



# Year Three Report

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

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# Acknowledgments

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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](http://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

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- Executive Summary ..... 1**
  - DDS Accomplishments Since Year 2 Report ..... 1
  - Year 3 Methodology ..... 1
  - Key Findings ..... 2
  - Summary of Recommendations ..... 2
- 1. Introduction ..... 4**
  - Reminder: Year 2 Recommendations ..... 4
  - DDS Accomplishments Since Year 2 Report ..... 4
  - Year 3 Evaluation ..... 5
- 2. Methodology ..... 6**
  - Mail and Online Surveys ..... 6
  - Review of DDS Data ..... 7
- 3. Person Directed Program ..... 9**
  - Participant Characteristics ..... 9
  - Reasons to Self-Direct ..... 9
  - Self-Direction Outcomes and Satisfaction ..... 9
  - Participant Budgets ..... 10
  - Support Brokers/Service Coordinators ..... 11
  - Experience with Public Private Partnerships (PPL) ..... 11
  - Considerations ..... 11
- 4. Agency with Choice ..... 13**
  - Participant Characteristics ..... 13
  - Reasons to Self-Direct ..... 13
  - Self-Direction Outcomes and Satisfaction ..... 13
  - Participant Budgets ..... 14
  - Experience with Agency ..... 14
  - Support Brokers/Service Coordinators ..... 15
- 5. DDS Staff Responses ..... 16**

Characteristics of Respondents .....	16
Benefits of Self-Direction .....	17
Knowledge of Self-Direction Programs .....	17
The Process of Self-Direction .....	18
Candidates for Self-Direction .....	19
How to Expand Self-Direction .....	20
Suggestions for Improvement .....	21
<b>6. Supports Budgets .....</b>	<b>23</b>
Supports Budgets .....	23
Objective Assessment .....	24
Supports Budgets Framework .....	25
Considerations .....	26
Findings of Review of DDS Readiness to Develop Supports Budgets .....	27
<b>7. Recommendations .....</b>	<b>28</b>
Support Brokerage .....	28
Staff Recruitment .....	29
Complexity of Self-Direction.....	30
Supports Budgets .....	31
Supporting All Families.....	32
Outreach .....	33
<b>Appendix .....</b>	<b>34</b>
Appendix A: Sampling Design, Survey Design and Dissemination .....	34
Appendix B: Participant Directed Program Survey Results .....	37
Appendix C: Agency with Choice Survey Results.....	75
Appendix D: DDS Staff Survey Results .....	105

# Executive Summary

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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 (DDS) to inform potential participants about the self-direction initiative. The second year focused on the infrastructure necessary to support self-direction. The third year, detailed in this report, focused on the perceptions of the program administrators regarding the implementation of the program, a final assessment of participants' views, and an assessment of what it would take to make the budgeting process for self-direction more uniform, equitable, and linked to assessed need.

## DDS Accomplishments Since the Year 2 Report

DDS staff have undertaken the following self-direction initiatives in the past year:

- Completed four ten-minute videos of stories from individuals directing their services
- Reviewed other stories to complete future videos
- Created and disseminated “start-up kits” for support brokers who are enrolling new participants
- Field tested “soup to nuts” portal training for new and inexperienced support brokers to use
- Prepared an Agency with Choice manual in final draft revision
- Completed a Presentation Skills Curriculum pilot series that is being distributed to provider agencies
- Expanded the Participant Leadership Group to a second Leadership group
- Included self-direction participants in the Boston Self-Direction Symposium
- Implemented a new guide and matrix for the Participant Directed Program
- Held multiple family forums in each region
- Held two statewide trainings for support brokers and area liaisons

## Year 3 Methodology

The evaluation findings in this Year 3 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 and support brokers
  - Program Coordinators II or Program Monitors
  - Service Coordinator Supervisors
  - Assistant Area Directors

- Area Directors
- Autism Service Coordinators
- Transition Coordinators
- Review of DDS data to determine what additional data would be needed to develop supports budgets

## **Key Findings**

Selected key findings include:

- Participants in the Participant Directed Program (PDP) and Agency with Choice (AWC) models overwhelmingly report that their life is better since they started self-directing, that they would recommend self-direction to others, that they have more choices and control in their lives, and that they feel more confident.
- DDS staff surveyed support the values of self-direction and assert that people who are self-directing are more empowered to make choices, are happier, are more included in their communities, and are challenged to learn new things.
- DDS needs to expand the data it collects on individuals in order to build and implement a supports budgets framework for participants who are self-directing.
- Many staff continue to see the self-direction process as overly complex both for themselves and for participants and families.
- Because the process is complex and requires a certain amount of “system savvy,” there is a perception that only “certain types of families” can cope with the complexity.
- There are staff who would be interested in supporting people to self-direct, but they do not feel they have the time and energy to take on the paperwork and individual support necessary to make it work.
- Staff and participants report that recruitment of support staff is a major challenge to self-direction.

## **Summary of Recommendations**

In this third and final year of the Real Lives Evaluation, we note that substantial progress has been made to reach out to potential participants and families to inform them of the nature and benefits of the self-direction option. DDS has also moved to standardize the implementation of self-direction across the Commonwealth and has engaged self-advocates who are self-directing to help introduce the option to others. Some of the issues noted within the first two years of the evaluation remain—specifically, the negative impacts of the program’s complexity, service coordinators’ large caseloads, and the small number of support brokers on the growth of the self-direction option.

The major recommendations based on the Year 3 evaluation results include:

- Explore ways to expand the availability of support brokers, including through increases in funding and/or by including “independent facilitation” as a waiver service.
- Expand the capacity of the “Rewarding Work” platform managed by TILL to provide enhanced staff recruitment support to participants who are self-directing and their families.
- Continue to make the self-direction option less complicated; staff surveys suggest that the complexity may be restraining service coordinators/support brokers from encouraging their clients to self-direct.
- Assess the feasibility of moving to supports budgeting including facilitating the linkage of data across platforms, adding new data elements, evaluating the current individual assessment process, making the budgeting process more transparent, and determining the impact on rate structure.
- Determine the breadth of the system change that could accompany the development of supports budgets including whether to revisit services and supports available to self-direct, the person-centered planning process, and changes in waiver provisions (e.g., support brokers).
- Depending on the breadth of change that is anticipated as part of the supports budget initiative, it will be important to lay out a road map for the change and to ensure that stakeholders are informed about the supports budget process and changes that impact supports, and to ensure that the voices of stakeholders are front and center at each stage of the process—from initial planning discussions and all the way through implementation.
- Explore ways of attracting and supporting culturally and economically diverse participants and families to opt for self-direction.
- Continue to expand and enhance outreach activities to people with disabilities and their families; ensure that the approach is consistent and offers a coherent and realistic picture of self-direction by offering examples from current participants in the self-direction model.
- Convene a statewide conference on self-direction to learn from people who are currently self-directing, to understand strategies to reach out to staff, families, and people who receive supports, and to hear from people who are coordinators and staff for self-directed supports about ways to streamline and enhance the model.

# 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. The second year of the evaluation focused on examining the infrastructure of self-direction, including service coordination, budget determination, services and supports that can be self-directed, and participant and provider perceptions of the program. (See the sidebar on this page for a reminder of the Year 2 Recommendations.) In this third and final year, evaluation efforts focused on assessing the experiences and outcomes of self-directing participants, the perceptions and recommendations regarding self-direction among DDS staff, and the potential for embedding self-direction opportunities across the service system by establishing a supports budget framework for all to utilize.

## DDS Accomplishments Since Year 2 Report

During Year 3 of the Real Lives evaluation, DDS staff have continued to clarify the process of self-direction, conducted numerous trainings, developed educational and promotional materials, and worked directly with self-advocates to publicize and describe the experience of self-direction. Specifically:

- DDS has worked to clarify the AWC program for staff and providers through the development of an AWC manual, which is now in final revisions. DDS is also in the process of developing a “soup to nuts” road map of the self-direction process for new support brokers, along with “startup kits” for support brokers to use

## Reminder: Year 2 Recommendations

- Explore the possibility of making support brokerage a waiver service
- 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 for self-direction.
- Ensure that individuals who are self-directing are given information about their budget prior to finalization of the plan and know how to access their budgets through the PPL portal.
- Examine current methodology regarding the development of individual self-directed budgets to determine whether there are more ways to link level of need to budget amounts.
- Each region should develop a long-range plan to facilitate the adoption of self-direction with timelines and enrollment targets.
- Continue to educate stakeholders and staff regarding self-direction.
- Encourage participation in AWC both by participants and providers.
- Convene a statewide conference on self-direction to showcase both the PDP and AWC programs and to highlight the experiences of individuals who are self-directing.
- Continue to monitor 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.

when enrolling new participants. Finally, DDS has implemented a new guide and matrix for the Participant Directed Program

- To further educate staff and stakeholders regarding self-direction, DDS conducted multiple family forums in each region and convened two statewide trainings for support brokers and area liaisons.
- To promote self-direction, DDS developed four ten-minute videos showcasing individuals who are self-directing their services. They plan on developing more stories of self-direction going forward.
- DDS has worked to enhance the voice of self-advocates by developing a Presentation Skills Curriculum that has been distributed to providers. They have also expanded a Participant Leadership Group to a second Leadership Group. Finally, they have developed a speakers bureau of self-advocates who can present on self-direction around the state.

### Year 3 Evaluation

The third year of the evaluation, detailed in this report, includes the results of surveys of participants in the Participant Directed Program (PDP) and Agency with Choice Program (AWC) conducted over the past three years. It also includes an expanded survey of staff of the Department of Developmental Services. Staff surveys in the first two years of the evaluation were limited to service coordinators and support brokers. In Year 3, the survey was expanded to include additional management staff at the area and regional office level. The expanded survey was intended to determine staff attitudes regarding self-direction in general as well as staff attitudes toward specific self-direction policies and procedures. Finally, HSRI was asked to assess the feasibility of moving to a more systematic, needs-based method of developing supports budgets for people who are self-directing. The HSRI team sought to answer four research questions with its evaluation:

1. What do service coordinators and support brokers see as the **challenges** to supporting people who are self-directing and the ways the process can be **improved**, and have their perceptions changed over the past three years?
2. What do program managers other than service coordinators and support brokers see as the **challenges and benefits** of self-direction and **specific policy and regulatory reforms** that can improve the implementation of self-direction?
3. How do participants in the PDP and AWC models view the **strengths and challenges** of self-direction and the ways in which the process can be **improved**?
4. What would be required in terms of data on **participant characteristics, service utilization, and costs** to move to a needs-based support budget process for participants in self-direction and to expand the opportunity to self-direct services?

## 2. Methodology

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### Mail and Online Surveys

In Year 3, HSRI continued to survey participants in PDP and AWC, as well as service coordinators and support brokers, in addition to program management staff. (See Appendix A for a description of the sampling design, the survey design, and the dissemination procedures.)

- **Survey of Participant Directed Program participants.** The PDP survey was mailed out to 1,088 participants. Respondents were given the option of completing the paper survey or using a link to SurveyMonkey to respond online. HSRI received 208 valid surveys between February 18, 2019 and April 4, 2019—a 20% response rate and a decrease from the 34% response rate in Year 2. The survey was confidential. Participants were told in the cover letter that they could get help if they needed it from family or friends and were offered translation services if they needed it. Although zip codes were requested from respondents, the numbers in any one area were too low to justify a regional analysis. (See Appendix B for detailed survey results.)
- **Survey of Agency with Choice participants.** The AWC survey was mailed out to 821 participants. Respondents were given the option of completing the paper survey or using a link to SurveyMonkey to respond online. HSRI received 120 valid surveys between February 18, 2019 and April 4, 2019—a 14% response rate. As with the PDP survey, this response rate was lower than in Year 2 of the evaluation, when it was 29%. The survey was confidential. Participants were told in the cover letter that they could get help if they needed it from family or friends and were offered translation services if they needed it. Again, similar to the PDP survey, the numbers of responses were too low to do a sub-state analysis. (See Appendix C for detailed survey results.)
- **Survey of DDS Staff.** In Year 3, the service coordinator/support broker survey was expanded to include program managers, specifically Service Coordinator Supervisors, Assistant Area Directors, Area Directors, Autism Service Coordinators, staff in Program Coordinator II or Program Monitor roles, and Transition Coordinators. The revised survey was intended to provide a broader canvass of attitudes, perceptions, and recommendations regarding self-direction among DDS staff across the Commonwealth. The expansion of the survey was in part to determine the impact of significant policy changes that were made by DDS leadership during the early months of Year 3 of the evaluation.

In addition to a background section, the survey was divided into three parts that coincided with the respondents' familiarity with the self-direction program. The third section was limited to respondents who had people who are self-directing on their caseloads. The survey

included many of the same questions in the service coordinator/support survey circulated in Years 1 and 2.

DDS leadership emailed an introductory letter with the survey link to all 608 service coordinators and supervisors. Additionally, links were sent to the other DDS personnel noted above. The total number of those potential respondents is not known since staff were asked to forward the survey to other staff who might be involved in self-direction. Among service coordinators/support brokers/supervisors, a total of 260 surveys were returned for a 43% response rate—significantly higher than the 20% response rate in Year 2. (Question-by-question results are included in Appendix D.)

## Review of DDS Data

HSRI staff undertook a review of the data that DDS made available in Years 1-2 to assess the characteristics, regional distribution, and service utilization of self-directing participants. In Year 3, this DDS data was used to identify data elements that could be leveraged for supports budgeting purposes, such as the number of service recipients and their demographic characteristics, results of objective assessments of the support needs of service recipients, and the amount spent in aggregate per service category.

**Data reviewed:** DDS provided two types of information to the evaluation team: (a) person-level characteristics (FY15-17), and (b) service-level information (FY15-17)

- **Person-level characteristics (FY15-17)** included base information regarding the individual and his/her circumstances (i.e., personal ID, age, sex, region, race/ethnicity, preferred language, need of interpreter, guardianship), and available assessment information from the state’s HCBW assessment and scores generated through use of the Inventory for Client and Agency Planning (ICAP; see sidebar for details). ICAP scores are a major component of the Massachusetts Comprehensive Assessment Profile (MASSCAP),

### About the ICAP

The Inventory for Client and Agency Planning (ICAP) was published in 1986. It was designed as a structured assessment of adults and children over 3 and is composed of 77 items related to adaptive behavior and problem behaviors (maladaptive behavior). The instrument also captures personal information (e.g., age, types of disabilities, services received, and services desired). It generates a composite scale score for four adaptive behavior dimensions plus a composite “broad independence” score that cuts across all four dimensions. Maladaptive behavior is assessed along three dimensions and is rated by frequency and severity. These items are consolidated into four maladaptive behavior scale scores and an overall maladaptive behavior index score.

The ICAP includes an algorithm that produces an ICAP Service Score. This Service Score consists of the adaptive behavior score (70%) and problem behavior score (30%) and is used to measure the overall intensity of supervision and/or training that a person might require. Service Scores are grouped into nine levels, with a score of 1 indicating the highest level of need and a score of 9 indicating the lowest need. Notably, the ICAP does not gather much information support for medical conditions.

which is used to assess the types of services that an individual needs and how urgently those services are needed.

- **Service-level information (FY15-17)** included personal ID, region, enrollment start/end dates, and a count of services used by type (traditional vs. PDP vs. AWC). DDS also provided a file to illustrate aggregate spending per category for FY16-18. To complement this information, DDS also provided service ID/activity codes for the PDP and an Activity Codes listing (FY17) which included descriptive information of service IDs/activity codes.

## 3. Participant Directed Program

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### Participant Characteristics

About 97% of respondents to the Participant Directed Program survey fall within the DDS service population of ages of 18-65. Only 3% were over age 65. More than half (60%) live at home with their family; 27% live in their own home or apartment; 5% live in a group home<sup>1</sup>; 4% live with a foster family or in shared living; and 5% live in other residence types. A larger proportion of respondents have been self-directing for less than 4 years (59%) compared to those self-directing for 4 or more years (39%). This marked a change from Year 2 when more respondents had been self-directing for 4 or more years.

Given the low response rate to the survey (20%), the results are suggestive but may not be representative of the universe of PDP participants.

### Reasons to Self-Direct

Participants were asked why they chose self-direction, specifically what changes they wanted to see in their lives. Participants were given a list of 16 potential reasons. Among the responses, participants indicated that: I wanted to make more choices in my life (67%); I wanted to be more independent (58%); I wanted to hire my own staff (52%); I wanted to get a job (29%); and I wanted to have a girlfriend or boyfriend (18%).

### Self-Direction Outcomes and Satisfaction

In looking at outcomes for people who are self-directing, respondents were asked: Now that you're self-directing and making choices about your services and staff, how has your life changed? Again, people were given a list to choose from as well as an open-ended response option. Among the responses, 62% said I am making more choices in my life, 46% responded, I feel better about myself, 42% said they feel like they are in charge of their lives, and 45% said they are more confident. Further, participants were asked: "If there are things in your life that you would like to change, please tell us what those changes would be." Those answers ranged from getting a driver's license to finding friends and more social activities to stopping smoking.

Respondents were asked if their lives were much better, somewhat better, the same as before, or not better since they have been self-directing. Most said their lives were better (87%) while 9% said their lives were the same as before; only a small percentage (4%) said their lives were not better since they have been self-directing. When asked about problems since they started self-directing, equal numbers said either they had not had any problems or if they had, someone had helped them

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<sup>1</sup> Though people living in group homes cannot self-direct their services within that setting, they may access supports not covered by group home payments (e.g., communication devices) through self-direction funding.

with their problem (48% each) and a small number (5%) said they have had problems that no one has helped them with. Some problems that respondents indicated having are: It's hard to find and keep good staff, there is not enough money in my budget for me to do what I want, and I still have questions about the process.

In Years 1 and 2 of this evaluation, respondents indicated feeling lonelier since they started self-directing. Several said they did not have many friends and/or a social life. In Year 3, participants were asked about feeling lonely and if they wanted more help to make new friends or keep in contact with their friends. Just over half (54%) indicated that they do not feel lonely and 47% said yes, they want more help to make new friends or keep in contact with their friends, 16% said maybe, and 37% said no, they didn't want help in this area.

With respect to satisfaction with staff, just over two thirds of respondents said they hire and manage their own staff (68%) either independently (11%) or with support (57%). When asked whether staff do what the participant wants them to do, arrive on time, and help in ways that the participant wants, 85% said yes and 11% said sometimes.

Finally, the majority of respondents participating in PDP (90%) said they made the right decision and will continue to self-direct in the future; 96% said overall, they are happy with their decision to self-direct through PDP, and 95% said they would recommend self-direction to others.

## **Participant Budgets**

The survey also included questions about the participant's budget. More than half (56%) of respondents said they could make changes to their budgets, 30% said maybe they could but they weren't sure, and 15% said they could not. Most people (90%) said they get help to make changes to their budget from their DDS Service Coordinator/Support Broker and 10% said they get help from "others" including family members. When asked about whether they get enough help deciding how to use their budget, 83% said they did, 11% said maybe they did, and 6% said they did not. More than half (55%) said their support coordinator helps them make decisions about their budget, 86% said their family member helps, and 1% said they did not need any help making decisions about their budget. Most (85%) respondents said they get information on how much money is left in their budget, 7% said maybe/not sure, and 8% said they did not. People got information regarding their budget from PPL (62%) and from their DDS Service Coordinator/Support Broker (50%); 51% said they got this information from their family member. According to 83% of respondents, the information about their budget is easy to understand; 13% of respondents said maybe it is easy to understand, and 4% said no, it is not easy to understand.

## **Support Brokers/Service Coordinators**

When asked about DDS, 95% of respondents know who their service coordinator/support broker is, and 85% said it is easy to get in contact with their service coordinator/support broker. Three quarters of respondents indicated that they get all the help they need from their support broker/service coordinator. The remaining 25% who wanted more support were asked what additional support they needed; responses included:

- “Finding someone to work with me as a social assistant. He [service coordinator] has lots of contacts with others who do this work.”
- “DDS support coordinator does not listen or ask what I want for our ISP goals.”
- “Someone to make a home visit every now and again.”
- “Someone to have more understanding of what my life is like.”

Overall, 94% of respondents said they have had a good experience with their support broker/service coordinator.

## **Experience with Public Partnerships (PPL)**

Being involved in PDP means that participants use PPL as a fiscal intermediary. Participants were asked whether, when they enrolled in PDP, someone explained PPL’s role and the services that PPL provided. Four fifths of respondents said yes; 8% said no, and 12% said they weren’t sure. When asked if they could use more information about PPL, 87% of respondents said yes; 78% said they knew how to contact PPL if they had a problem. Almost all (95%) of participants understand that PPL pays their staff and 78% understand how to submit a timesheet to PPL.

Respondents were asked if they have had problems with PPL and if so, what kinds of problems they have had. Less than a quarter (24%) of respondents reported having problems with PPL. Of those who reported problems, some individual responded, they don’t always return my phone calls or emails, others said they don’t understand the answers that PPL give a them when they call, and PPL doesn’t always pay my staff on time. Respondents also made open-ended comments such as: “Verification got delayed weeks” and “When there is an issue with a timesheet or forms, they wait weeks to inform us and you get tossed around because no one knows what's happening.”

## **Considerations**

The results of the PDP survey—though with a low response rate—strongly suggest that participants are happy to be self-directing and are experiencing positive outcomes in their lives. Almost half of respondents (47.5%) said they had difficulty keeping good staff. Participants by and large understand the process of self-direction, and if they don’t, they say that they get help when they need it. Slightly less than half of participants feel lonely and would appreciate more help developing relationships. Though participants generally appreciate the services provided by PPL, there is still room for

improvement including verifying timesheets and paying staff. With respect to budgets, participants seem to be able get changes to the amounts when necessary, and most respondents were aware of their particular budget amount.

The survey also makes clear that many individuals rely on their families to assist with decisions about services, the process of negotiating the budget, and the resolution of problems encountered during the year. Reliance on families begs the question that DDS staff raised regarding whether self-direction is more tailored to families with more resources and bureaucratic savvy than to families without such resources.

## 4. Agency with Choice

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### **Participant Characteristics**

Of the respondents to the AWC survey, 99% were aged 18 to 65. Only 1% were over age 65. About 70% live at home with their family, 19% live in their own home or apartment, 7% live with a foster family or in shared living, and a very small percent (3%) live in group homes or other residence types. More people have been self-directing for more than 4 years (52%) than those who have been self-directing for less than 4 years (43%).

