a bit more.
- It is very important to me that I be able to remain home with my family during my end of life (terminal condition)This can only continue as long as the support and budget sustain this. Thank you.
- I'd like to tell DDS thank you. This program has been a vital support. These funds have allowed the participant to volunteer, do some work and participate in the community resulting in better physical and mental health. A meaningful and productive, enjoyable life.
- This program has totally changed mine and my families life
- Finding staff can be a challenge, finding appropriate services that aren't at capacity is a challenge.
- Everything is going great
- Please don't recommend this program until more support is provided. Re: Hiring and maintain staff
- I would like to get someone to come in our apartment to do the cleaning for us and I would pay for the service!
- (name) wants (name) in her life- more involved
- I love my helper (name)- she is a good friend. She is my 2nd helper. I loved (name) too - she is still my friend. I feel grown up and have friends.
- What will happen to me when my mom dies?
- more flexible with housing option, which include section 8 (allow parents to rent their property to disabled child.)
- There is an incredible lack of qualified individuals for staffing needs
- I think it's a great program, just wish coordinator would contact me periodically to set up meeting to see if I need any help or have any questions. I especially think it would be good

near end of fiscal year if they contacted me in a meeting and be sure I know how much money I have left to spend before the fiscal year is up

- Thank you, our family really appreciates the opportunity to self direct
- The service delivery model for my services may be changing but I have not been informed or part of the process. I do not have a ISP, I do not know my budget, I am unclear on the process. Have had very positive experience in the current setting and hate to complain!
- I think it is very important to treat us as individuals and not put us in a large group activity, I like that my service helps me on one with what I want to do for employment.
- you should have a survey version for caregivers/ guardians is client is unable to answer.
- I could not even imagine my son living in a traditional setting. His developmental disability and his behavioral challenges are very involved and challenging. He has a custom designed program which works for him! He is very functional throughout the day (self care activities, household activities, recreational opportunities, free access to the community to what he can tolerate and when he can tolerate them due to a fluctuating nervous system. He works between 12-15 hours/week on 2 different farms and is helpful and handy in his home as well as the house of his grandparents and helpers homes. He is active and eats wonderfully healthy foods. He lives as normal life as possible. He has real friendships and people he loves/ love him. My concern: sustainability when I am no longer able.
- do a better job preparing us
- No I don't have anything else to say. Thank you all for all your support. I really appreciate it.
- We are grateful for all the help and services. We hate (name). from (Name) and DDS - thank you
- I really enjoy working with my staff and I get along with them. We do a lot of fun things to do
- Wonderful program, we just wish their activities were closer to where we live.
- there needs to be training and support programs during the day for young adults like myself since I can't work or go to college
- Not sure how I can move to 5 day AWC although I love it, as it changes day to day so much due to staff availability and the effect that has on my family.
- I've have good staff for a year in a half but now I'm finding it hard to find staff. Currently I have no staff for Monday & Friday
- I want to succeed in life.
- Agency with Choice has allowed me to have a life and receive the necessary supports to help me continue to grow and thrive in my own community, for work and social activities. This was the very best choice for me when I graduated last year, and continues to be.
- Agency with Choice is the only option that allows me to get the services that I need to maintain my skills and also have fun. With my complex medical issues, it allows a safe option for me to enjoy my life and contribute to my community.

- define what you mean by support broker-unclear of what service role you assume is being delivered by DDS coordinator. Defining their role would be helpful as well as understanding the training that is required to be called a support broker. My DDS person is nice.
- survey questions were answered by father and mother
- life changing, quality, dignity
- "thank you for taking the time to be concerned with our well being.
- My son is too disabled cognitively to answer so I answered for him.
- I like living with my family. I like that my sister is given resources to help take me places.
- government supported housing purchasing for group home and shared living.
- college students affiliated, shared living arrangement with housing stipends in exchange for overnight services which also benefits student financial burden
- the percentage that my agency with choice gets is outrageous based on what they do (how little they do). There should be a scaled rate based on services provided not a flat rate. Then I would get more of the budget to use as I want.
- AWC is the best. I was abused by staff at a group home. My family and I can choose people who care about me and love me.
- Without this service I would not be able to have the support necessary to live my life at home or in the community.

Appendix H: Service Use Categories and Groupings Used in the Service Category Analysis

Activity Code	Charge Category	HSRI Category Used for Analysis	Waiver Service Title	Waiver Group
3150	Residential	Residential	Placement Services T-2	Residential Habilitation
3153	Residential	Residential	Residential Habilitation	Residential Habilitation
3163	Day	Day	Group or Center-based Day (CBDS)	Group or Center-based Day Supports
3164	Supports	Day	Day Habilitation - Mass Health	x Non-Waiver
3165	Supports	Day	Adult Day Health Services	x Non-Waiver
3168	Employment	Employment	Supported Employment	Supported Employment
3170	Supports	Supports - Personal (Clinical)	Clinical Teams	x Non-Waiver
3174	Supports	Supports - Personal	Support Services LUSA	x Non-Waiver
3180	Employment	Employment	CIES - Competitive Employment	Supported Employment
3181	Employment	Employment	Group Supported Employment	Supported Employment
3182	Residential	Residential	Emergency Stabilization Residence - Site Based	Stabilization
3196	Transportation	Transportation	Transportation	Transportation
3240	Supports	Supports - Personal (Clinical)	Physical Therapy	x Non-Waiver

Activity Code	Charge Category	HSRI Category Used for Analysis	Waiver Service Title	Waiver Group
3243	Supports	Supports - Personal (Clinical)	Occupational Therapy	x Non-Waiver
3245	Supports	Supports - Personal (Clinical)	Speech Therapy	x Non-Waiver
3253	Supports	Supports - Personal (Clinical)	Specialized Services for Vision and Rehab	x Non-Waiver
3274	Supports	Supports - Financial Assistance	Corporate Rep. Payee Services	x Non-Waiver
3283	Supports	AT/DME	Assistive Technology-Contract	x Non-Waiver
3284	Supports	Supports - Personal	Transitional Assistance Services	Transitional Assistance Services
3285	Supports	Supports - Personal	Day Habilitation Supplement	Day Hab Supplement
3664	Supports	Day	Day Habilitation Services	x Non-Waiver
3681	Employment	Employment	Group Supported Employment Partnership	x Non-Waiver
3700	Supports	Supports - Family	Family Support Navigation	Family Support Navigation
3701	Supports	Respite	Respite - Adult - In recipient's home-Daily	Respite
3702	Supports	Respite	Respite - Adult - in caregiver's home	Respite
3703	Supports	Supports - Personal	Individual Home Supports	Individualized Home Supports
3705	Supports	Respite	Respite - Child - in caregiver's home-Daily	x Non-Waiver
3707	Supports	Supports - Personal	Adult Companion	Adult Companion
3709	Supports	Supports - Family	Community/Residential Family Training	Community Res Family Training
3710	Supports	Supports - Personal (Clinical)	Behavioral Supports and Consultation	Behavioral Supports and Consultation
3712	Residential	Residential	Emergency Stabilization Residence - Caregiver's Home	Stabilization
3716	Supports	Supports - Personal	Community/Residential Peer Supports	Community/Residential Peer Supports
3731	Supports	Respite	Respite - Adult - in recipient's home-hourly	Respite
3735	Supports	Respite	Respite - Children's - in caregiver's home-Hourly	x Non-Waiver
3738	Supports	Supports - Personal	DDS/DESE Support - DESE	x Non-Waiver
3753	Supports	Residential	Occupancy	x Non-Waiver
3759	Supports	Respite	Respite - Adult - site-based	Respite
3764	Supports	Day	Facility Day Habilitation	x Non-Waiver
3769	Day	Employment	Facility Center Based Work Services	x Non-Waiver
3770	Supports	Supports - Family	Family Support Centers	x Non-Waiver
3771	Supports	Supports - Family	Cultural Linguistic Family Support Centers	x Non-Waiver
3772	Supports	Supports - Personal	Autism Support Centers	x Non-Waiver
3773	Supports	Supports - Family	Intensive Flexible Family Support Services	x Non-Waiver