As noted in the discussion of the PDP survey above, with a low response rate to the survey (18%) the results are suggestive but may not be representative of the universe of AWC participants.

### **Reasons to Self-Direct**

Participants were asked why they chose self-direction, specifically what changes they wanted to see in their lives. Participants were given a list of 16 potential reasons. Among the responses, participants indicated that: I wanted to make more choices in my life (62%), I wanted to be more independent (53%), I wanted to hire my own staff (46%), I wanted to get a job (29%), and I wanted to have a girlfriend or boyfriend (10%).

### **Self-Direction Outcomes and Satisfaction**

In looking at outcomes for people who are self-directing, respondents were asked: Now that you're self-directing and making choices about your services and staff, how has your life changed? Some of the responses included: I am making more choices in my life (61%), I feel better about myself (34%), I feel like I am in charge of my life (32%), and I am more confident (36%). People had a wide range of responses to: If there are things in your life that you would like to change, please tell us what those changes would be. Answers ranged from moving to a different group home to sharing staff to being more involved in civic and political issues. One comment listed was: "To live independently, have a job, be married."

Respondents were asked if their lives were much better, somewhat better, the same as before, or not better since they have been self-directing. Most people said their lives were better (85%) while 13% said their lives were the same as before; a small percentage (2%) said their lives were not better since they have been self-directing. When asked about problems since they started self-directing, half of the respondents (50%) said they do not have problems and that everything is going well, 20% said their agency handles problems for them, 27% said that they have had problems, but someone helped with them, and a small number (4%) said they have had problems that no one has helped them with. Some of the problems noted by respondents included: It's hard to find and keep good

staff; There is not enough money in my budget for me to do what I want; and I still have questions about the process.

With respect to staffing issues, just over a quarter of respondents said they hire and manage their own staff (27%), 26% said their agency case manager helps them manage their staff, 56% said a family member helps them manage their staff, and 13% said they do not hire and manage their staff. When asked whether staff do what the participant wants them to do, arrive on time, and help in ways that the individual wants, 81% said yes and 14% said sometimes.

In Years 1 and 2 of this evaluation, respondents indicated feeling lonelier since they started self-directing. Several people noted that they didn't have many friends or a social life. In Year 3, participants were asked about feeling lonely and if they wanted more help to make new friends or keep in contact with their friends. Just over half (57%) indicated that they do not feel lonely; meanwhile, 43% said yes, they want more help to make new friends or keep in contact with their friends, 25% said maybe, and 32% said no, they didn't want help in this area.

The majority (94%) said they will continue to self-direct in the future; 95% said overall, they are happy with their decision to self-direct through AWC, and 96% said they would recommend self-direction to others.

## **Participant Budgets**

The survey also asked participants about their experiences with their budget. About half (49%) said they could make changes to their budgets, 40% said maybe they could but they aren't sure, and 12% said they could not. When asked who helps them make changes to their budget, more people (58%) said they get help from their agency than from their service coordinator/support broker (45%). With respect to help deciding how to use their budget, 85% said they did get help, 9% said maybe they did, and 6% said they did not. Almost three quarters (73%) of respondents said their family member helps them make decisions about their budget, 45% said they receive help from staff at their agency, 23% said from their DDS Support Coordinator, and 1% said they didn't need any help. Most respondents (78%) said they get information on how much money is left in their budget, 12% said they get this information only sometimes, and 10% said they did not know how much money is left in their budget. According to 77% of respondents, the information about their budget is easy to understand, 18% said maybe it is easy to understand, and 5% said no, it is not easy to understand.

## **Experience with Agency**

Most of the participants know who to contact in the agency they are working with (92%), and 91% reported it was easy to get in touch with the agency representative. In terms of what type of help participants receive from the agency, respondents said they got help to interview staff, choose staff, pay staff, manage staff schedules, and track timesheets. Respondents also said they got help to share

information about their budget, become involved in their community, make decisions about what to do during the day, and plan for emergencies. The percent of respondents who said they got such support was 61%; 21% said they get some help, and 14% said they could use more help.

Of those who wanted more help, some of the specific items they listed included: “Access to other services,” “direction to locate services,” “running errands, cleaning, and helping prep meals,” and “connecting with others who are self-directing/Agency with Choice program,” “unable to get contact info of individuals or parents.” Other topics included help with budgets, finding better trained staff, and finding a job. When asked if they have had a good overall experience working with the agency, 92% responded that they have.

### **Support Brokers/Service Coordinators**

Most respondents (93%) know who their DDS support broker/service coordinator is, 86% said it is easy to get in touch with that person if they need to, and 97% reported having had a good experience working with that person. When asked about the help they get from their support broker/service coordinator about self-direction, 62% said they get all the help they need, 26% said they get some help, 7% said they could use more help, and 5% said they weren’t sure. A follow-up question asked what kind of help was needed, and responses ranged from moving to a new home to better email response time.

## 5. DDS Staff Responses

The Year 3 staff survey was expanded beyond service coordinators and support brokers to include other DDS field staff. There was a concerted attempt on the part of DDS central office staff to ensure a good response rate. Because service coordinators and support brokers were surveyed in Years 1 and 2, it is possible to compare their response rates over the 3 years. In Year 1, 103 responded, in Year 2, 117 responded, and in Year 3, 346 responded—almost a three-fold increase. However, given differences between the Year 3 survey and Years 1 and 2, it was not possible to do a longitudinal look at the results on a question by question basis.

### Characteristics of Respondents

Over half (65.6%) of respondents to the staff survey were Service Coordinators (54%) and Support Brokers (12%).

Answer Choices	Responses	
<b>Service Coordinator/Support Broker</b>	65.60%	225
<b>Program Coordinator II or Program Monitor</b>	7.58%	26
<b>Service Coordinator and/or Support Broker Supervisor</b>	10.20%	35
<b>Autism Service Coordinator</b>	4.96%	17
<b>Transition Coordinator</b>	4.37%	15
<b>Assistant Area Director</b>	3.50%	12
<b>Area Director</b>	3.79%	13
<b>Other (please specify)</b>		33

When asked about their responsibilities with respect to self-direction, 30% of respondents reported being directly involved with individuals self-directing, 23% had administrative responsibilities related to self-direction, and 48% reported not having any responsibilities related to self-direction. Of the 104 respondents who were supporting participants, 40% were supporting individuals enrolled in both PDP and AWC, 38% were only supporting individuals involved in PDP, and 18% were only supporting individuals involved in AWC.

With respect to the distribution of responses by region, the following table shows the breakdown.

Answer Choices	Responses	
<b>Metro</b>	26.01%	90
<b>Northeast</b>	28.90%	100
<b>Southeast</b>	15.90%	55
<b>Central West</b>	29.19%	101

### Benefits of Self-Direction

Respondents were asked to rank the benefits of self-direction from 1 to 7 with 7 being the highest. The top ranked benefit was that people are empowered to make their own decisions, followed by people are happier (5.31), people being more included in their communities (4.97), and people learning new things (4.31). Lower ranked benefits included: people have more friends (2.9), people have jobs (2.7), and people have romantic relationships (1.47).

<b>People are more empowered and make their own choices</b>	6.77
<b>People are happier</b>	5.31
<b>People are more included in their communities</b>	4.97
<b>People are learning new things</b>	4.31
<b>People have more friends</b>	2.9
<b>People have a job</b>	2.7
<b>People have significant other(s) or romantic partner(s)</b>	1.47

### Knowledge of Self-Direction Programs

Respondents did not differ significantly in their knowledge of the two programs: 84% reported being “very” or “somewhat” familiar with PDP, while 86% reported being “very” or “somewhat” familiar with AWC. Most individuals (63%) reported becoming familiar with PDP or AWC in a formal setting such as a training session or staff meeting. When asked if they wanted to know more about the programs, 65% said they were interested in knowing more about PDP and 67% said they wanted to know more about AWC. Of those respondents who reported no interest in learning more, the reasons most commonly noted were that self-direction was “not a part of [their] job,” and therefore any efforts to learn more about it would be “useless” or “a waste.”

## The Process of Self-Direction

With respect to the clarity of the self-direction process, only 3% said “No, it was not clear,” but 40% said it was “Only Somewhat Clear.” The three most frequent answers given as to why the process was unclear were lack of clarity around how budgets are developed (61%), how the fiscal management service works (60%), and what services/supports can be self-directed (60%). Some of those who responded “Other” questioned why systems were designed the way they were and how decisions regarding the process were arrived at. When asked how DDS could help clarify the process, the most common responses were:

*“It’s a lot of upfront work, and maintenance the first year. Second year can also be challenging if things did not go well the first year and changes need to be made. Caseloads are high, staff are already behind in their work, so not too many staff are interested in adding that kind of intense work to an already over burden caseload.”*

conducting more specific trainings (60%) and including self-direction as part of new staff orientation (57%).

When asked to compare self-direction to conventional services, 83% of respondents reported that self-direction is more complicated; however, 51% noted that self-direction becomes less time-consuming in later years.

Answer Choices	Responses	
<b>The process can be complex at the beginning but is easier in later years</b>	51.20%	149
<b>The process can be complex and labor intensive</b>	31.96%	93
<b>The process is no more complicated than supporting conventional services</b>	12.03%	35
<b>Don’t know</b>	4.81%	14

Respondents reported that by far the two most important reasons why self-direction was more time-consuming was because it required more work with billing and fiscal management issues (70%) and required additional time to assist participants with staff recruitment (64%). In the write-in responses, many reported being especially frustrated with issues around the initial paperwork.

Answer Choices	Responses	
<b>Helping people to hire and manage staff</b>	70.59%	60
<b>Having enough time to work with people who are self-directing, given other responsibilities</b>	60.00%	51
<b>Tracking down all of the information I need regarding the rules and regulations that govern self-direction</b>	42.35%	36
<b>Determining what services can be self-directed</b>	31.76%	27
<b>Developing the self-directed budget</b>	30.59%	26
<b>How to talk about self-directed services with individuals and families</b>	14.12%	12
<b>The process is not complicated/ cumbersome</b>	8.24%	7

While staff did not think that it was challenging to convey the complexities of self-direction to individuals and families (only 14% agreed that it was complicated), some thought it was difficult to develop a budget (31%), to determine what services could be self-directed (32%), and to understand the rules and regulations (42%). A majority of respondents indicated that it was hard to find the time, given other responsibilities, to work with individuals who were self-directing (60%) or to help people hire and manage staff (71%).

Finally, staff were asked to make suggestions about reforms to the process of self-direction going forward. There were a number of suggestions, but a handful were consistent throughout. Staff recommended there be a comprehensive self-direction training manual, with clear up-to-date guidelines, for every region in the state and a formalized education series for individuals and families entering self-direction (that individuals/families could take on their own or that could be administered by a service coordinator/broker). In order to improve staff recruitment, it was suggested that DDS create a statewide pool of resumes for potential service providers that individuals and families could review. As might be expected, many of the suggestions were variations on “reduced caseload”—with one staff person making the case that dedicated support brokers were essential to providing equitable support to all individuals and to serve those who are disadvantaged due to their race, socioeconomic background, or the weakness of their natural support network.

### **Candidates for Self-Direction**

Almost three fourths (73%) of respondents noted that the best candidates for self-direction were individuals with supportive families and friends (73%). Slightly over half of respondents (53%) said people who were dissatisfied with conventional services were good candidates for self-direction. In the open-ended responses (both for this subset and for other questions), respondents reported being disappointed that, given the current structure and complexity of self-direction, only individuals from “families of means” who had the time and “education” to navigate the complexity of self-direction were drawn to the program. They said that self-direction should work for everyone irrespective of their income level or origin.

## How to Expand Self-Direction

Respondents were asked how DDS might enhance the growth of self-direction. Three options garnered the most votes: a simplified process, better education and outreach to families and individuals, and better staff training. Slightly less than half chose peer mentors.

Answer Choices	Responses	
<b>Simplified self-direction process</b>	65.73%	188
<b>Better education and outreach to families and people with disabilities</b>	61.89%	177
<b>Better training of service coordinators and DDS staff</b>	60.84%	174
<b>Peer mentors for self-advocates considering self-direction</b>	45.45%	130
<b>Improved operations manual</b>	34.97%	100
<b>Other (please specify)</b>		41

In write-in answers, some responses indicated that given

the magnitude of their current caseloads, there is resistance—even among staff who agree that self-direction is a positive program—to encouraging the individuals they support to pursue a program that they believe will increase their burden.

When staff who are involved in the self-direction program were asked about the training, 60% said that they believed they needed more training about self-direction. There was broad interest in all of the topics suggested: lessons learned from across DDS was the most popular (73%), followed by training about what types of services/supports could be self-directed (63%), a comparison of PDP and AWC (55%), and how to introduce self-direction to individuals and their families (49%). In contrast only two of the suggested training formats were popular among staff: regularly scheduled “Learning Community” meetings (67%) and webinars (50%). These formats were significantly more popular than roleplaying (23%), conference calls (23%), and all other suggestions (21%).

To promote self-direction to individuals, 83% of staff report that they emphasize the positive benefits of self-direction to participants, inform participants about training sessions in their area (56%), and provide individuals with a brochure (55%). Fewer respondents said that they introduced participants to other people who are self-directing (33%), referred them to the DDS website (15%), or showed them DDS videos (3%).

When asked if there is a need for more training for participants and their families, respondents overwhelmingly said yes. In fact, 80% agreed that there should be more training while only 3% disagreed, and 16% neglected to answer either way and/or said they didn't know. In terms of specific topics for training, the most popular topic was a realistic portrayal of the benefits and challenges of self-direction (87%), training on recruiting and managing staff (79%), adopting topics from those who are currently self-directing (70%), and including families and participants as trainers (62%). Only 30% of respondents thought potential abuse would be a good topic for training.

*"If support brokers had substantially lower caseloads and could put in a higher degree of assistance to each family, this would be more feasible than it currently is for a great deal of families."*

Service coordinators and support brokers were asked if they received enough ongoing training and support regarding self-direction: 71% agreed that they did; only 29% said they didn't. Among those service coordinators who were not supporting individuals in either AWC or PDP, they were asked what it would take for them to support self-direction -- 31% noted that they needed to have a better understanding of self-direction, 42% said that the process needed to change to make it less complicated, and 69% said that they needed more conversations with support brokers who were already working with individuals who were self-directing. However, the most popular response was a reduced caseload (69%).

## **Suggestions for Improvement**

There are a number of suggestions that were advanced by DDS staff that could potentially improve self-direction in the state and that would make it a more manageable and effective tool. (Appendix D lists the full range of suggestions.) Some of the major categories of suggestions include:

- Review the process of self-direction and simplify wherever possible
- Change regulations less frequently and with more transparency about the reasons for the change
- Provide more robust and formalized training to families and individuals
- Make the online portal more accessible
- Create a comprehensive training manual with up-to-date statewide guidelines
- Do a better job of supporting all individuals in an equitable way, including those with weaker natural support networks
- Reduce caseloads
- Provide more information on how to engage with PPL and improve their responsiveness to employees and participants

Undoubtedly, implementing some or all of the above changes could increase the number of people who are self-directing and improve the lives of many of those that DDS supports. But, DDS's most

pressing issue, and the idea this survey has expressed most clearly, is that staff are overburdened. Even if all of the above changes are implemented, that issue will persist. And, the magnitude of any positive changes, as well as the extent to which the program will be able to grow, are both fundamentally constrained by the ability of staff to provide the time and effort required to support individuals and families who are self-directing.

## 6. Supports Budgets

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A primary intent of the Real Lives legislation is to offer individuals greater opportunity to direct their own lives. DDS has created the opportunity to self-direct through two options, the Participant Directed Program (PDP) model and the Agency with Choice model. The survey results suggest some difficulties with these options, including a need to simplify the demands of participation on the part of the person with a disability as well as on service coordinators/support brokers. Moreover, individuals are sometimes not clear about how decisions are made over the amount each individual can be allotted to spend or on what services the funds might be spent. Finally, individuals must “self-select” into these programs, so the opportunity for participation is limited to those who know about the programs, have the capacity to participate, and who choose one of the two options.

*“The budget process is incomprehensible, and isn't addressed equitably”*  
—PDP participant

The creation of a supports budget framework offers the possibility of both simplifying the process and making it more transparent and understandable to the individual participants. To explore the possibility of moving to supports budgets, DDS asked HSRI to conduct a feasibility analysis. The results follow.

### Supports Budgets

A supports budget is an individually based, targeted amount of money (or other allocation, such as support hours) that an individual is assigned and has authority over to acquire the services they need and prefer. The amount is determined given an objective assessment of an individual's support needs, as well as the person's type of residence (e.g., community residence, with family) and age (e.g., up to 22 years old, and older than 22 years). In the event of extraordinary personal needs, an “exceptions review process” is also used to ensure that such needs are appropriately addressed.

Once the amount has been assigned, the individual (and his or guardian where indicated) is made aware of the supports budget in advance of a service planning meeting. The person can then exercise some amount of discretion over how the allocated funds are used to acquire preferred services. The amount of discretion afforded to the individual depends on the person's type of residence as well as other decisions made by policymakers. For instance, policymakers may decide that an entire allocation cannot be used for a single service such as respite. Overall, however, given an allocation, the idea is to grant the individual as much authority as possible over how the allocation is spent. After all, these specifics of exactly what types and amounts of services are provided are best determined during planning meetings to set individual person-centered plans. In other words, while policy makers may impose some limits on what an allocation may be used for, individuals should be otherwise free to build their own personalized support plan.

In addition, reliable assessment information helps policymakers understand the amount of support people need in relation to others receiving services. This type of information is essential so that the support needs of individuals can be arrayed from low to high, with some proportion of individuals having additional extraordinary need for medical or behavioral support. By establishing needs along a spectrum in this way, policymakers have a broader, data-informed view about the needs of the entire service population and may make informed decisions about the types and amounts of services people need, commensurate with their assessed need, and ultimately, decide on the budget allocations people should be granted.

## **Objective Assessment**

To apply this approach, the support needs of each service recipient must be assessed. A good tool for this requirement will satisfy the following criteria:

- ***Be valid for assessing support need across essential life domains.*** This includes covering domains such as:
  - **Activities of Daily Living (ADLs)** – ADLs include skills such as bathing, maintaining personal hygiene, dressing, mobility inside and outside the home, transferring, using the toilet, and communicating with others.
  - **Instrumental Activities of Daily Living (IADLs)** – IADLs are an additional set of life functions necessary for maintaining a person's immediate environment.
  - **Cognition/Memory** – Areas to explore include noted difficulties in areas of attention/concentration, learning, perception, task completion, awareness, communication, decision-making, memory, planning or problem-solving.
  - **Medical Conditions/Diagnoses** – These include medical conditions that affect an individual's daily functioning.
  - **Challenging Behavior** – These are characterized as behaviors that are: self-injurious, hurtful to others, destructive to property, disruptive, unusual or repetitive, socially offensive, uncooperative or withdrawn, or inattentive.
- ***Query for sufficient background information.*** In this way, the state can identify who was assessed by tying individual demographic information to the assessment.
- ***Result in scores that are consistently accurate and reliable.*** To ensure that the instrument does indeed test what it purports to test (validity) and does so regardless of the

interviewer/rater/respondent (reliability), it is critical that the assessment tool have documented validity and reliability.

- **Be scored in measurable ways to distinguish relative need.** That is, to identify need on a spectrum from low to high across targeted domains and among those assessed.
- **Be constructed in ways to promote easy automation of data entry, aggregation, and scoring.** Automating the survey/interview protocol can potentially reduce data entry errors and facilitate interview protocols.

## Supports Budgets Framework

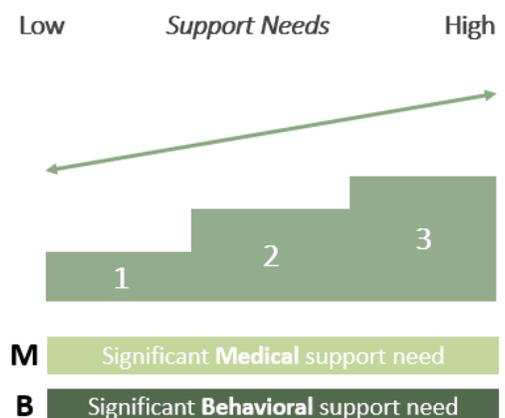
There are many ways to crosswalk assessment results into an individual support budget allotment. Most states use a *level-based approach*. Level-based approaches entail establishing clearly defined groups that are characterized by the amount of support common to members of each group. Level-based approaches recognize that when large numbers of service recipients are assessed, their measured support needs will distribute from low to high. People with the least need may require periodic, drop-in assistance. People with the greatest need may require constant physical assistance and oversight. And a range of support needs falls in between these two ends of the spectrum. Separate levels may also be established and dedicated to extraordinary needs, such as medical, behavioral, or other unique support needs.

Membership in these support levels is determined by the scores that result from the assessment. Specific scores or combinations of scores are associated with each level. For instance, a designated low score that indicates little overall support need may be used to define membership to “Support Level 1.” Likewise, other scores, indicating greater support need or exceptional medical or behavioral support need, are used to define membership to other support levels. In this way, “decision criteria” for each level are defined and individuals are assigned to a support level that best illustrates their need for support.

Next, the type and amount of public services that, on average, should be made available to individuals within each of these categories are considered. Once agreed upon, the type and amount of services allocated to each group is tied to the unit cost for delivering the specified services, so that a budget amount for each group can be computed. In general, these budgets increase from low to high in accordance with assessed needs.

The accompanying figure displays a five-level support need framework. Levels 1, 2, and 3 depict the low, moderate, and high general support needs groups. The levels “M” and “B” include individuals with extraordinary medical needs and extraordinary behavioral needs. Many iterations on this

### Example of a Five level Framework



framework are possible, but the principal idea is to separate individuals into a reasonable number of groupings based on their assessment scores, and to compute budgets for each level.

## Considerations

A supports budget framework may be established in any jurisdiction at any point in time. But it is important to keep in mind the larger context of the overall service system and account for: (a) the intentions that policymakers have in advancing this approach, and (b) supportive systems elements that must be aligned with these policy intentions.