Activity Code	Charge Category	HSRI Category Used for Analysis	Waiver Service Title	Waiver Group
3774	Supports	Supports - Personal	Medically Complex Programs	x Non-Waiver
3775	Supports	Respite	Respite - Children's - site-based	x Non-Waiver
3776	Supports	Supports - Family	Family Leadership Program	x Non-Waiver
3777	Supports	Supports - Personal	Active Treatment	x Non-Waiver
3779	Supports	Supports - Financial Assistance	Stipends	x Non-Waiver
3780	Supports	Supports - Financial Assistance	Financial Assistance	x Non-Waiver
3781	Supports	Supports - Financial Assistance	Financial Assistance Administration	x Non-Waiver
3798	Supports	Supports - Personal	Individual/Community Supports	Individualized Home Supports
4157	Residential	Residential	State Ops	Residential Habilitation
4163	Day	Day	State Op Group or Center-based Day (CBDS)	x Non-Waiver
4168	Employment	Employment	Supported Employment - State Op.	x Non-Waiver
4169	Day	Employment	State-op center-based work	Group or Center-based Work Supports
4182	Residential	Residential	State Op Emerg Stabilization	x Non-Waiver
4743	Supports	AT/DME	Assistive Technology-MassHealth	x Non-Waiver
4798	Supports	Supports - Personal	Individual/Community Supports - State Op.	x Non-Waiver
5153	Residential	Residential	Self-directed residence - SD	x Non-Waiver
5154	Residential	Residential	Self-directed Residential Supports - SD	Residential Habilitation
5155	Residential	Residential	Self-directed Residential Supports - day rate - SD	Residential Habilitation
5156	Residential	Residential	24 Hour Self Directed Home Sharing1 - SD	24 Hour Self-Directed Home Sharing
5157	Residential	Residential	24 Hour Self Directed Home Sharing2 - SD	24 Hour Self-Directed Home Sharing
5158	Residential	Residential	24 Hour Self Directed Home Sharing3 - SD	24 Hour Self-Directed Home Sharing
5168	Employment	Employment	Supported Employment - SD	Supported Employment
5180	Employment	Employment	CIES - Competitive Employment - SD	Supported Employment
5196	Transportation	Transportation	Transportation - SD	Transportation
5197	Transportation	Transportation	Transportation-pass/unit - SD	Transportation
5198	Transportation	Transportation	Transportation- Mileage - SD	Transportation
5240	Supports	Supports - Personal (Clinical)	Physical Therapy - SD	Physical Therapy
5243	Supports	Supports - Personal (Clinical)	Occupational Therapy - SD	Occupational Therapy
5245	Supports	Supports - Personal (Clinical)	Speech Therapy - SD	Speech Therapy
5282	Supports	Supports - Personal	Personal Agent Services - SD	x Non-Waiver
5283	Supports	AT/DME	Assistive Technology - SD	Assistive Tech

Activity Code	Charge Category	HSRI Category Used for Analysis	Waiver Service Title	Waiver Group
5284	Supports	Supports - Personal	Transitional Assistance Services - SD	Transitional Assistance Services
5300	Supports	Supports - Personal	Non-Waiver Services - SD	x Non-Waiver
5400	Supports	Supports - Financial Assistance	Non-Waiver Financial Services - SD	x Non-Waiver
5505	Supports	Supports - Personal	Homemaker - Ind - Aut - SD	xAutism
5506	Supports	Supports - Personal	Homemaker - Agency - Aut - SD	xAutism
5510	Supports	Supports - Personal	Habilitation - Community Integration - Ind - Aut - SD	xAutism
5511	Supports	Supports - Personal	Habilitation - Community Integration - Agency - Aut - SD	xAutism
5520	Supports	Supports - Personal (Clinical)	Expanded Habilitation - Sr. Ther. - Ind - Aut - SD	xAutism
5521	Supports	Supports - Personal (Clinical)	Expanded Habilitation - Sr. Ther. - Agency - Aut - SD	xAutism
5522	Supports	Supports - Personal (Clinical)	Expanded Habilitation - Ther. - Ind - Aut - SD	xAutism
5523	Supports	Supports - Personal (Clinical)	Expanded Habilitation - Ther. - Agency - Aut - SD	xAutism
5524	Supports	Supports - Personal	Expanded Habilitation - Dir. Supp. Worker - Ind - Aut - SD	xAutism
5525	Supports	Respite	Expanded Habilitation - Dir. Supp. Worker - Agency - Aut - SD	xAutism
5530	Supports	Respite	Respite - Ind - Aut - SD	xAutism
5531	Supports	Respite	Respite - Agency - Aut - SD	xAutism
5532	Supports	Respite	Respite - Caregiver's Home - Aut - SD	xAutism
5535	Supports	Supports - Family	Family Training - Ind - Aut - SD	xAutism
5536	Supports	Supports - Family	Family Training - Agency - Aut - SD	xAutism
5540	Supports	AT/DME	Assistive Tech/Adaptive Aids - Aut - SD	xAutism
5545	Supports	Home Mods	Home Adaptations - Aut - SD	xAutism
5550	Supports	Transportation	Vehicle Adaptations - Aut - SD	xAutism
5555	Supports	Goods and Services	Individually Directed Goods and Services - Aut -SD	xAutism
5560	Finance	Supports - Financial Assistance	Worker's Compensation - Aut - SD	x Non-Waiver
5565	Supports	Supports - Personal (Clinical)	Occupational Therapy - Aut - SD - IC	xAutism
5566	Supports	Supports - Personal (Clinical)	Occupational Therapy - Aut - SD - Agency	xAutism
5568	Supports	Supports - Personal (Clinical)	Physical Therapy - Aut - SD - IC	xAutism
5569	Supports	Supports - Personal (Clinical)	Physical Therapy - Aut - SD - Agency	xAutism
5571	Supports	Supports - Personal (Clinical)	Speech Therapy - Aut - SD - IC	xAutism