- **Complementing policy considerations.** The supports budget framework, including the associated supports budgets, should not reinforce historical service use and spending. Building a framework based on legacy patterns makes forward progress difficult. It is more effective to fashion the framework to factor in new and preferred ways of supporting people to live the most inclusive lives possible.

Person-centered thought entails regard for individual needs and preferences, and inevitably, for promoting favorable outcomes consistent with each person's goals and objectives. However, policymakers must account for all those receiving services. As a result, the supports budgets framework must accurately characterize the needs of each individual while also accounting for the collective well-being of all.

- **Complementing system elements.** Having a means to allocate individualized budgets through an objective assessment is fundamental to a self-directed service system that utilizes a level-based supports budgeting framework. However, having such means, while necessary, is not sufficient. Other system elements must also be fashioned to accommodate individual needs in ways that promote system policy intentions. Complementary system elements include having a diverse service array available so that individuals may choose their services from. In this way, individuals may apply their budgets to acquire the actual services or goods they prefer with reasonable reimbursement rates that attract staff and providers.

In addition, systems instituting supports budgets must be prepared to support people to make choices about their funding. That is, systems must be simple for service recipients to navigate, must have clear expectations about how money can be spent (including detailing any specific limits on funding), and must have people knowledgeable enough to help service recipients to spend their individualized budgets according to their needs and preferences. There must also be publicized means for individuals to request exceptions to their budget when the funding cannot accommodate their needs, or to assist individuals to find additional support. Most important, there must be a robust means of educating people about their funding so that they can responsibly use needed funds to get what they need.

## Findings of Review of DDS Readiness to Develop Supports Budgets

As noted in the Methodology section of this report, HSRI reviewed existing DDS data on the characteristics of individuals receiving services to determine what additional data would be required to develop supports budgets. That review found several gaps:

- The data reviewed did not include comprehensive, up-to-date assessment information: ICAP scores were only present for roughly 26% of Non-Self-Directing individuals and 35% of Self-Directing individuals in FY17.
- We could not ascertain the dates of the ICAP assessments.
- We noted that the ICAP does not include information on extraordinary medical needs.
- We learned that data from an alternative assessment methodology, the Supports Intensity Scale (SIS), were available. The SIS is meant to measure the supports that individuals with I/DD need. There are three sections in the SIS that cover activities of everyday living, activities to protect and advocate for oneself, and medical and behavioral support needs.. These assessment data, however, were only available for a small number of individuals during certain fiscal years, and so are not helpful.
- We could not determine the living arrangement or residential type of each person. This information is essential to developing a supports budgets framework.
- We remained uncertain of whether all data sources can be readily linked under a unified data structure.

To build a supports budgets framework, DDS will need to strengthen its present capacity to utilize the data it has and will also need to gather new assessment data regarding individual support needs. For instance, to a large extent the data regarding personal demographics is available, though having information on everyone's residence type is a notable gap that must be addressed. Likewise, the absence of useful per person supports needs assessment data was noted earlier and must also be addressed. Moreover, while aggregate data regarding spending per category is available, in order to move to supports budgets, DDS will need to unpack these data to reveal service use per individual along with associated costs.

Finally, no matter the type of data, DDS will need the capacity to tie each dataset together using common identifiers. Setting up a plan and infrastructure for creating a database that links these disparate sources is a critical component of both the analysis and implementation phases of assigning support levels and budgets. Eventually, if selected quality output data were also added, DDS' capacity to make data-based policy decisions would be further enhanced.

## 7. Recommendations

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As in Years 1 and 2, there continue to be “pain points” that make the expansion of self-directed services slower than the expansive aspirations in the original Real Lives legislation. Some of these sticking points were addressed in previous reports and will be summarized in the following recommendations. There are five general issues that continue to constrain the growth of both the PDP and the AWC programs: 1) limited availability of support brokerage and prohibitive caseloads for service coordinators; 2) participant difficulty in recruiting and retaining staff; 3) complexity of the self-direction process; 4) transparency of the budget process; 5) inclusion of minority and low-income families in self-direction.

To put some of these recommendations in context, portions of the Real Lives legislation have been revisited to ensure that the legislative intent has been honored.

### **Support Brokerage**

As the results of the staff survey suggest, while most service coordinators/support brokers think that self-direction is a valuable option for people with I/DD and their families, they do not feel that they have the time or resources to take on self-directing participants given the demands of their ongoing caseloads. As one service coordinator put it in response to the staff survey:

I have worked with this service and with my current caseload, it is way too time consuming . . . to try to manage, work with the families and keep track of spending. My experience is that the families . . . can't manage it well on their own and seek the SC to assist with finding direct care staff, activities and social rec to manage their child's time. The paperwork and calling PPL are painful.

One of the Year 2 recommendations—in addition to seeking funding to lower caseloads—was to explore the addition of a support broker/facilitator service to the current waiver. Though it would be important to ensure that the functions of broker/facilitators do not overlap with traditional service coordination, there are many examples around the country where such services can be purchased. In fact, the Real Lives legislation appears to have anticipated such a function in the definitions that precede the specific provisions:

“Independent facilitator,” a person selected and directed by the participant to assist in the development and execution of a person-centered plan and to assist the participant in making informed decisions about the participant’s choices regarding self-determination including, but not limited to, the short and long term planning goals for self-determination and the transition to self-determination; provided, that an independent facilitator shall meet minimum qualifications established by the department through regulation prior to assisting a participant; and provided further, that an independent facilitator shall not provide any services, supports or goods to

the participant under the participant's individual support plan and shall not be employed by a person providing services, supports or goods to the participant. (Section 19 (a)).

This language is somewhat similar to CMS guidance on self-direction as quoted in the Year 2 Report:

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.<sup>2</sup>

***Recommendation 1: DDS should explore the inclusion of “independent facilitation” as a waiver service***

In light of the presumed intent of the Real Lives legislation and the pressing need for more support for people interested in self-direction, the Department of Developmental Services should explore the possibility of including “independent facilitation” services in the HCBS waivers. This service would be particularly beneficial to people who are self-directing but could also be helpful to individuals receiving traditional services. Facilitators can enhance the person-centered properties of the individual’s plan and can function as an advocate for the participant. As noted in the Year 2 report, DDS already supports “service navigators” in family support centers, AWC agencies, autism centers and in the DESE program. Service navigators function much like the external “facilitators” envisioned in the Real Lives legislation.

**Staff Recruitment**

DDS staff and participants alike rate difficulties in staff recruitment as one of the top challenges to self-direction. This is especially true in times of low unemployment where workers are in great demand. One DDS respondent to the staff survey noted:

Helping individuals find reliable staff is an ongoing issue. I do keep a list of staff people interested in working with others so that if staff leave, we have a potential resource to help the individual locate new staff. Having something like this state-wide may be helpful

While some participants may find staff close to home from among neighbors, friends, and family, others may not have those connections or social capital. Internet worker networks make it possible to select from a pool of possible staff rather than taking on recruitment through traditional means (newspaper ads, etc.).

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<sup>2</sup> Medicaid.gov. “Self-Directed Services.” 2018, [www.medicaid.gov/medicaid/ltss/self-directed/index.html](http://www.medicaid.gov/medicaid/ltss/self-directed/index.html).

***Recommendation 2: DDS should expand access to the “Meaningful Work” Platform***

DDS currently has an internet-based resource through “Meaningful Work,” which recently merged with TILL (Toward Independent Living and Learning). The online platform includes a list of potential workers from which participants can choose and interview. The resource has been available for families seeking respite staff but is also intended to be made available to participants who are considering self-direction as well as to their service coordinators/support brokers. To date, it does not appear that many participants have taken advantage of the platform to seek workers. DDS should encourage the use of this resource by supplying participants and families with brochures that describe “Meaningful Work,” including a description of the resource in service coordinator training, ensuring that a full description is included in the “soup to nuts” self-direction manual, and advising participants and families about the platform during planning meetings.

**Complexity of Self-Direction**

As noted in Year 1 and Year 2 of the Real Lives Evaluation, the complexity of the process is daunting to service coordinators/support brokers as well as to some participants. While there may be some irreducible amount of procedures and requirements surrounding self-direction, there should be ways of streamlining the process. Respondents to the staff survey had some ideas regarding how to make the process less complicated, including:

- Review the process of self-direction and simplify wherever possible
- Change regulations less frequently and with more transparency about the reasons for the change
- Create a comprehensive training manual with up-to-date, statewide guidelines

***Recommendation 3: Convene focus groups of service coordinators and program participants to address the complexity of self-direction***

One way to help effectuate the changes suggested above is to convene focus groups among service coordinators/support brokers working with people who are self-directing in each DDS Region. In facilitated sessions, staff should be encouraged to discuss the specific aspects of the self-direction process that are challenging. Similar groups of participants and families could also be organized to reflect on the procedural complexities that they have encountered. After synthesizing the responses, DDS central office staff should circulate a draft of possible reforms back to focus groups participants for their review and comment. The results of these focus groups should be shared with the Real Lives Advisory Committee.

Preparation for these focus groups with DDS staff should involve a thorough review of the multiple recommendations for changes in the administration of self-direction that are detailed in Appendix D.

The results of the PDP and AWC participant surveys also provide useful suggestions that can be used as starting points for focus group conversations with participants.

## Supports Budgets

DDS should review the HSRI feasibility analysis to determine whether to move to supports budgeting, including assessing the feasibility of facilitating the linkage of data across platforms, adding new data elements, evaluating the current individual assessment process, making the budgeting process more transparent, and determining the impact on rate structure. The Real Lives legislation speaks directly to the importance of the budget as a key element in self-direction:

19 (e) (4). [DDS should] . . . set individual budgets annually in a fair, equitable and **transparent manner** [emphasis added] in consultation with the participant and the participant’s individual support plan; provided, that each individual budget shall be provided in a standard format that provides a breakdown of the individual budget into standard categories determined by the department including, but not limited to, services, supports and goods; . . . (5) in consultation with the self-determination advisory board, review existing methodologies and develop alternative methodologies for computing and adjusting individual budgets as needed

The move to supports budgets will require several steps enumerated below.

### ***Recommendation 4: DDS should explore the possibility of developing supports budgets for individuals who are self-directing***

The following steps are suggested in the exploration and development of supports budgets.

- **Make and implement plans for assessing individual support need.** Essential to a supports budget framework is an objective assessment of each service recipient’s support need. Having such information is essential to building a supports budget framework. Yet, even if the DDS were to forgo such a framework, this information will be helpful to DDS to understand the relative support needs of those it serves in relation to their living arrangements, service use and spending, and eventually to whatever quality outcomes that DDS values.
- **DDS should consider potential policy changes that could accompany the move to supports budgets.** If DDS becomes engaged in the development of supports budgets, DDS may take the opportunity to make larger system adjustments, to revisit services and supports available to self-direct, reimbursement rates, supports planning protocol, changes in waiver provisions (e.g., independent facilitation), and other complementary system elements. The decisions DDS makes in these regards will inform the scope of the systems changes it anticipates making and may affect the supports budget framework that is generated.

- **Regardless of the scope of change, involve key stakeholders.** It will be important to lay out a road map for the change and to develop a comprehensive communication plan to inform stakeholders of potential changes that will take place. It is crucial to maintain communication with key stakeholders throughout the process to minimize disruption and misunderstanding and to maximize buy-in and support.

## **Supporting All Families**

The results of the DDS staff survey included a concern that it was primarily families who have a certain level of education and system savvy who could manage the intricacies of self-direction. This is unfortunate especially given the intent of the Real Lives legislation:

19 (e) (11) [DDS should] make efforts to ensure that participants are reasonably *representative of the diversity of individuals* eligible for services from the department

For many culturally diverse families, the notion of self-direction may be somewhat foreign, so it is important to ensure that these families receive an introduction to the option from staff with relevant cultural training and insights. Further, for some families and participants who feel intimidated by the self-directed option, linking them with other families who may share similar circumstances may be helpful. Finally, moving to a more streamlined process should also attract families who previously might have felt overwhelmed.

### ***Recommendation 5: DDS should develop strategies and supports to engage economically and culturally diverse participants in self-direction***

DDS should make efforts to conduct more intense outreach to communities of color and diverse economic groups to introduce the benefits of self-direction. To ensure that these families and participants are supported once they opt for self-direction, it will be important to identify personnel at the area office level who have training regarding cultural differences, have language/translation capabilities, and the time to provide targeted support. With respect to participants from families that feel they don't have the time and resources to manage self-direction, the availability of a dedicated external facilitator could be very helpful in assisting these families to navigate the system. As one respondent to the DDS staff survey noted:

Dedicated Support Brokers are absolutely necessary. Systemically disadvantaged people (lower income, people of color, and people without strong natural support networks) need more hands-on support to be successful and as it stands people can't realistically explore self-direction unless they have their own resources to manage the program.

DDS could also explore building in more support to these families through the PPL contract. Matching these families and participants with mentor families could also enhance their participation. Finally, DDS should ensure that service coordinators/support brokers don't prejudice—knowingly or

unknowingly—the ability of participants and families to self-direct. This should be a component of any training regimen for service coordinators/support brokers.

## **Outreach**

In addition to the “pain points” noted above, there is a need for continued and robust outreach to people with disabilities and their families regarding the availability of self-direction. DDS has mounted significant outreach activities since this evaluation began, thanks in large part to the Regional Self-Direction Coordinators. The development of videos and the self-advocate speaker’s bureau are great marketing initiatives. However, as noted by DDS staff and described above, individuals and families who are taking advantage of self-direction tend to be more engaged and involved; this suggests that educational efforts may have yet to reach those individuals and families who are less engaged.

### ***Recommendation 6: DDS, with co-sponsors, should convene a statewide conference to showcase experiences with self-direction***

DDS should continue its outreach efforts and assess the extent to which it is reaching culturally and economically diverse families. In addition to standardizing outreach across the state, DDS should revisit the recommendation from Year 2 regarding sponsoring a conference on self-direction. It could be a celebration of the Real Lives legislation and could showcase individuals who are self-directing. It could also provide the opportunity for support brokers to present on lessons they have learned supporting individuals to self-direct. To support the conference, DDS could reach out to collaborators and sponsors including The Arc, the Federation, Families Organizing for Change, the Developmental Disabilities Council and other statewide I/DD organizations.

# Appendix

## Appendix A: Sampling Design, Survey Design and Dissemination

### Sampling Design

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 1088 surveys were sent (208 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 821 surveys were sent (120 valid surveys returned)
DDS Staff Survey	Service Coordinator/Support Brokers Program Coordinators II or Program Monitors Autism Service Coordinators Transition Coordinators Assistant Area Directors  A total of 608 surveys sent to service coordinators/ support brokers (260 valid surveys returned). The number of surveys sent to the other categories of staff is unknown since recipients were asked to forward the survey to others involved in self-direction.

### Survey Design

Three survey questionnaires were developed. To do this, the evaluation team reviewed the evaluation goals and research questions, drafted samples for each survey, and gave DDS the opportunity to review and provide feedback; finally, 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.

### **1. Self-Direction Participant Survey for people enrolled in the Participant Directed Program (Herein referred to as “PDP Survey” in short)**

The PDP survey has 29 questions, divided into six sections: Participant Characteristics, Reasons to Self-Direct, Self-Direction Outcomes and Satisfaction, Participant Budgets, Support Brokers/Service Coordinators, and Experience with Public Partnerships (PPL). Most questions were single choice from provided responses, though some contained a write-in option (“Other”); six questions were select-all-that-apply.

### **2. Self-Direction Participant Survey for people enrolled in Agency with Choice (Referred to as “AWC Survey” in short)**

The AWC survey also has 29 questions, but the structure differed from the PDP survey as participants choose a provider agency to help them hire and manage staff and to support decision-making about services and supports. Therefore, the AWC survey also contained questions about participant experience with the agency. Similar to the PDP survey, most questions were single choice from provided responses, though some had a write-in option (“Other”); seven questions were select-all-that-apply.

### **3. Survey of DDS Staff Regarding Implementation of Self-Direction Pursuant to the Real Lives Legislation (Referred to as “Staff Survey” in short)**

The Staff Survey has 22 questions, divided into four sections: (1) Background Characteristics of Respondents, (2) Overview of Self-Direction, (3) Promoting Self-Direction, and (4) Experience of Support Brokers/Service Coordinators with Self-Direction. All staff respondents could answer Sections 1 and 2; meanwhile, Section 3 was answered only by staff who have self-direction responsibilities and all support brokers/service coordinators, and Section 4 only by support brokers/service coordinators, regardless of whether they have any individuals on their caseload who were self-directing. Questions cover topics such as Benefits of Self-Direction, Knowledge of Self-Direction Programs, The Process of Self-Direction, Candidates for Self-Direction, Promoting Self-Direction, and Suggestions for Improvement.

A majority of the Staff Survey questions were select-all-that-apply, and most also had a write-in option (“Other, please specify”). In one question (#17), survey respondents were asked to rank eight items (write-in option included) in the order of importance (“1” being most important, “8” being least important).

The questions and response options for each survey are presented in Appendices B-D.

## ***Dissemination***

Two modes of survey were employed: mail and online. In both modes, participants consent to participate. Confidentiality and privacy were ensured in all stages of the surveys.

Mail Survey. All surveys were mailed by DDS. HSRI did not receive any individually identifiable information. Results from the paper survey were entered by HSRI staff and contractors into an online data collection tool (SurveyMonkey).

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

# MA Real Lives Evaluation

For internal review. DDS Quality Assurance Evaluation

## Real Lives Participant Directed Program Survey Results

November 2019

Prepared for:

Massachusetts Department of Developmental Services

Prepared by:

HUMAN SERVICES RESEARCH INSTITUTE

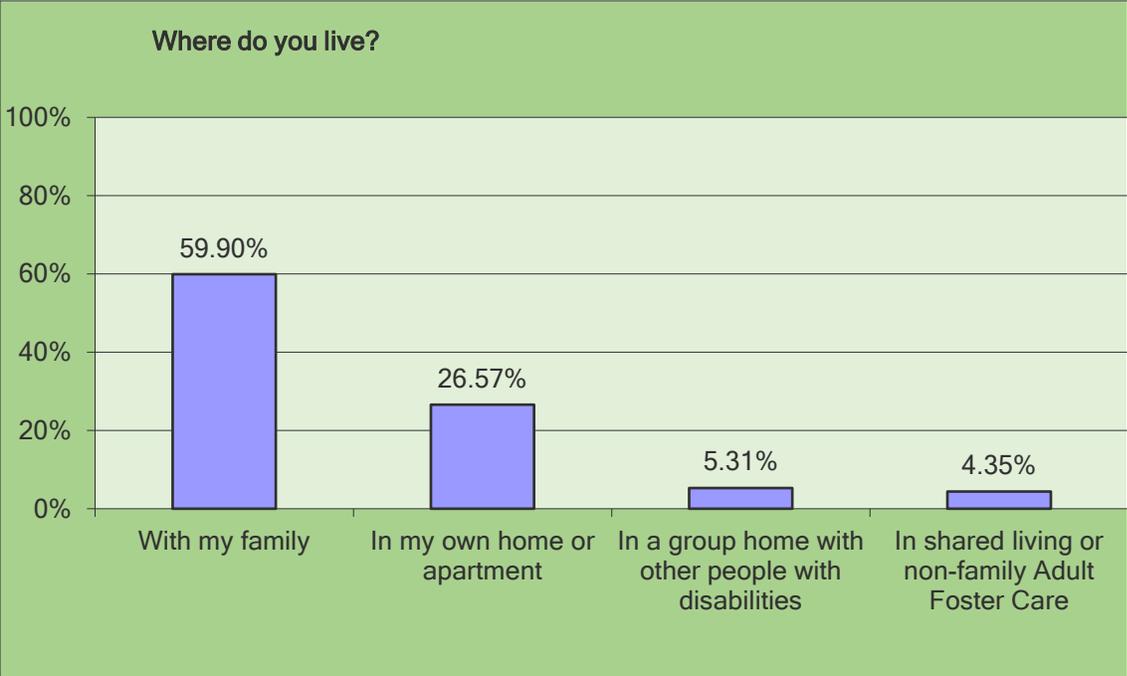
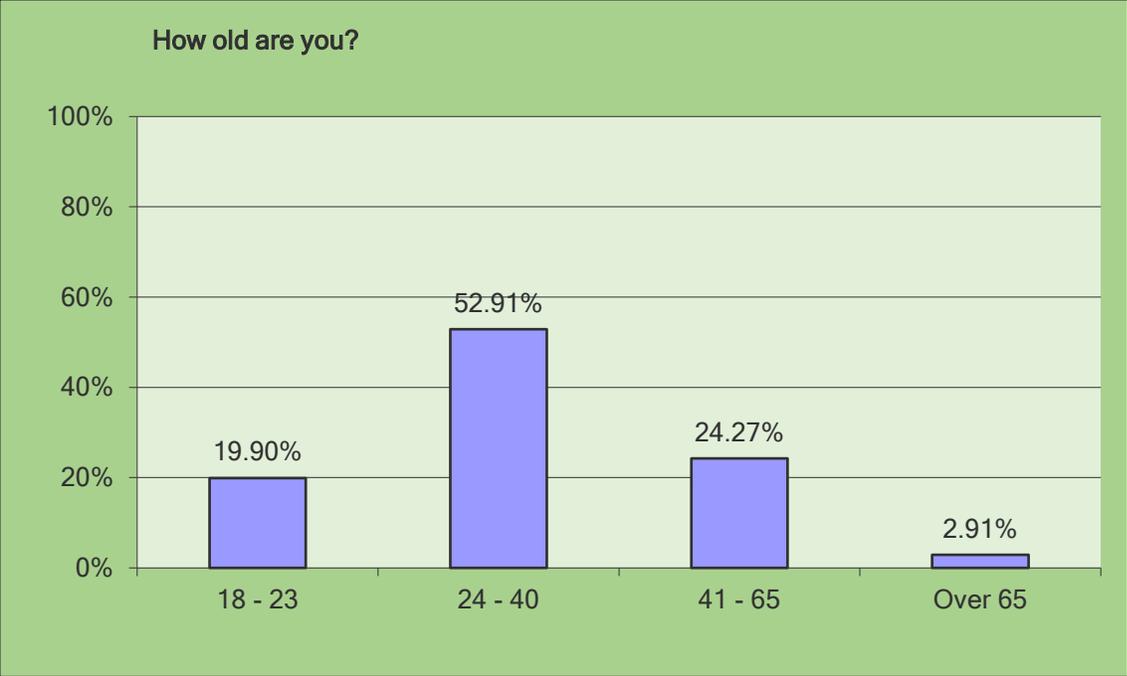
November 27, 2019

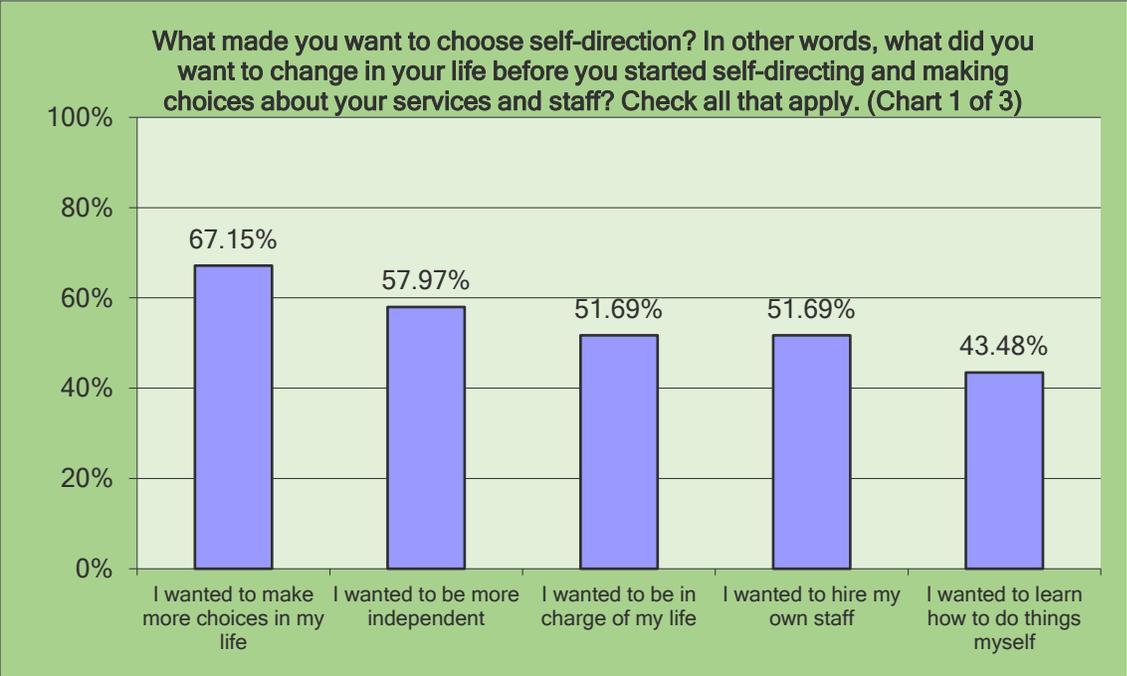
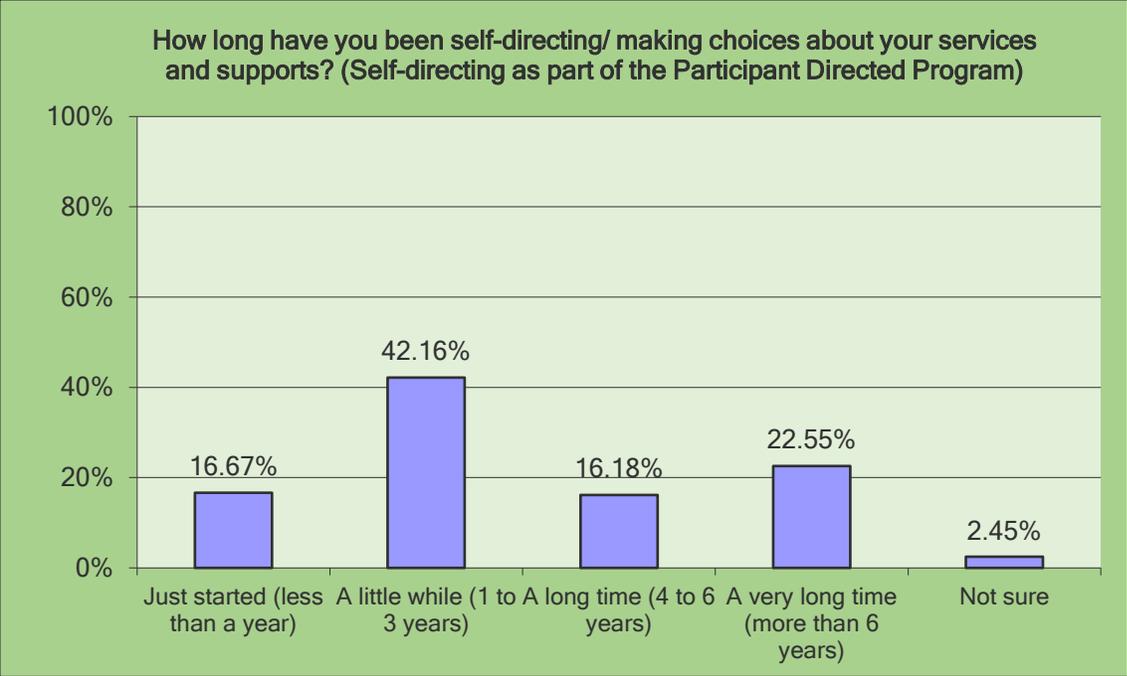
## Background

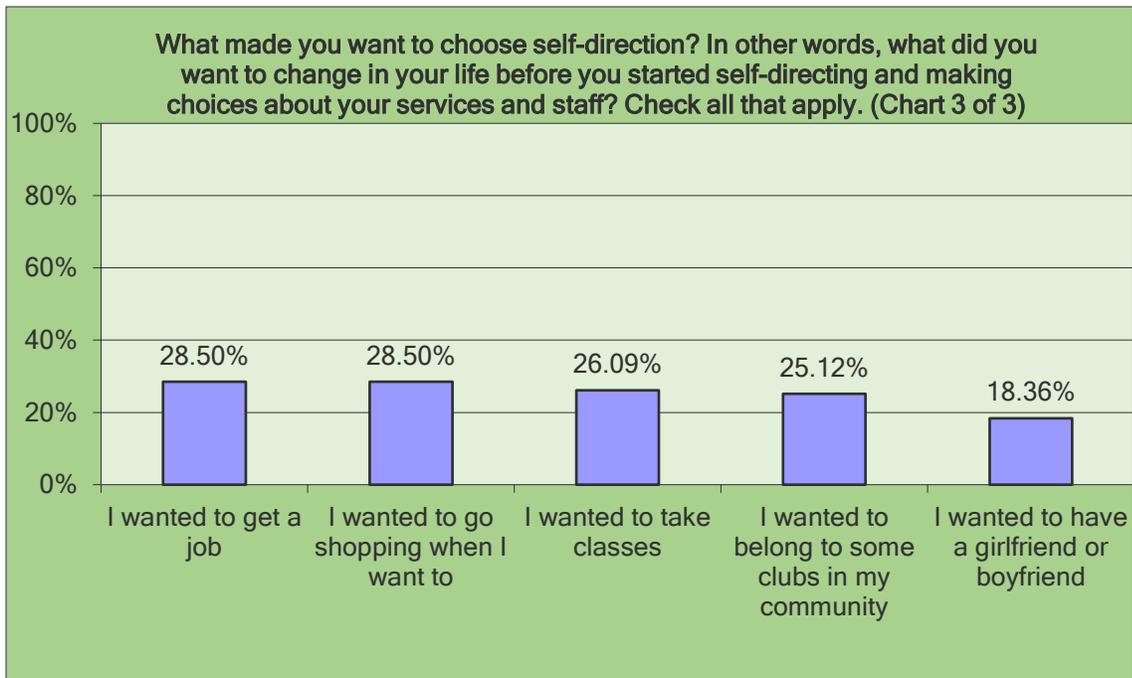
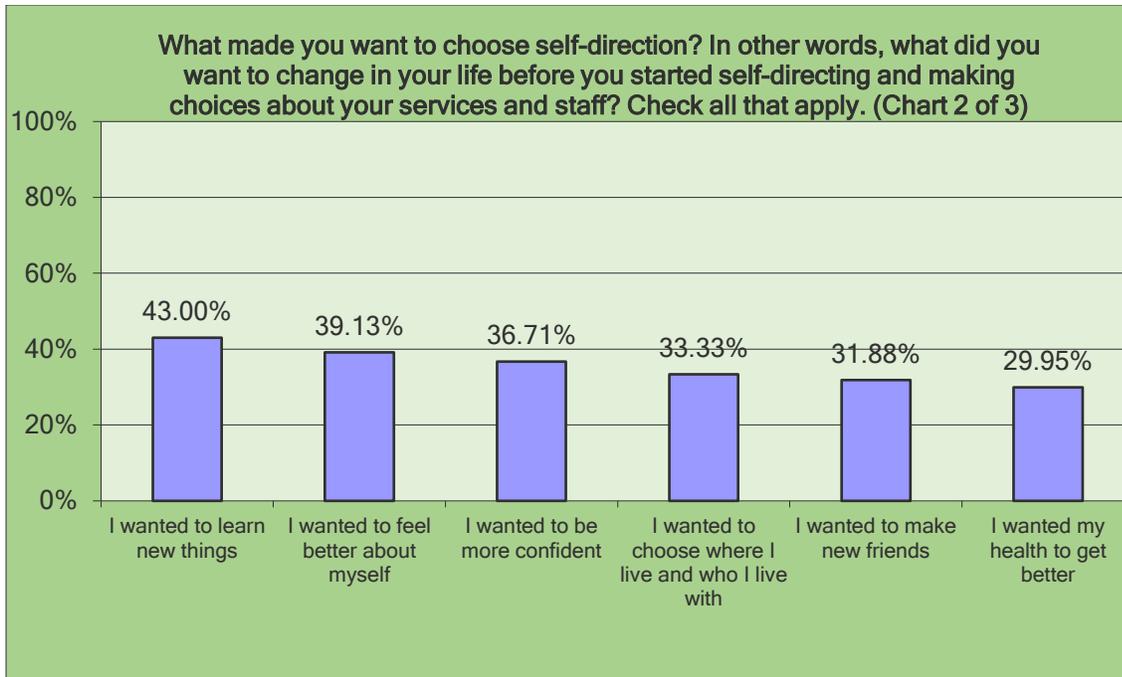
The following data were collected using a survey that was mailed out to 1088 individuals who are participating in the Participant Directed Program. Participants were given the option of completing the paper survey or using a provided link to SurveyMonkey to complete the survey online. HSRI received 208 valid surveys between February 18, 2019 and April 4, 2019. Survey respondents were not identifiable in the surveys, but they did provide their zip codes to allow for reviewing findings by region. However, responses were not sufficient to analyze at the sub-state level.

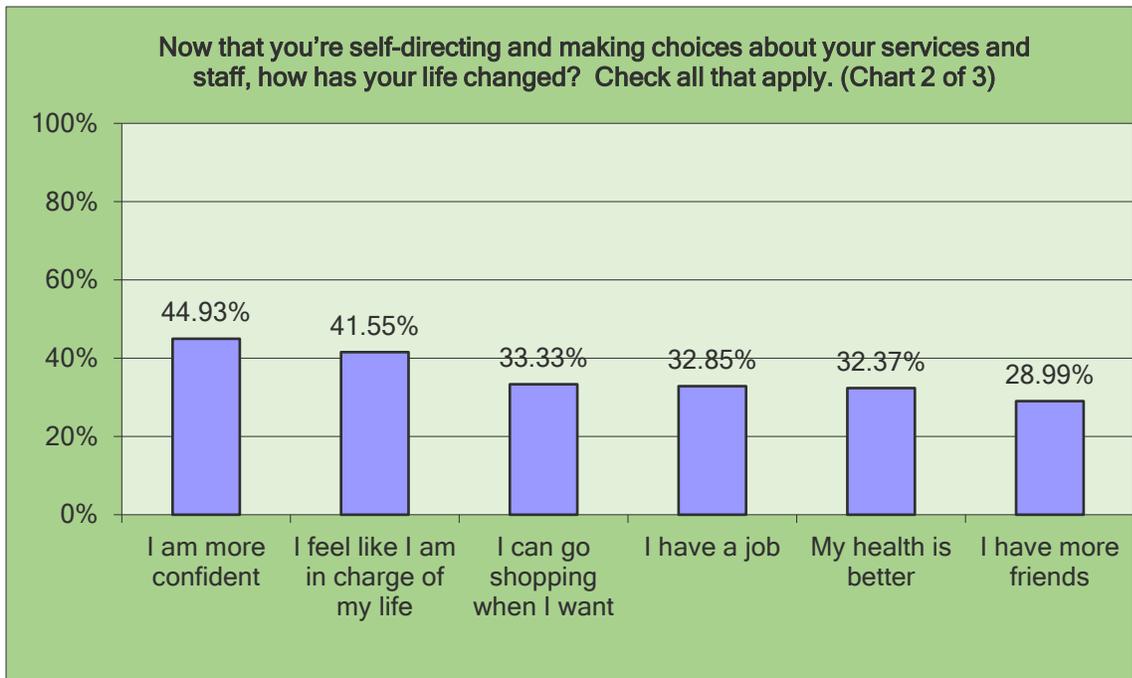
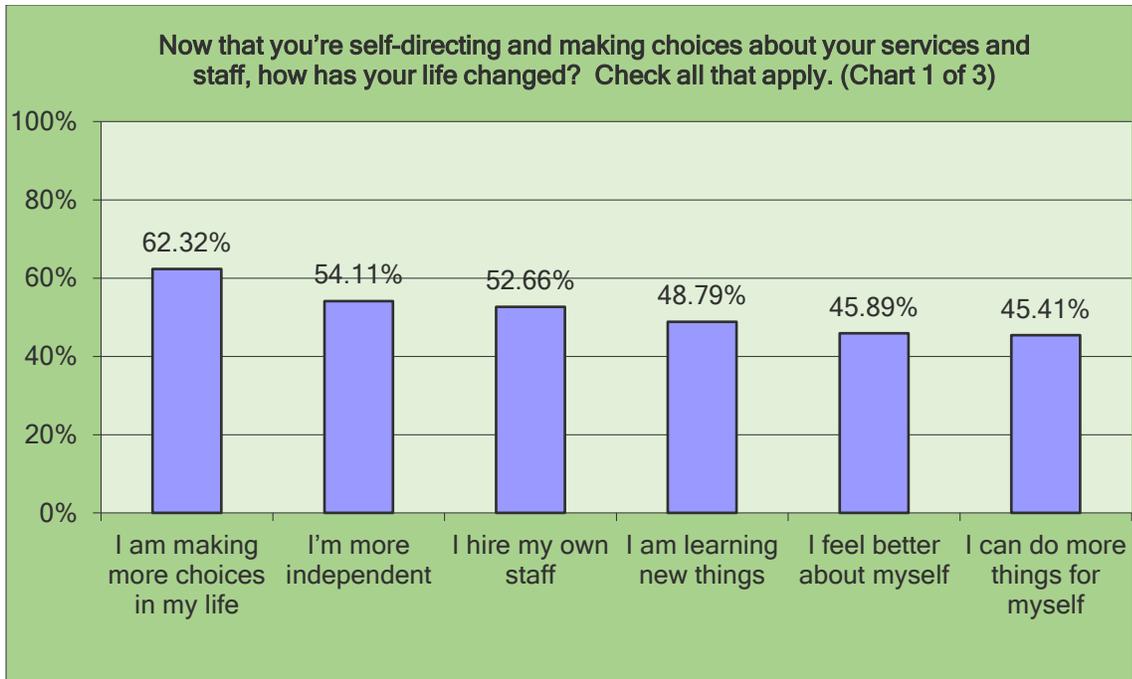
## Results by Question

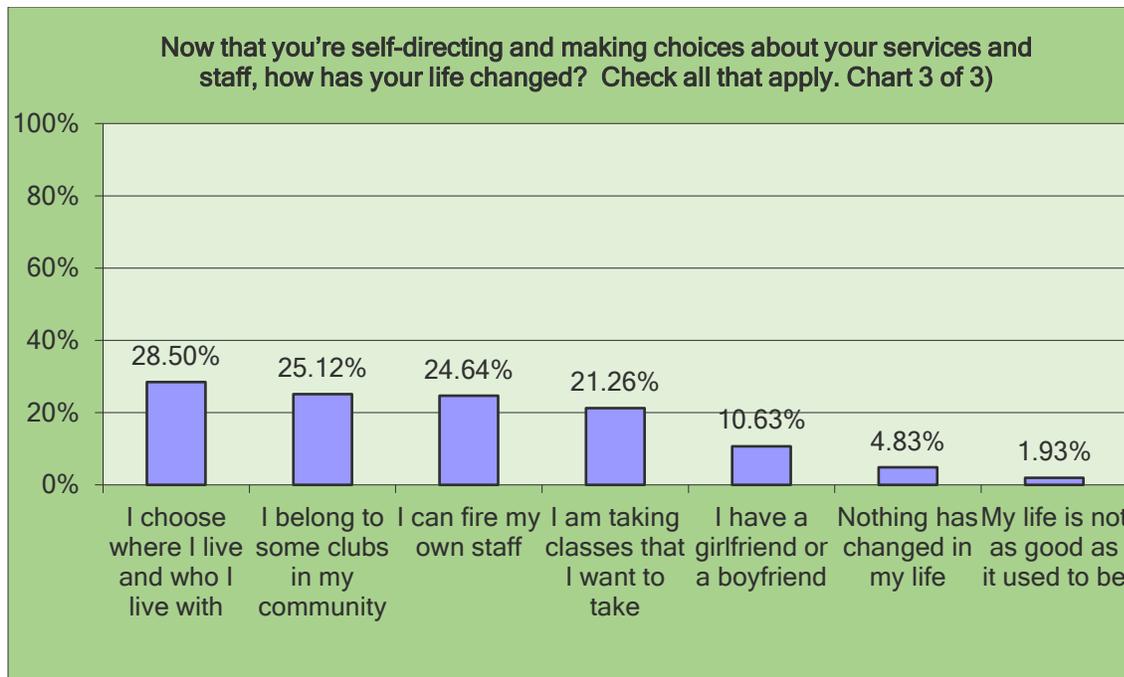
Detailed results and graphs for each question on the survey are presented below.











*Other responses (as quoted from survey respondents):*

- Opportunity to do interesting things/activities
- it takes up a lot of time
- My life is more complicated. Most days are different.
- The number of people I call family has grown.
- It's still hard to find friends to do activities with me. It's really hard to find someone for the add on job of Social Asst to take me and a friend places that I want to go. My mom has contacted many agencies people with little success.
- I wish I had more friends in my life
- Learning to cook
- I am working with a painting coach
- Doing more exercise
- I can have my own agenda and not live everyone else's agenda
- I would like to have co-workers, peers.
- I want to qualify for supported housing but my IQ is too high. I need more help than people realize because of all my disabilities.
- My anxiety has been reduced due to working in a quiet environment
- I am not isolated due to my mental/developmental illness and issues!!!
- have a baby
- Guardian (mom) runs program for me.
- I am happy

- I can hire private tutors for academics
- The staff helps me be able to live at home with my mom
- Restriction from State Office on wealth, clothes, food, and recreation this year have set restrictions
- I need help with my money
- Overall quality of life is so much better
- I can stay within my comfort zone
- completed desired classes
- I have an online business
- I get enough sleep each night (so I am happy every day). I participate in several activities in my community every week
- I'm happy now
- Medical issues heighten some things currently
- I received an award for "volunteer of the year" from united way
- Neutral, hard to find staff
- As caregivers we are not in a constant state of worry
- I am safe
- I can get to a program that is helping me find a career

**If there are things in your life that you would like to change, please tell us what those changes would be.**

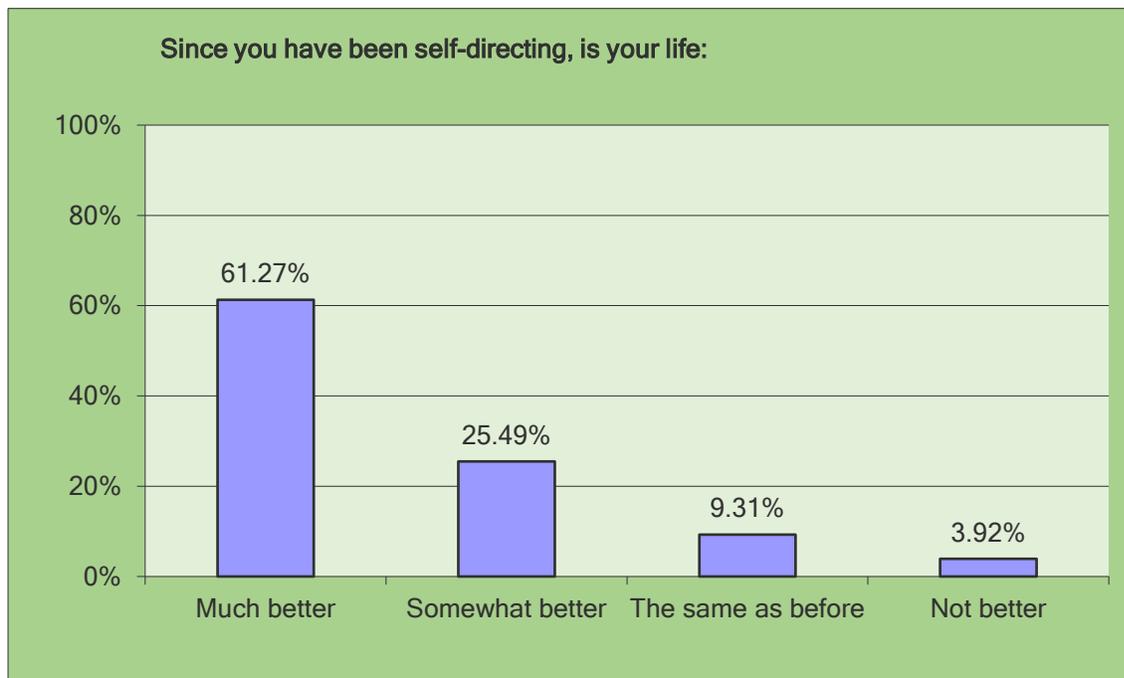
- Would like to have a girlfriend and a real job (not volunteer)
- The one downside to this program is the isolation. Having more peer interaction would be good I'd like more friends.
- Better support from DDS support broker - no help now
- Not being idle
- More vacations down the Cape.
- I want to be able to go wherever I want but I can't drive.
- I would like to see my support people more
- Get my own apartment
- Find a girlfriend and do activities that include girls who want to make new friends. Girls at dances stay with their friends. Want to find staff to take me and a friend or meet friends at hockey games. Want to find PT job. Had one and case manager didn't come to my work like she promised and I lost job. We told her that there were problems and she did nothing. Want DDS to help me find way to get to hockey games to meet my friends if

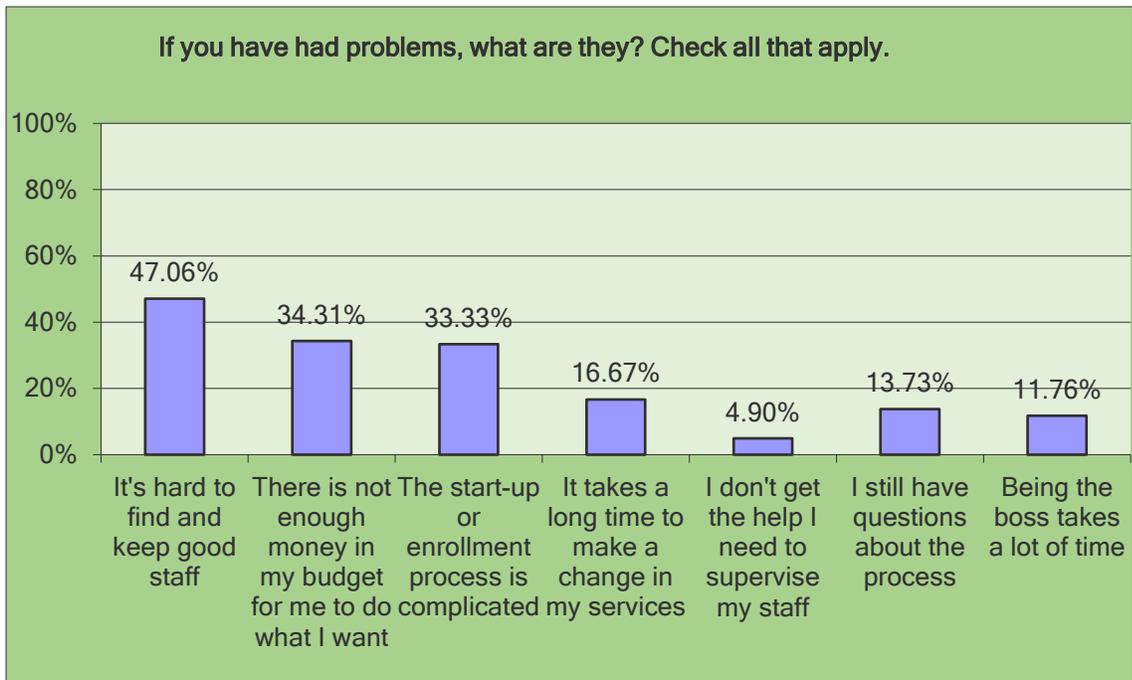
my mom can't find someone again this season. Need contacts to find suitable girls that want to date and how would I get to go? Agency said there were peers with same interests but there is not. Hard to get to meet new peers to go out and have money.