Activity Code	Charge Category	HSRI Category Used for Analysis	Waiver Service Title	Waiver Group
5572	Supports	Supports - Personal (Clinical)	Speech Therapy - Aut - SD - Agency	xAutism
5574	Supports	Supports - Personal (Clinical)	Behavioral Consultation - Senior - IC - Aut - SD	xAutism
5575	Supports	Supports - Personal (Clinical)	Behavioral Consultation - Senior - Agency - Aut - SD	xAutism
5577	Supports	Supports - Personal (Clinical)	Behavioral Consultation - Therapist - IC - Aut - SD	xAutism
5578	Supports	Supports - Personal (Clinical)	Behavioral Consultation - Therapist - Agency - Aut - SD	xAutism
5580	Supports	Supports - Personal (Clinical)	Behavioral Consultation - Direct Support - Individual - Aut - SD	xAutism
5581	Supports	Supports - Personal (Clinical)	Behavioral Consultation - Direct Support - Agency - Aut - SD	xAutism
5702	Supports	Respite	Respite - Adult - in caregiver's home - SD	Respite
5703	Supports	Supports - Personal	Individual Home Supports - SD	Individualized Home Supports
5704	Supports	Day	Individual Day Supports - SD	Individualized Day Supports
5705	Supports	Respite	Respite - Adult - in recipient's home - SD	Respite
5707	Supports	Supports - Personal	Adult Companion - SD	Adult Companion
5709	Supports	Supports - Family	Community/Residential Family Training - SD	Community Res Family Training
5710	Supports	Supports - Personal (Clinical)	Behavioral Supports and Consultation - SD	Behavioral Supports and Consultation
5716	Supports	Supports - Personal	Community/Residential Peer Supports - SD	Community/Residential Peer Supports
5719	Supports	Residential	Live-in Caregiver - SD	Live-in Caregiver
5725	Supports	Supports - Personal	Chore - SD	Chore
5728	Supports	Goods and Services	Individual Goods and Services - SD	Individual Goods and Services
5731	Supports	Home Mods	Home Modifications and Adaptations - SD	Home Modifications and Adaptations
5734	Supports	Transportation	Vehicle Modifications - SD	Vehicle Modifications
5738	Supports	Supports - Personal	DDS/DESE Support - DESE - SD	x Non-Waiver
5756	Supports	AT/DME	Specialized Medical Equipment - SD	Specialized Medical Equipment and Supplies
5888	Supports	Residential	Shared Living - No Agency - SD	x Non-Waiver
6700	Supports	Supports - Family	Family Support Navigation - AWC	Family Support Navigation
6701	Supports	Respite	Respite - Adult - in recipient's home - AWC	Respite
6703	Supports	Supports - Personal	Individual Home Supports - AWC	Individualized Home Supports
6704	Supports	Day	Individual Day Supports - AWC	Individualized Day Supports

Activity Code	Charge Category	HSRI Category Used for Analysis	Waiver Service Title	Waiver Group
6705	Supports	Respite	Respite - Child - in caregiver's home - AWC	x Non-Waiver
6707	Supports	Supports - Personal	Adult Companion - AWC	Adult Companion
6709	Supports	Supports - Family	Community Family Training - AWC	Community Res Family Training
6716	Supports	Supports - Personal	Community Peer Supports - AWC	Community/Residential Peer Supports
6735	Supports	Respite	Respite - Child - in recipient's home - AWC	x Non-Waiver
6753	Finance	Supports - Financial Assistance	Administration Fee - AWC	x Non-Waiver
6780	Supports	Supports - Financial Assistance	Financial Assistance - AWC	x Non-Waiver
7100	Supports	Supports - Personal	Adult ASD Coaching - Agency	x Non-Waiver
7101	Supports	Supports - Personal	Adult ASD Coaching - Individual	x Non-Waiver
7200	Supports	Supports - Personal	Adult ASD Clubhouse	x Non-Waiver
9150	Residential	Residential	Placement Services T-2	Residential Habilitation
9153	Residential	Residential	MCB Residential	Residential Habilitation
9163	Day	Day	MCB Day Supports	Group or Center-based Day Supports
9168	Day	Employment	MCB Work	Group or Center-based Day Supports
9798	Supports	Supports - Personal	MCB Individual/Community Supports	Individualized Home Supports