- I would love to have people around me that are nice and going to drive and dance
- I would like someday to get off SSI
- "that staff people/support people don't go away"
- New serious medical issues created an increased need for our daughter. Medical expenses have depleted our savings and forced me to stop working. We hoped this program would help. It did not.
- Ways to make friends.
- Have a wheelchair van so I could do more with my family and friends on weekends
- I would like to go out more, but need more support so my family is not the only people to bring my places.
- Ability to community more clearly. Travel more.
- Someday I want to get married and live with my husband.
- I would like to have more respite staff to take me to recreation on nights and weekends. My parents are old.
- My parents are helping me achieve emotional stability so that I can access a community college and more job opportunities.
- math class
- more assistance with technology, more activities on the weekends
- Handicap accessibility house - specifically bathroom
- Being able to get to grocery store and appointments without depending on my parents to drive me.
- Recreation and activity is very important to me but sometimes with self directions and the many changes I cannot afford to so all that I want to do. I would like to have younger staff to help me in the community.
- To get my driver permit and learn how to drive a car.
- Get a girlfriend. Get a place with supports
- I would like to attend classes at a community college
- Need more money to choose more activities to do
- I would like to get a drivers license
- Take computer classes
- I would like more staff hours to help get me places because my parents are older and won't always be able to help.
- I would lose weight
- I would like to get my own apartment and living on my own

- shared living
- I would like to have additional self-direction funds so I could do more activities and school.
- Reduction of paperwork; choices to hire professional staff such as life coach, job counselor, mentors
- I would like to take a course but I really do not know how I could do it on my own. It is so difficult to be able to try.
- Have more flexibility with my budget and fundings. To controlled and budget restricted. This year has had a negative effect on community activities have been reduced
- These are things I would to have changed
- Improve my vocabulary; improve how I interact with friends
- I want a job, I want to volunteer more
- Independence
- Better public transportation to get places
- Yes, I would like to find a larger (3 bedroom) apartment to share with my live in provider (and her kids)
- Have help finding good staff
- My son is working towards and would eventually like to have his own apartment
- Not at present time
- Transportation is still an issue. I do use the ride and it is great for to/from work.
- Obtain a drivers license
- would like to find a life partner
- I would like a job and more social activities. I would like to get my own place and possibly get a service pet.
- My diagnostries[sic] because they make my life especially difficult.
- I want to gain independence
- To get my driver permit and learn how to drive a car.
- I would like to continue meeting more people and being more social by joining new social groups in or near my community. I would also like to try dating people in order to gain experience with dating.
- I need a paying jobs. At the moment I volunteer my time, but I am not paid
- Work less hours
- Just to get healthy
- Presently Bedridden - Want to Get Out More
- Being able to drive
- Doing more weekend activities learning compatin class / join exercise class
- Change amount of money now that my mother could (illegible) more of the time

- I would have friends and clubs in my community. I would like to learn how to drive and go to a special driving school.
- Roommates of similar age. More access to recreation and healthier foods/activities.
- More exercise. More info. About healthy earthy.
- More support esp in Medical/behavioral
- I'd own my own home
- I, as his mother, would like to be able to distribute his money into categories as I see fit. In other words, my son is very medically fragile. He has uncontrolled seizures. Going out in the community is a little tough on his safety.
- Not to be autistic people are mean my helper is great would keep her forever I need to learn a lot especially living and shopping
- I would like to find a love life partner.
- finding friends and more social activities
- I hope someday I can get my license
- Being normal like anyone else
- stop smoking
- Not self talking
- I'd like to travel more
- MORE MONEY



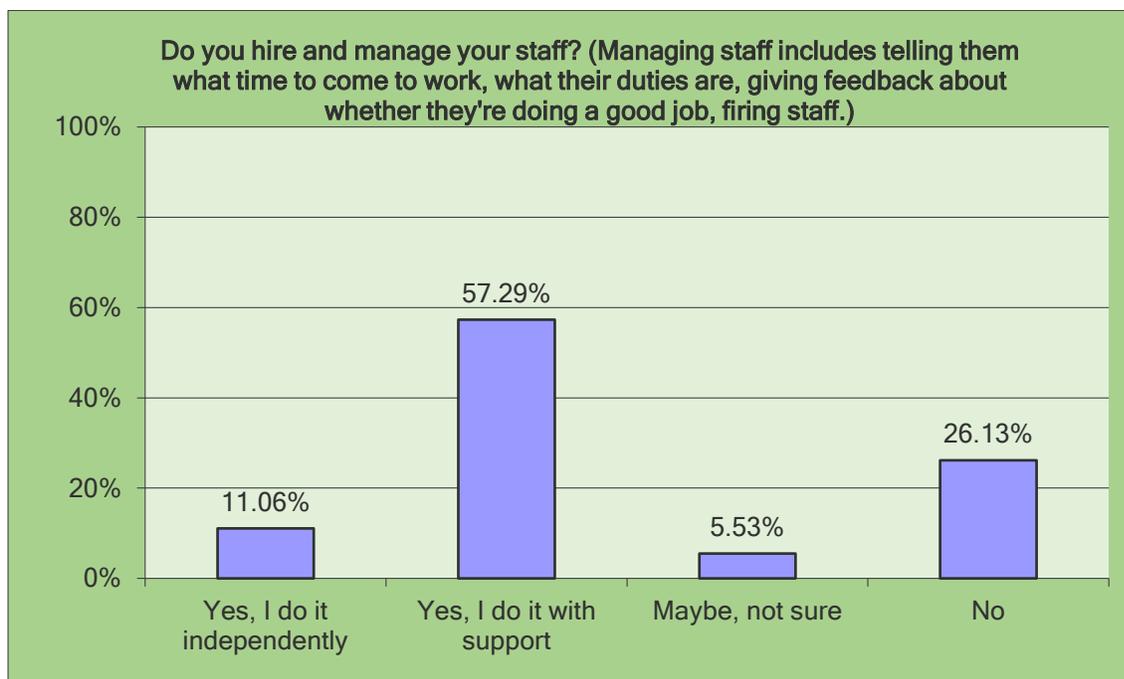


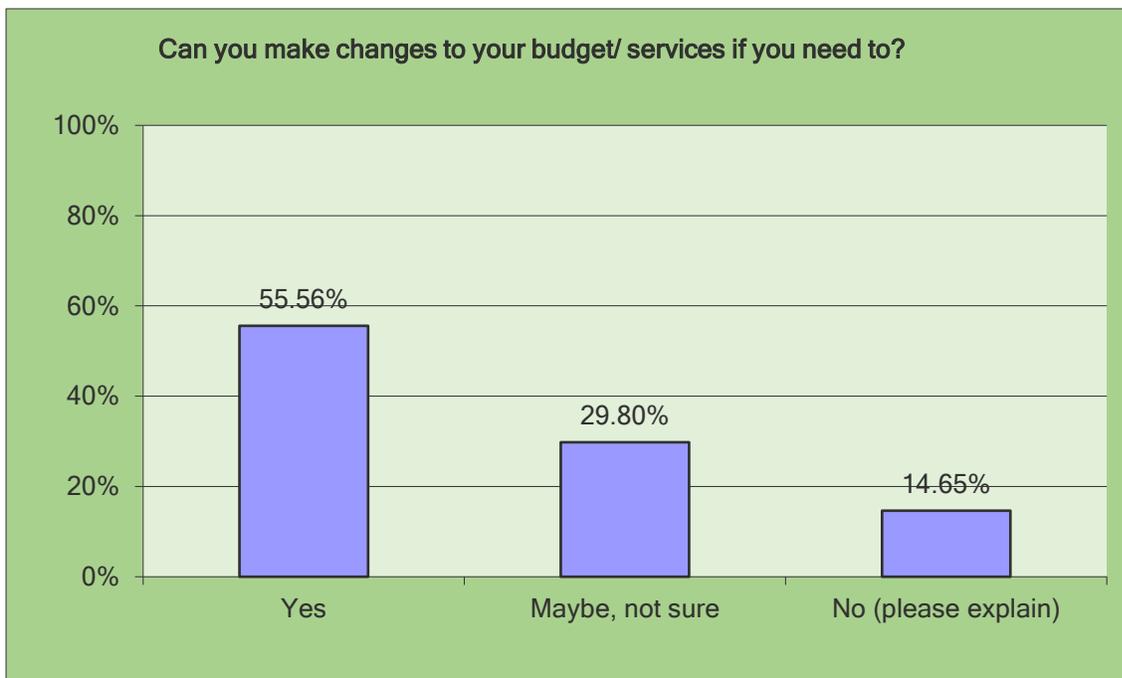
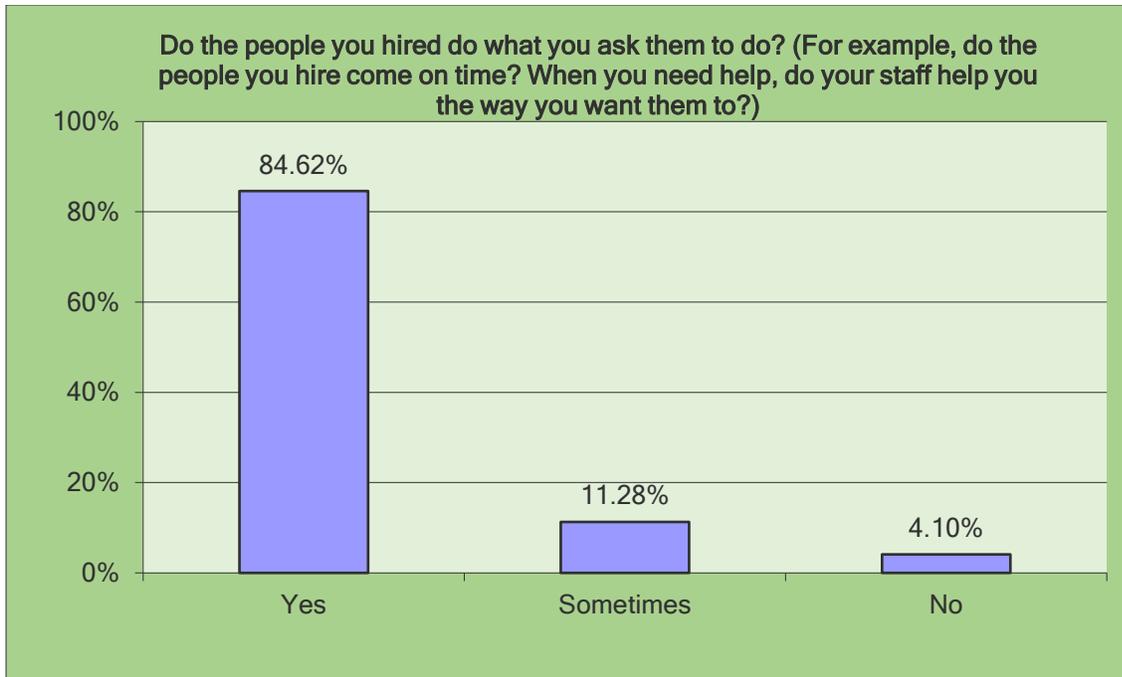
*Other responses (as quoted from survey respondents):*

- No support from DDS
- BCBA is not consistent
- Not sure we know what can be done with budget. Parents help a lot to help me go places I want. We waited a long time before finding out these supports could be self directed.

- When I ask her to do something like make food like a recipe she take her time so I don't do it at all
- (name) from DDS has been a huge help.
- It was challenging to get started but all good now!
- (name) from DDS has been a great support!
- PPL was helpful but initially problems in cutting check due to layers of bureaucracy
- Had an excellent DDS Service Coordinator in the past. Current SC is fairly new, still learning, takes a long time to follow through - especially with hiring/on boarding new staff
- Keeping a disabled person @ home is in the best interest of all. Yet the "process" is extremely challenging and frustrating. The state should facilitate these issues and not treat them as criminals.
- Now in a wheelchair - unable to visit family on the weekends b-bus too restricted and unreliable
- There are not enough opportunities in the community for non-verbal/behavioral adults to engage in volunteer/work opportunities
- This program is changing. Services and goods that were previously covered are no longer covered.
- I would like to be able to coordinate with my friends and share staff and activities and plan together.
- not sure how to answer this
- assistance with technology lacking, not enough recreational activities on the weekend
- DDS office only administers. they don't have an interest in the day to day of the individual.
- Sometimes its hard for me to make choices of what I want to do
- My parents do have to do a lot of paperwork for each month's reimbursements
- Sometimes Public Partnerships makes mistakes re paying my staff. Recently PPL failed to pay two months of a bill for me.
- I was notified that I was being kicked off of DDS. No one would return my phone calls for months I finally had to call a politician to get someone from DDS to call me back.
- public partnerships does a poor job - getting payroll done consistently makes mistakes and never issues pay on time.
- DDS changes budget codes and requirements which places more demands on administering the process. PPC and DDS managers don't always tell us the same information
- It gets tough to spend money the way I want such as entertainment for me and support and things like shredder and other household things
- It takes too long to set up staff
- This is more like controlled direction from the State Office. Not individualized with caps for all. People have unique needs with health, etc.
- It was hard to get an appropriate budget in place and to get approval for the services we needed.
- Sometimes I can choose how to spend my allocation - sometimes I can't, I have a hard time with reimbursements - it used to be easy just submitting my work statement. now I need to remember to get detailed receipts, save them, scan them

- need help with paper work
- very stressful, refunds take a long time, single mom, not a lot of money, 4 weeks is a long time to get 100 or more back, don't have this money to dish out
- staff training opportunities are difficult to find need more money for mileage/travel
- Budgeting my own accounts and money has always been a challenge [for] me. Something I always have [to] work on.
- (1) The hiring process through DDS/PPL takes too long & is badly coordinated. I've lost staffing candidates waiting for the process to complete. (2) DDS doesn't put my approved funds into my THE RIDE account in a timely fashion (months late), forcing my family to pay up front and be reimbursed later. (3) The reimbursement process may take months.
- Staff call out sick and I need to find someone to cover for them
- Payment for services is sometimes delayed
- Enrolling new staff is too complicated. Specifically downloading a new application. Requires a first step. Should be able to download a blank application.
- Problems with Public Partnerships. Getting locked out of partial hard to reach ppl public partnership menu options to choose when calling is confused.
- Mental health and budgetary issues
- I cannot do a lot of what is listed above alone without help from a family member or advocate
- The restrictions change yearly. Generally the changes make no sense and contradict the idea as self-direction.
- Need crisis / behavioral / medical support
- I am still waiting for refunds. Over one month now.
- when a person quits, it is difficult to find someone new and once you do, the process for them to start can take a long time and that leaves you without "services for months"

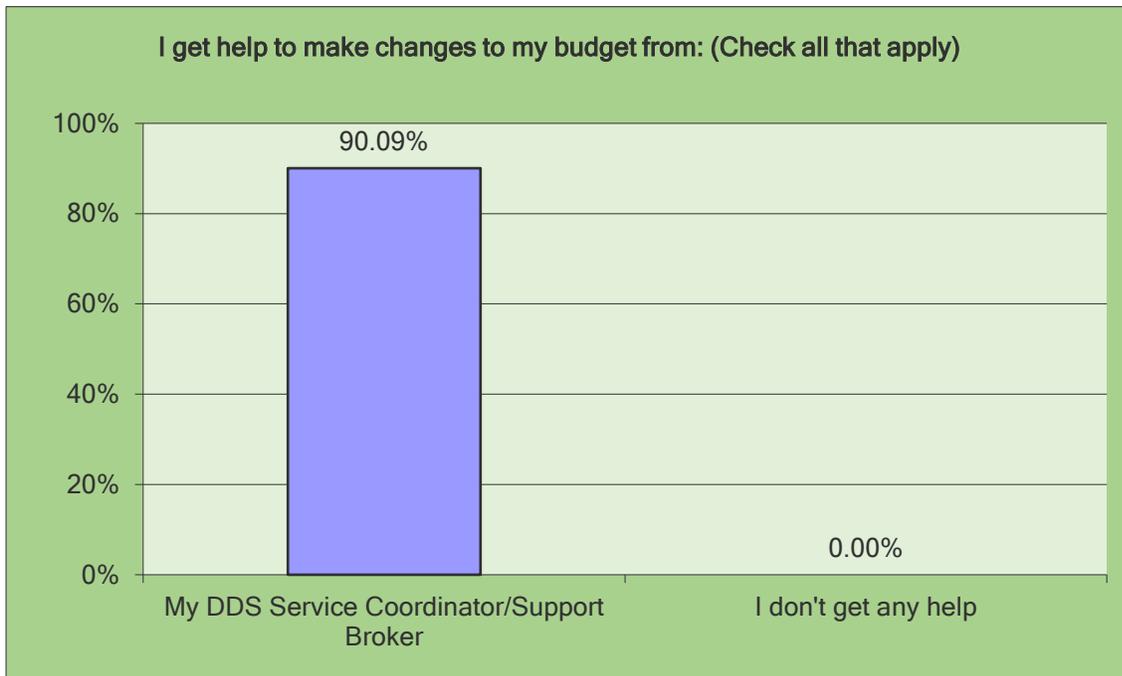




*Other responses (as quoted from survey respondents):*

- We just don't know. Often we are told something can't be done only to find out months later or by someone else that something CAN be done.
- Was informed it was set for a year
- changes decided by parents who handle finances and staff
- Cannot give staff a raise even after 6 years
- There are items -- goods and services -- that I want covered, but are not.

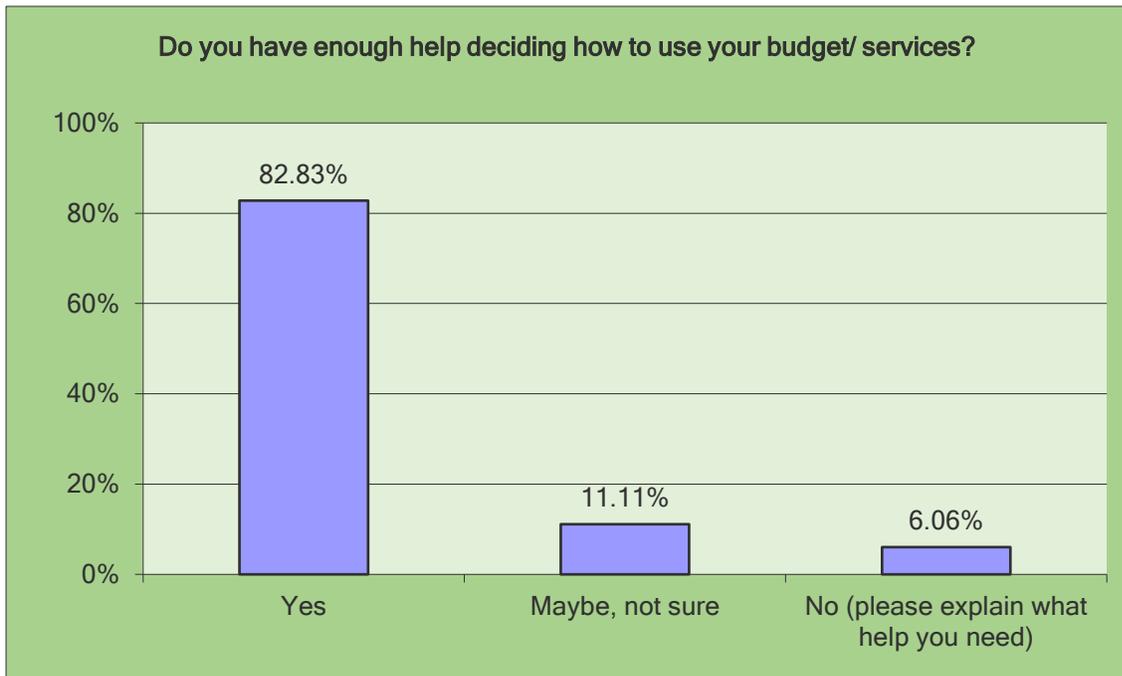
- I can change my services, but not my budget
- We have no increases in money to keep this going. It will have to end someday.
- Have asked for money to join gym but it hasn't happened
- I can't read or write
- no money in the budget
- Restricted live item limits
- My mom helps me
- I can make some of those changes with help
- DDS is in charge of the money
- not sure, never been discussed, new person in charge of my son now, have not met him only calls
- No raises for staff
- Have court appointed guardian - my brother Mark Spencer
- Self direction seems to mean restricted to what DDS says is ok
- Pop categories too restricted. For ex - no reimbursement for food (special diet) as of current year and recent changes
- Only a little, it's been tough
- Have help from brother and mom
- I use my budget to participate in the Education and Training Pilot modules. I could change services and utilize my budget differently if I chose, I suppose. But I am happy doing this and my budget is spent paying for these services.
- My mother helped me with everything.



*Other responses (as quoted from survey respondents):*

- my mother
- mother

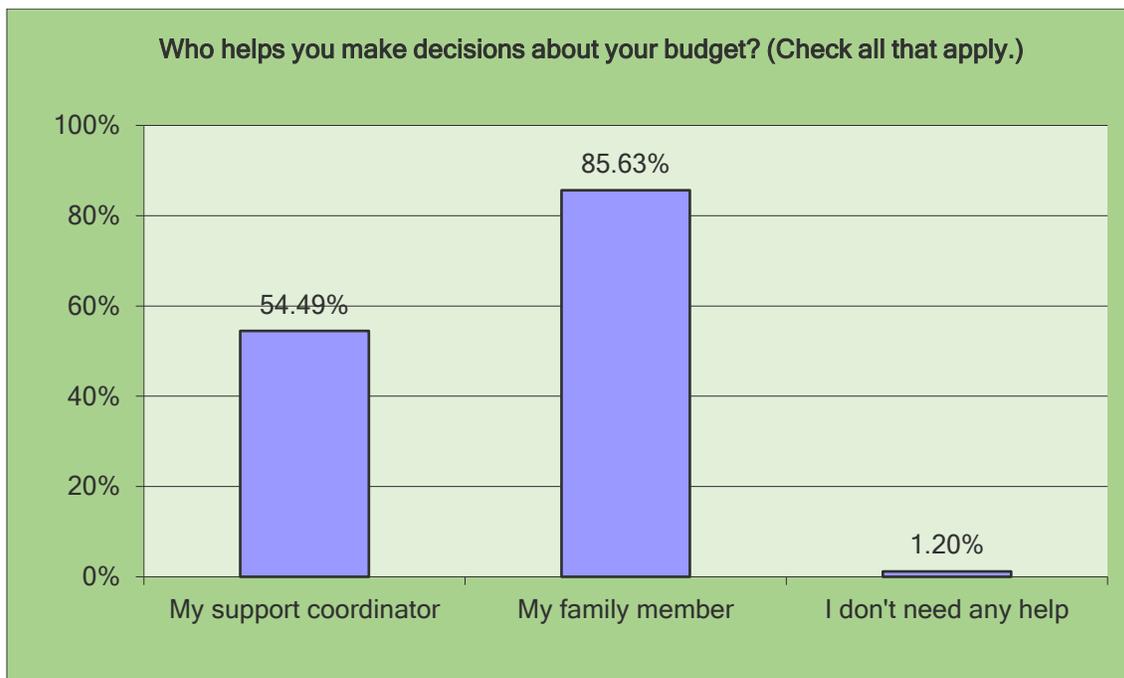
- my mother
- My younger colleen takes care of PPLs
- my mother
- my parents
- support from family
- my guardian
- Mentors and family advice
- Mom helps
- TGI program
- parent support
- my family
- My parents
- Parents
- My Mom works with the DDS service coordinator with me on budget/service issues.
- My mother is my responsible party. She handles budget & services for me.
- my guardian/mom
- Parents
- My mother who supports me



*Other responses (as quoted from survey respondents):*

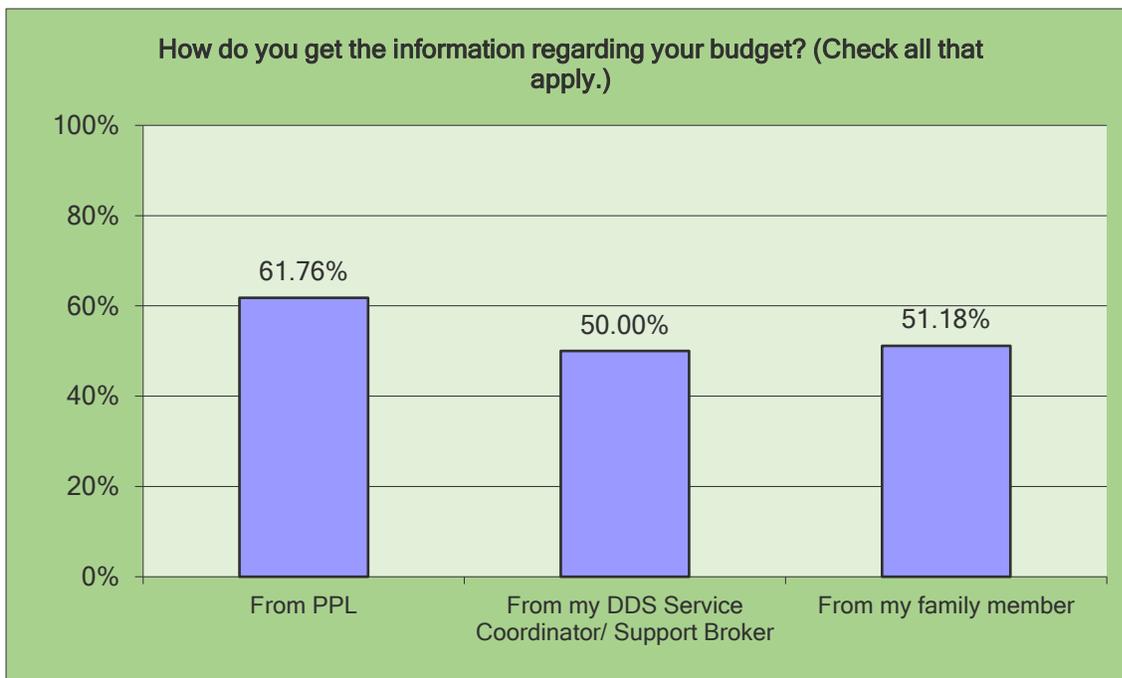
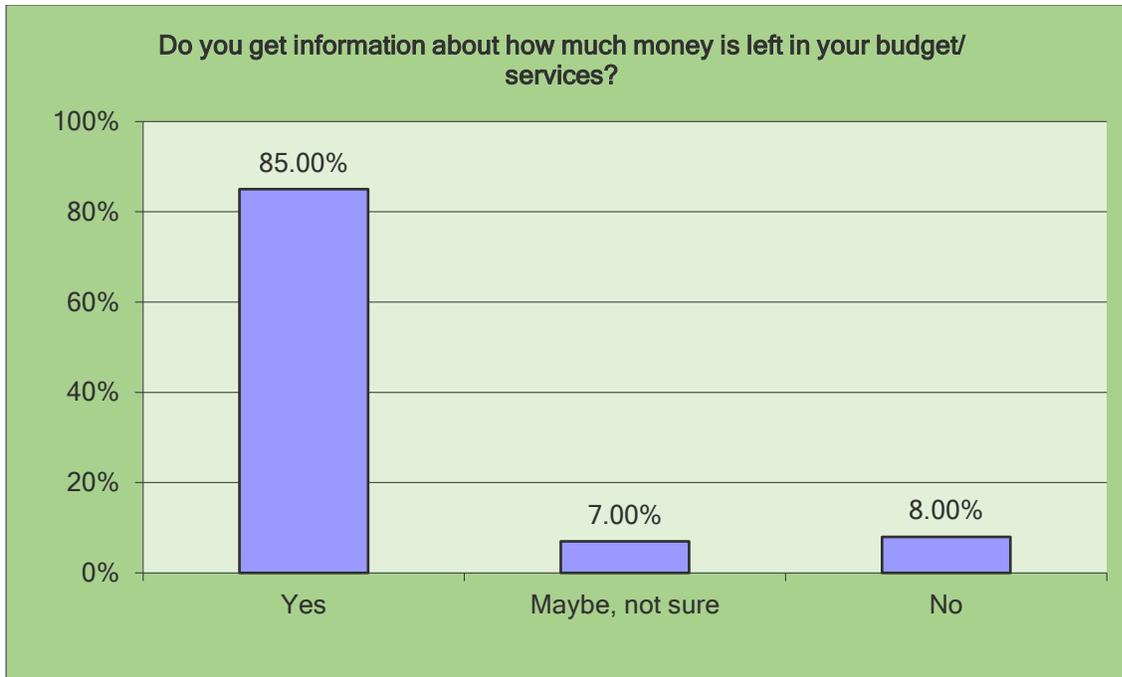
- It seems like things should change more to meet needs. Money used like transportation to pay because manager didn't support my son as she agreed.
- Parents help but have a hard time making changes during the fiscal year once money has been put in place.

- Not the right help. We need money for his activities and all they seem to want to pay for is care.
- I am not asked. My father takes care of it
- I would like to give them hours and also more money for gas to and from
- Again, the changes ultimately are dictated
- It seems that my broker's hands are tied.
- I know how I want to spend my budget but DDS is not straightforward in providing me with a budget that equals the budget I had through traditional services.
- My coordinator and his boss can be condescending at times, telling my my that buying a TV is luxury, when they don't live with me and know nothing about my needs.



*Other responses (as quoted from survey respondents):*

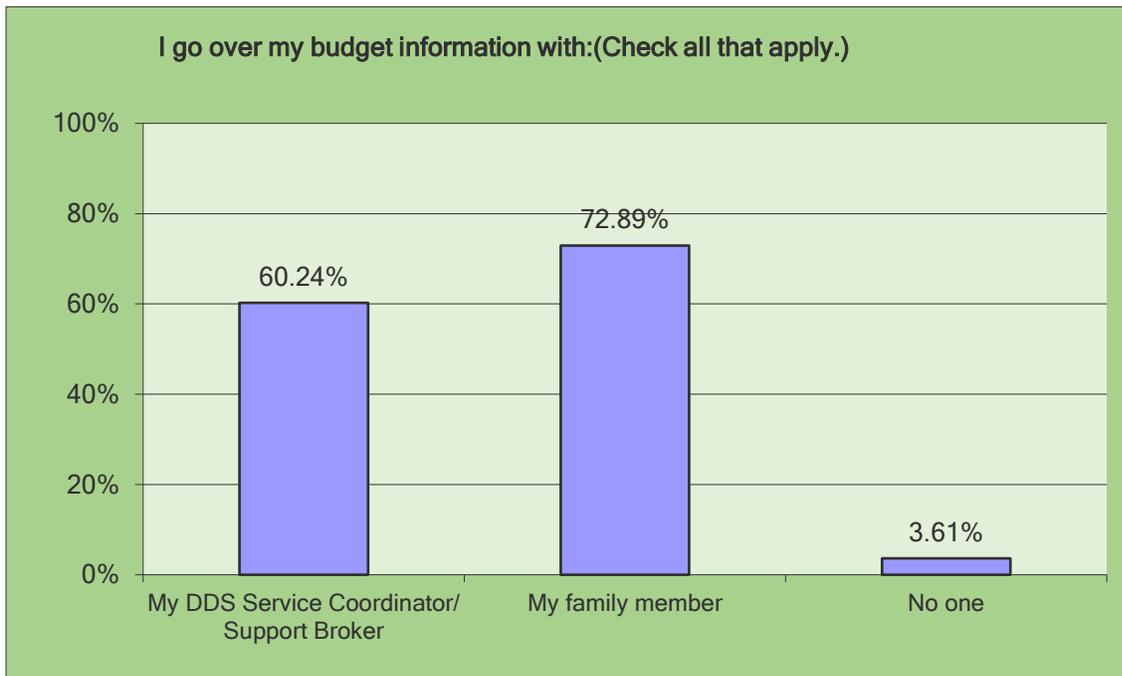
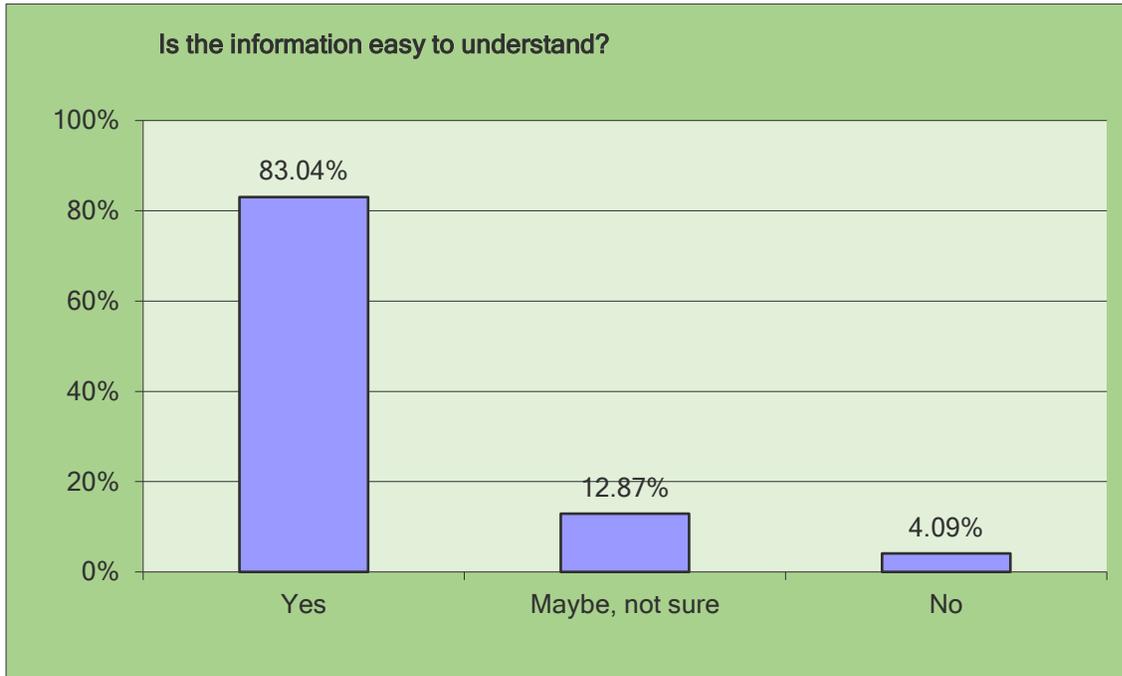
- I do it myself and that is if I save up my money to do the help or I go with a friend
- A friend and my rep payee
- DDS SC, guardian and parents
- my DDS Coordinator also suggests what is appropriate
- I also get help from a hired professional accountant
- my guardian
- The State has controlled line-item caps on budget that have restricted my activities.
- my shared living provider
- My partner



*Other responses (as quoted from survey respondents):*

- Access on-line
- I get two identical monthly reports from PPL each month
- web portal
- PPL Portal
- from my shared living provider

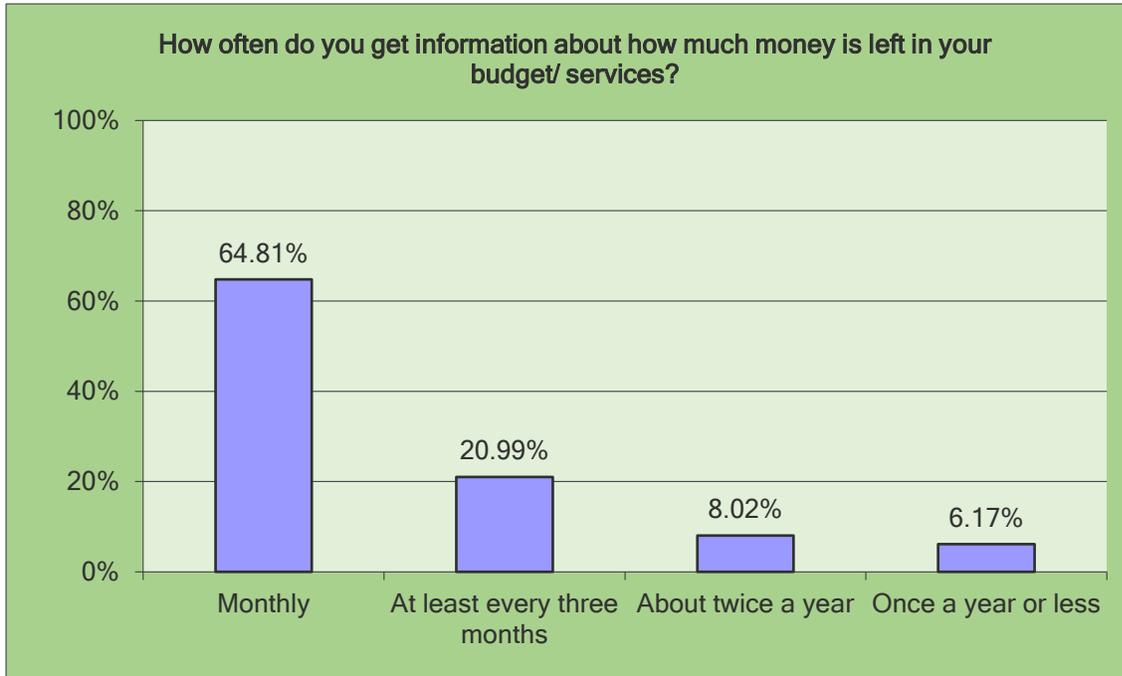
- we use the online tool to approve timesheets and check the budget.

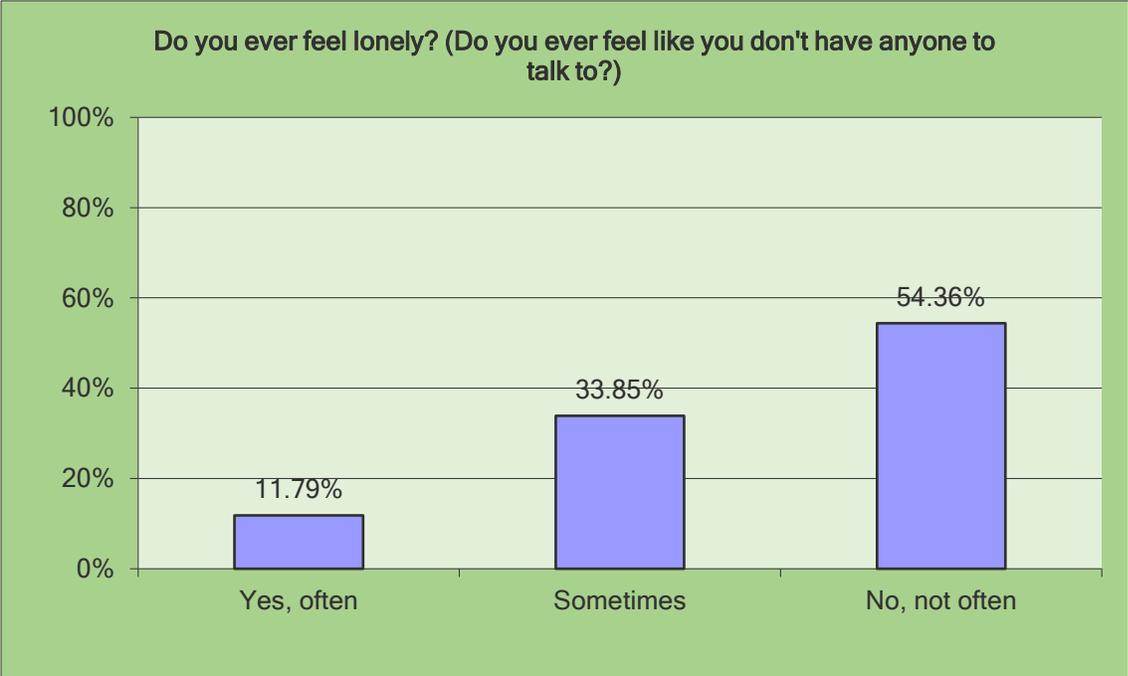
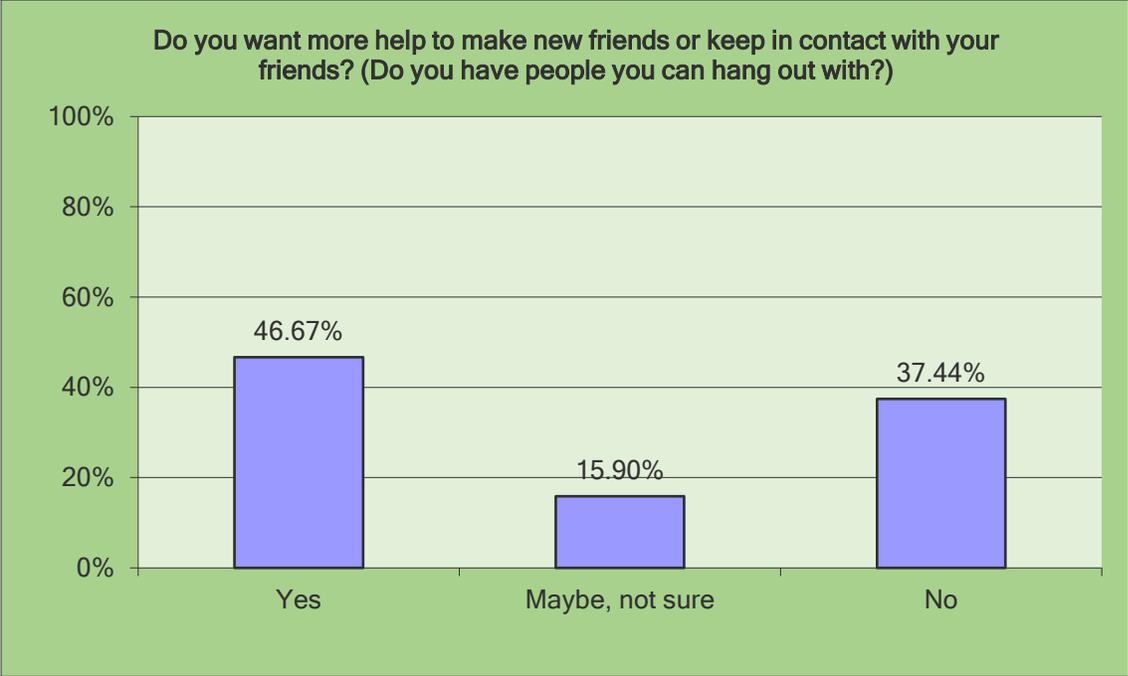


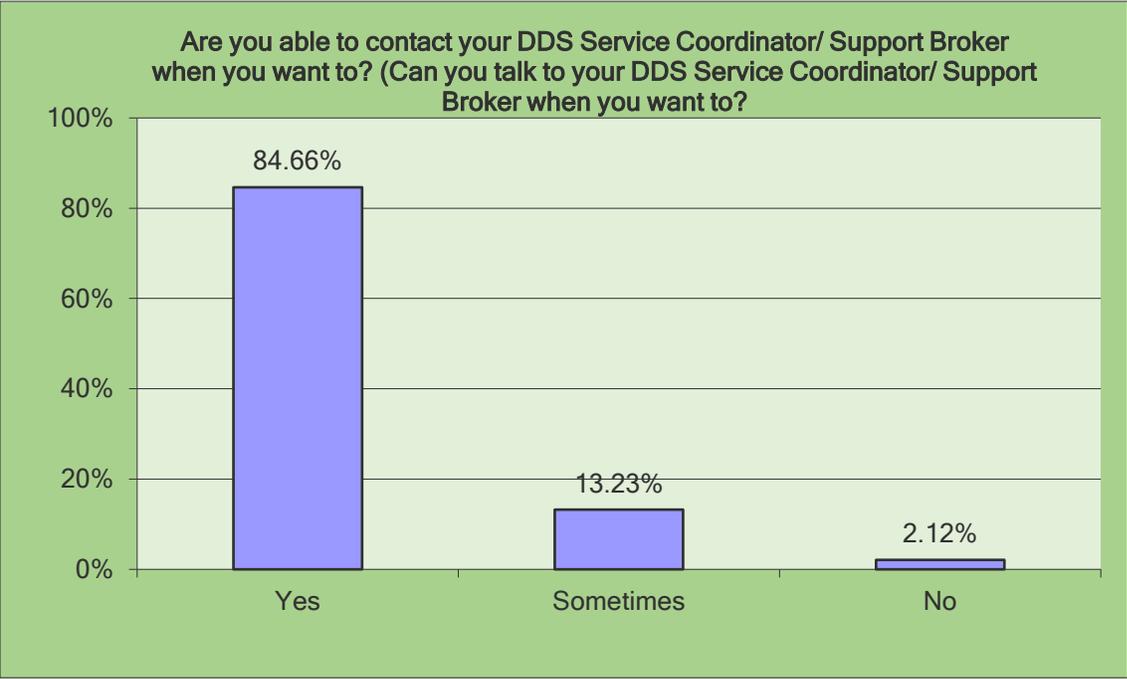
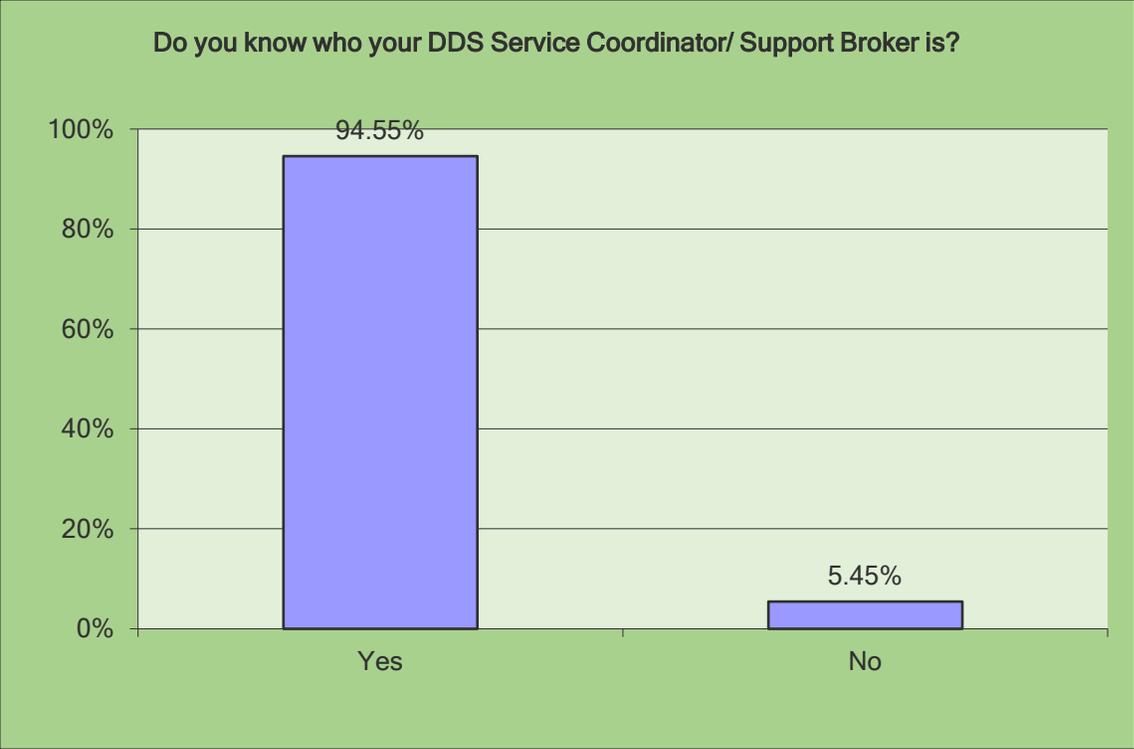
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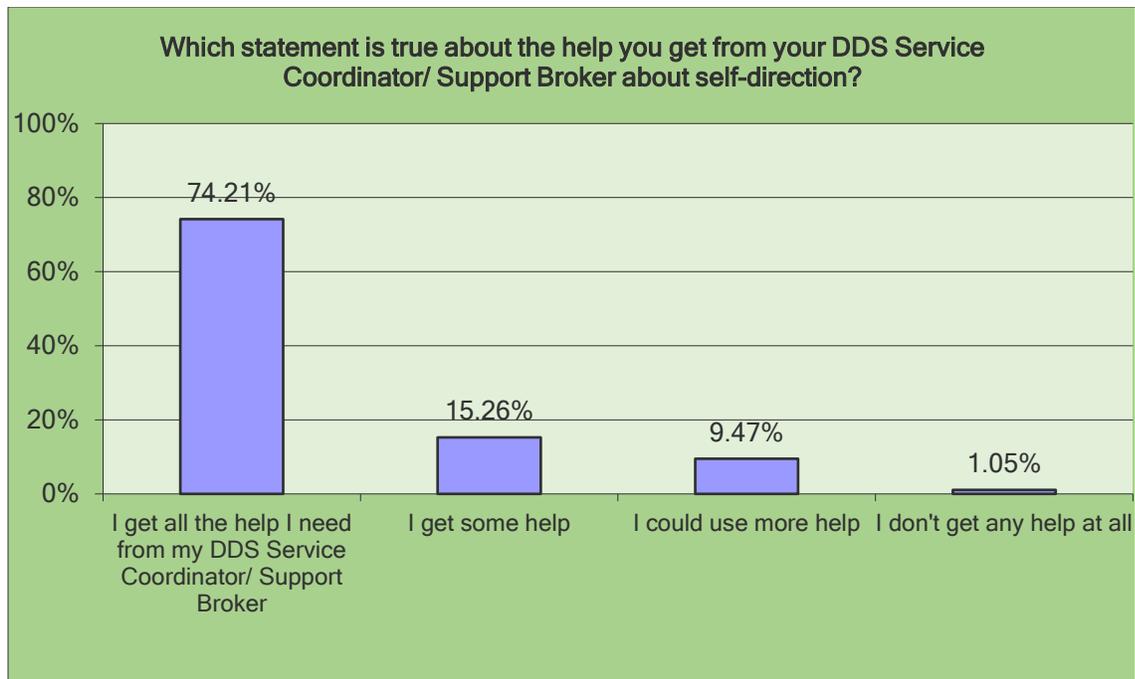
- I don't, my parent does
- Friends and Rep payee
- My family member works with DDS Service Coordinator on my behalf
- my parent takes care of it

- and my accountant
- my guardian
- my housemate
- (name) was having difficulty understanding budgeting but is working on money issues
- My Mom works on my behalf with my DDS service coordinator for the services I request & need.
- The budget process is incomprehensible, and isn't addressed equitably
- I just started, but I got the information about the size of my budget from my DDS service coordinator. My mom is contesting the budgeted amount through the Fair Hearing process. .





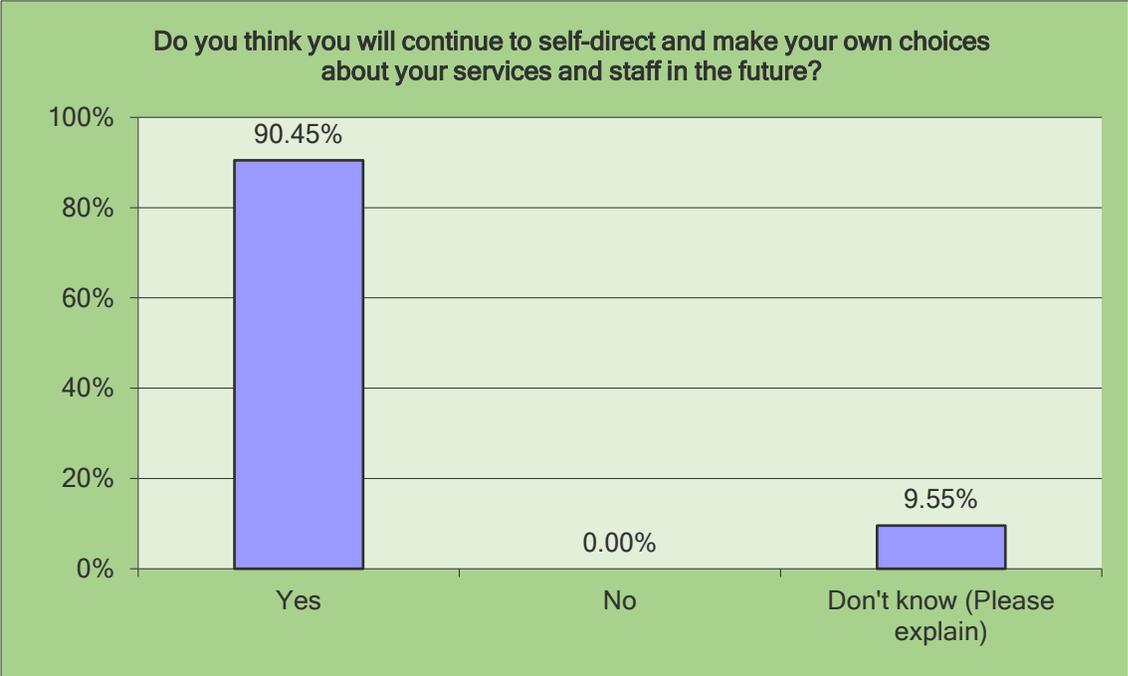
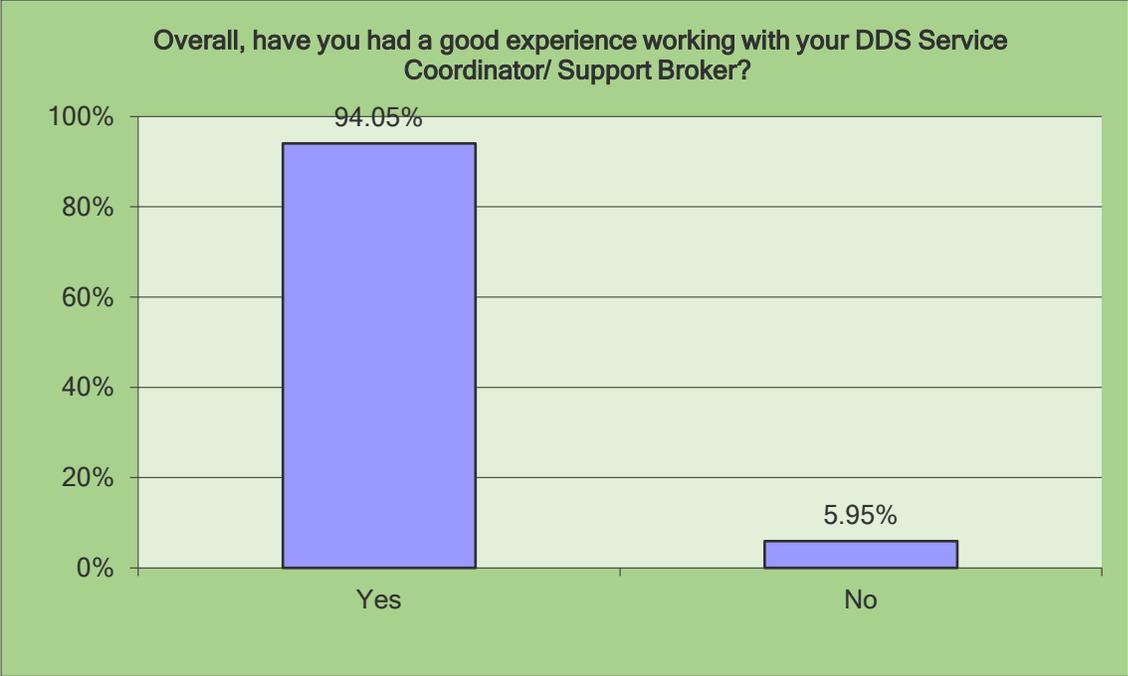


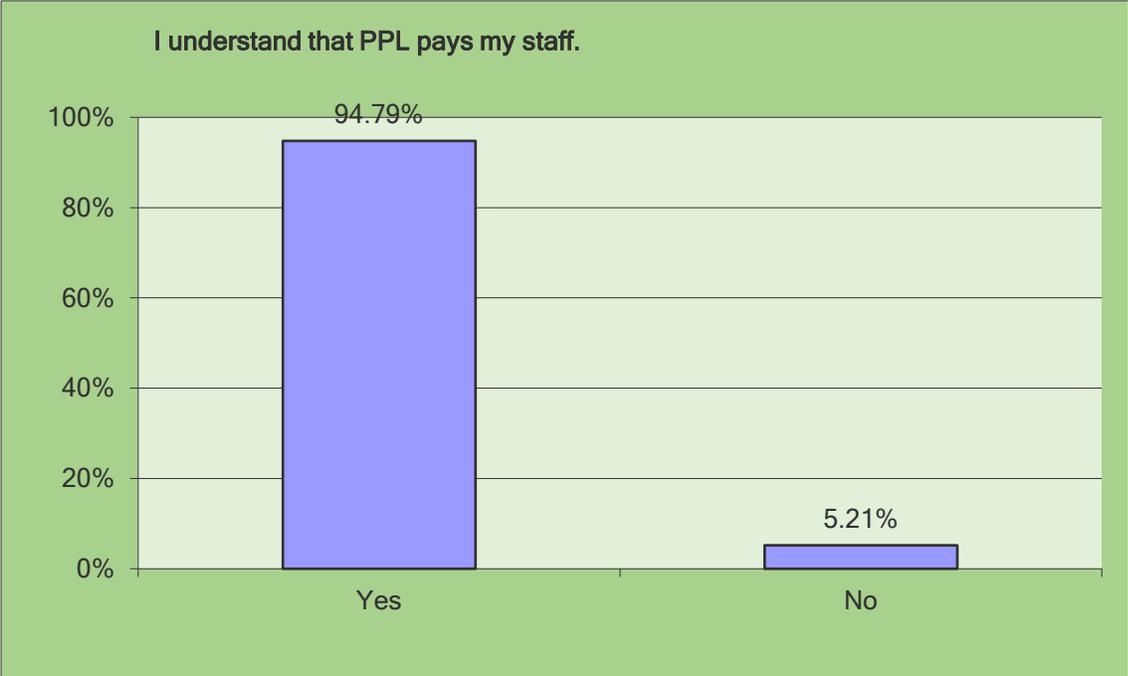
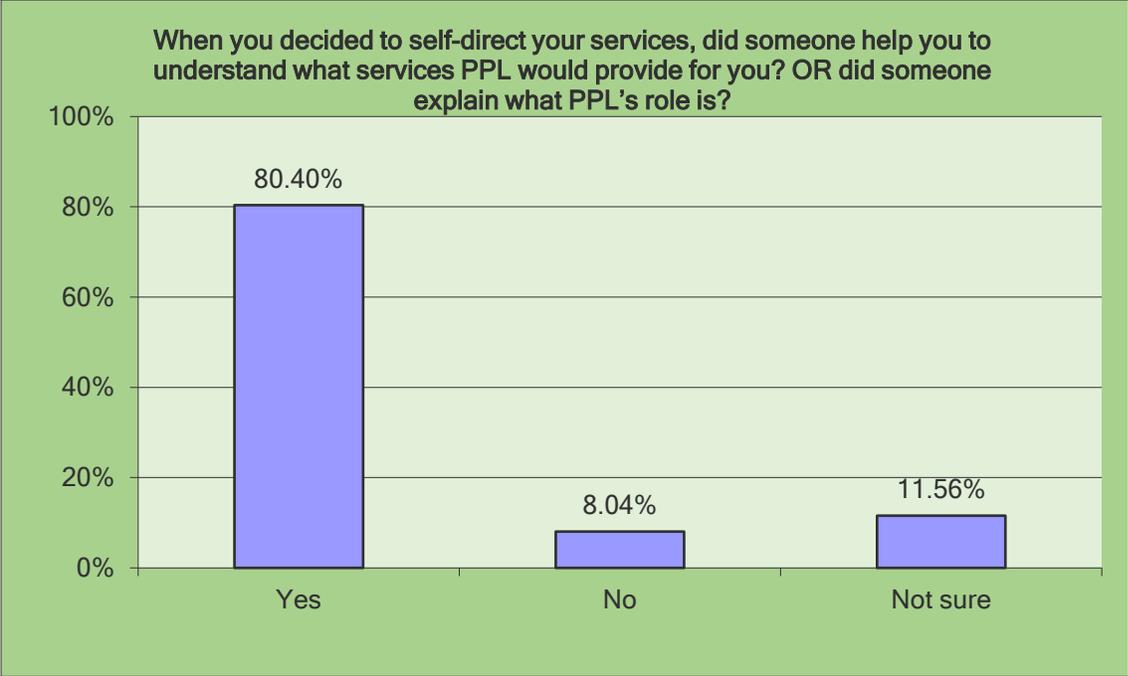


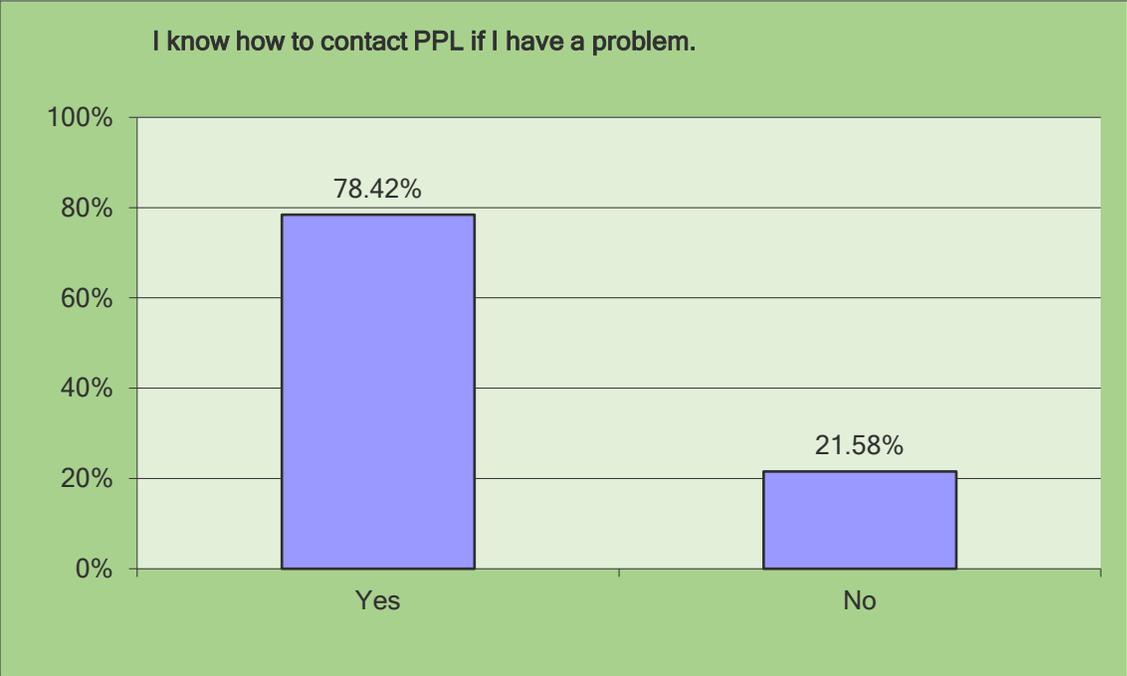
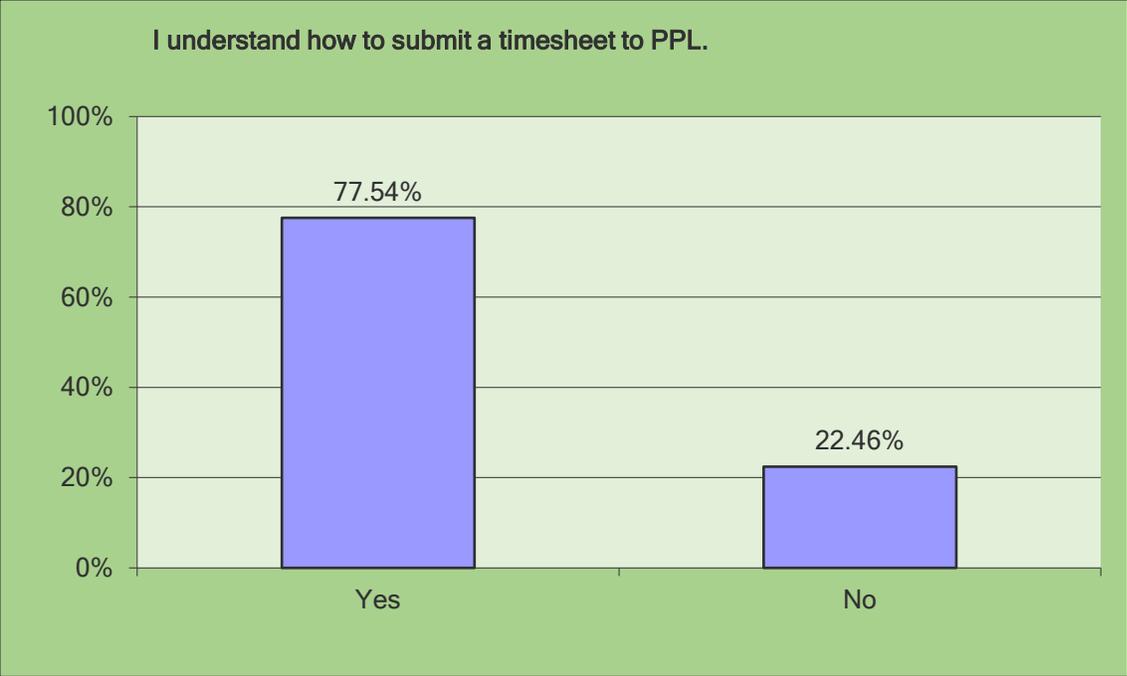
### **If you need more help, what kind of help do you need?**

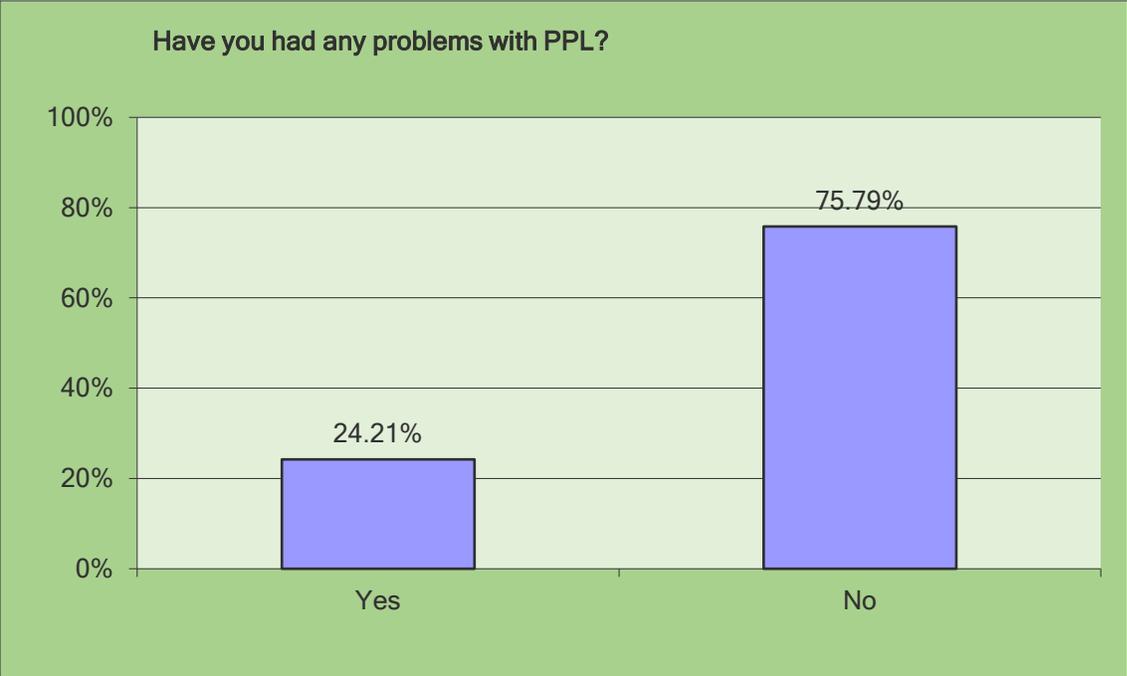
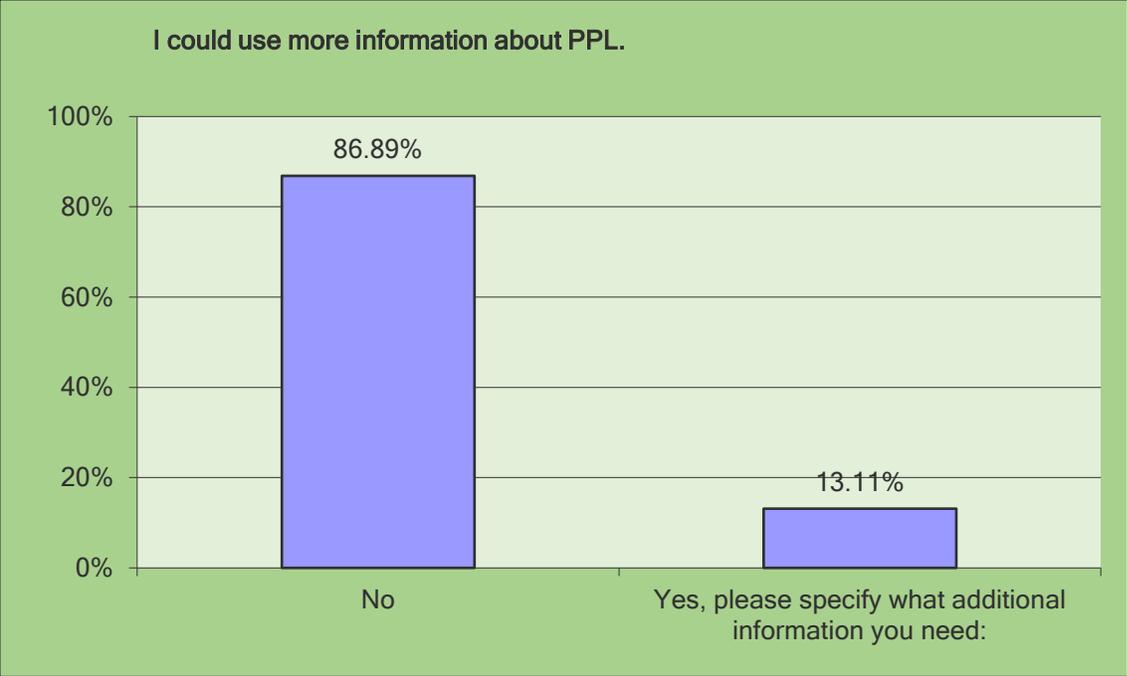
- getting more staff onto PPL faster
- (name) is wonderful and helpful. I could use any help finding staff -- not part of her job.
- She assists me and all access to PPL additional assistance and determining activities would be helpful
- Finding staff to hire and increasing my budget.
- Call back more
- Finding someone to work with me as a social assistant. He has lots of contacts with others who do this work. DDS support coordinator does not listen or ask what I want for our ISP goals. Says my mom is the problem. Talks about her in front of other people. There was a lot of pressure to direct care for whole program even though parents said they could not.
- I get the help I need from (name). But I need (name) to check in every month and to get back to me when I have questions.
- SC is relatively new and does not always have answers.
- I need w/c accessible transportation on the weekends.
- Finding more opportunities in the community that fit my needs.
- I would like statements and balances on my budget monthly
- technology assistance and activities on weekend
- more money please
- I need help in understanding boundaries in making relationships and deal with peer pressure.
- Someone to make a home visit every now and again. Someone to have more understanding of what my life is like.

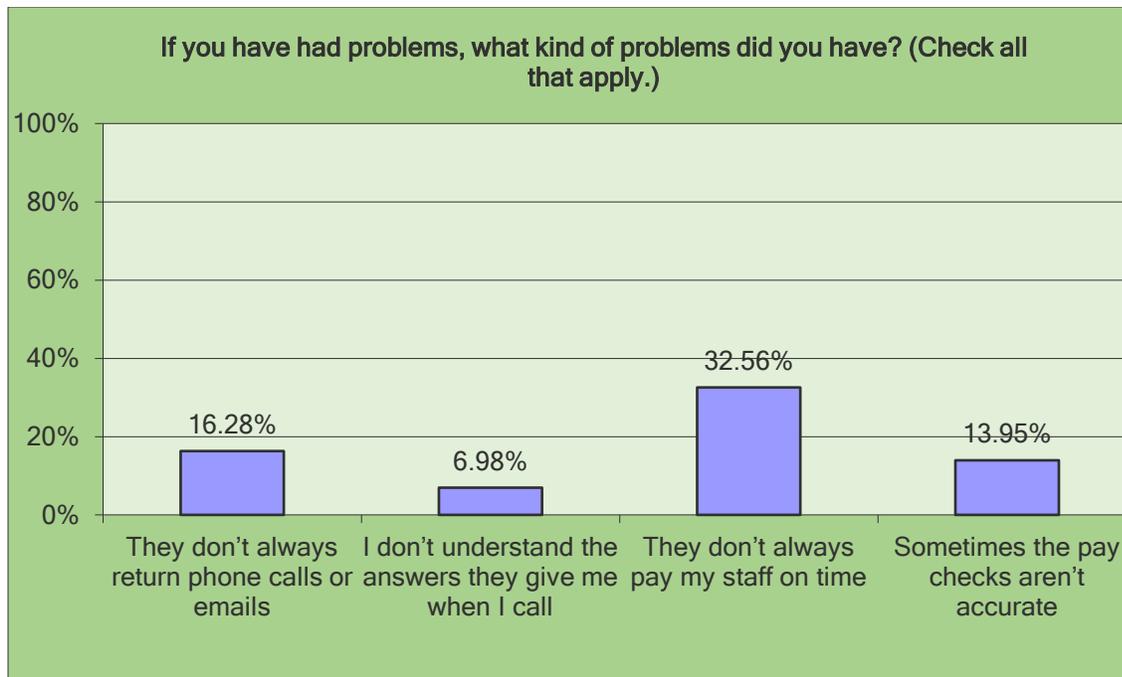
- My DDS Service Coordinator talks down to me and I do not like it.
- Own DDS Service Coordinator does her best but we need DDS policy changes to allow greater flexibility to hire the type of professionals needed centered on individual needs and competitive pay schedule to hire and retain the right individuals
- A voice to the state office on new budget line-items that have placed restrictions on activities and clothes
- finding a new place to live
- I want to increase self-direction budget to get a job and volunteer job
- social activities for a religious jewish person
- PCA, nurses
- Recommend DDS stop changing the system and communicate earlier if it needs to change
- Advocating for my needs to be met with my budget restrictions.
- I would like to know every service available to me and how to apply for services I am not currently getting but am eligible for.
- My budget is never enough for the year
- Find a home caregiver
- more resources on places to live and what my options are to be more independent. I want to move out of my families home. where I can get funding etc.
- There could be better parent training and communication doing self-direction.
- "(1) expediting the PPL admin & hiring process.
- (2) getting automated PPL payment to THE RIDE in a timely fashion
- (3) getting timely reimbursement for invoices from PPL. "
- Finding the right people to work with me.
- Doing community actions help getting I/O SSID card, learning the computer
- Peer support at college or a friend
- A better understanding of changes to the budget and the logic.
- Crisis support. Self direction doesn't include these services -- only staff.
- Figuring vacation. Plan vacation.
- It can be difficult to reach her. I've already spoken to the area director about that.
- Weekend and evening transportation to [illegible]
- Clarity. My DDS coordinator always needs to ask someone in upper management.
- budget, changes, more concrete examples of what to do together - specific ideas
- I someone is sensitive and understanding what my disability is and my capability is instead telling my family that I can have or able to use something ..
- Ask a family member









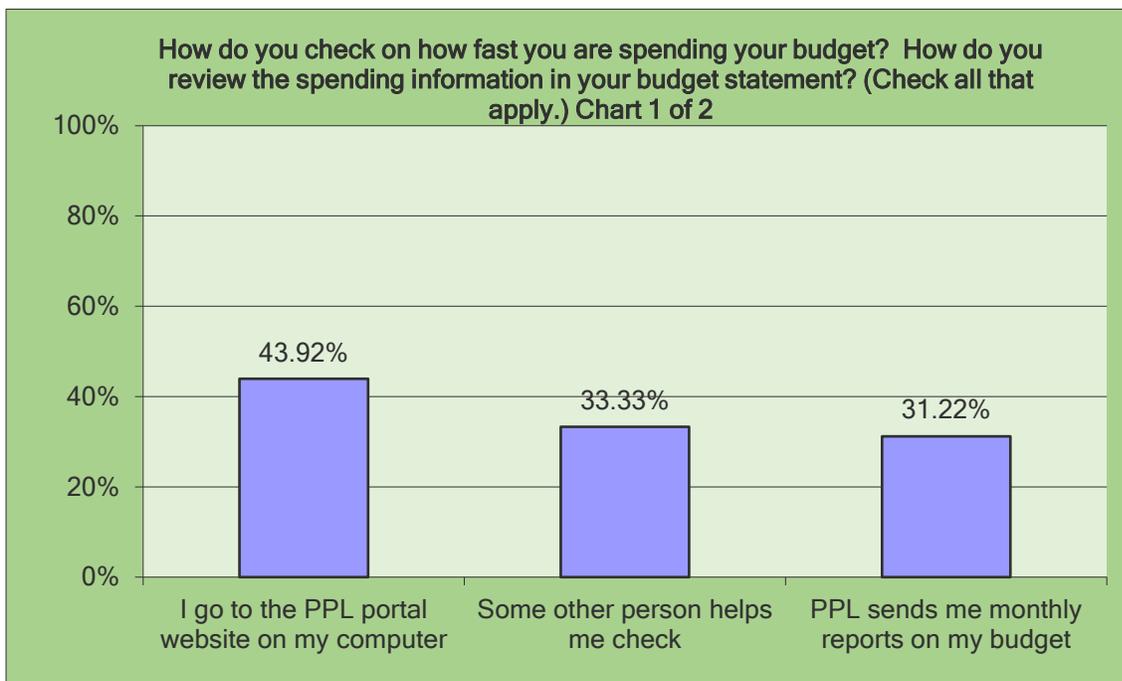


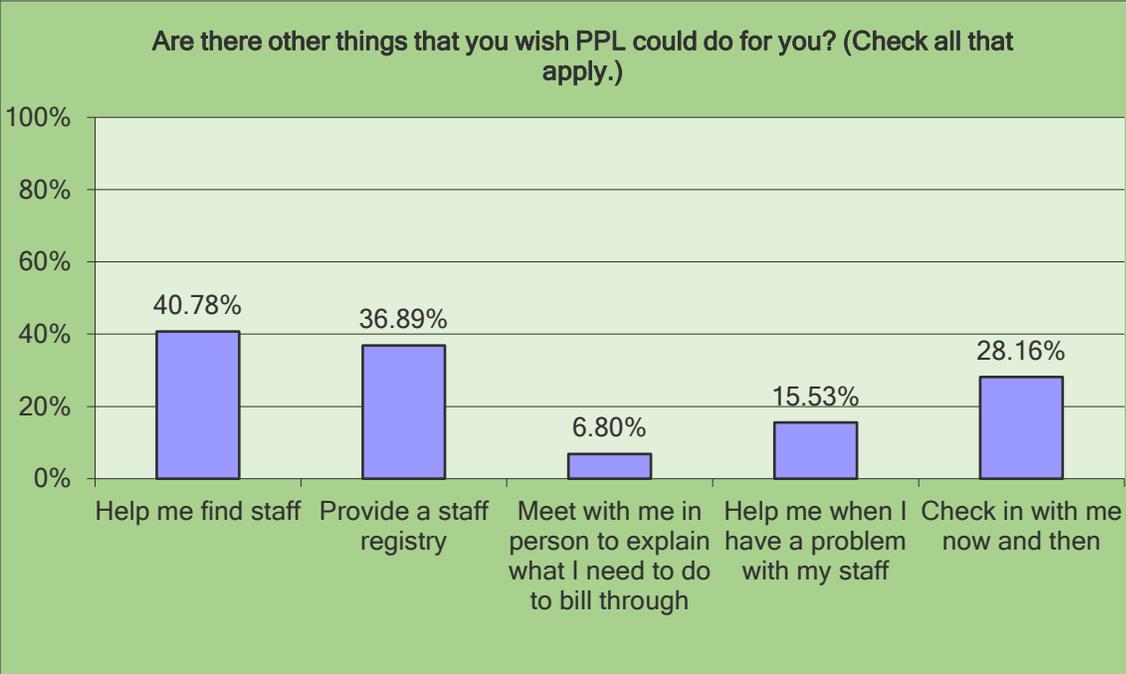
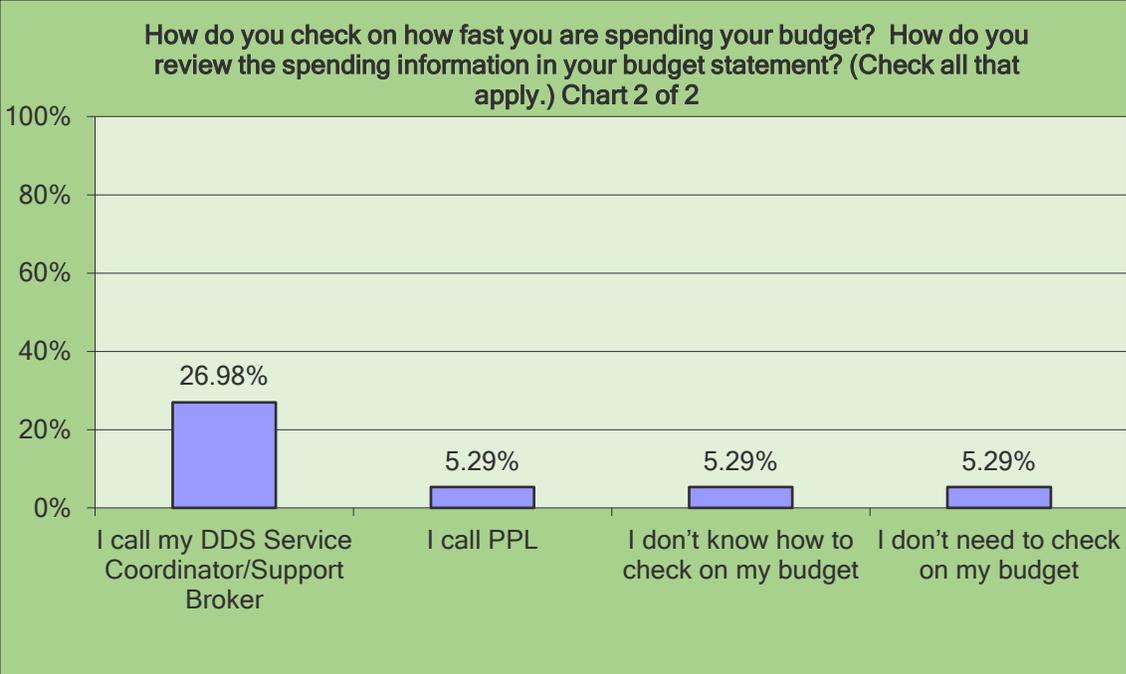
*Other responses (as quoted from survey respondents):*

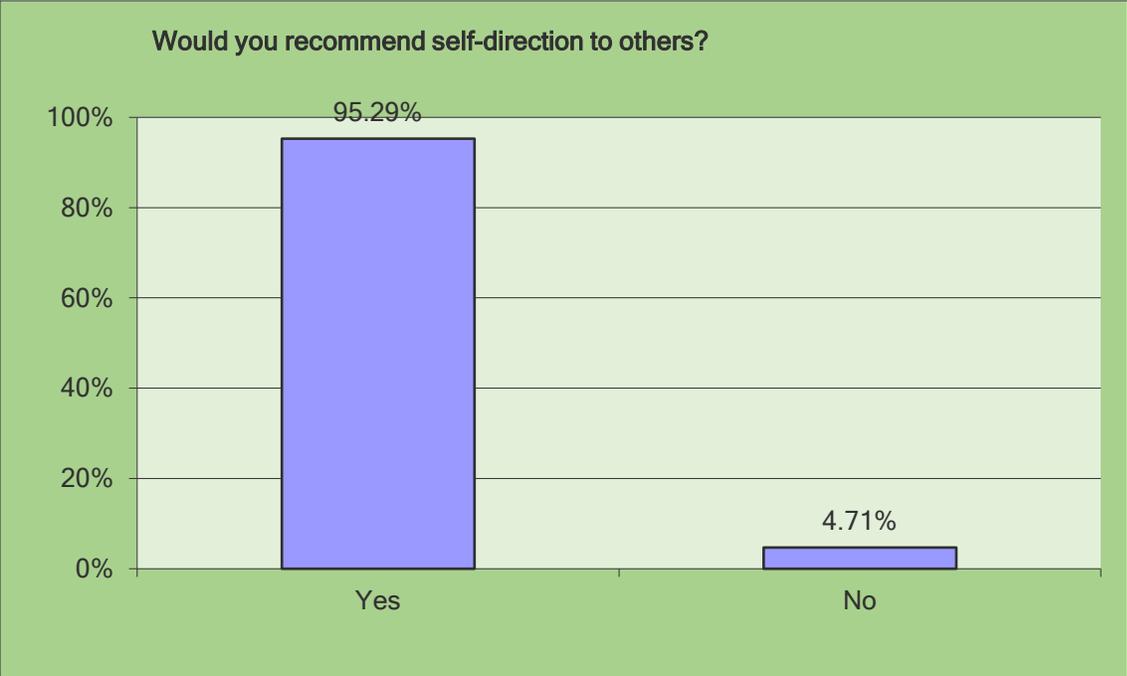
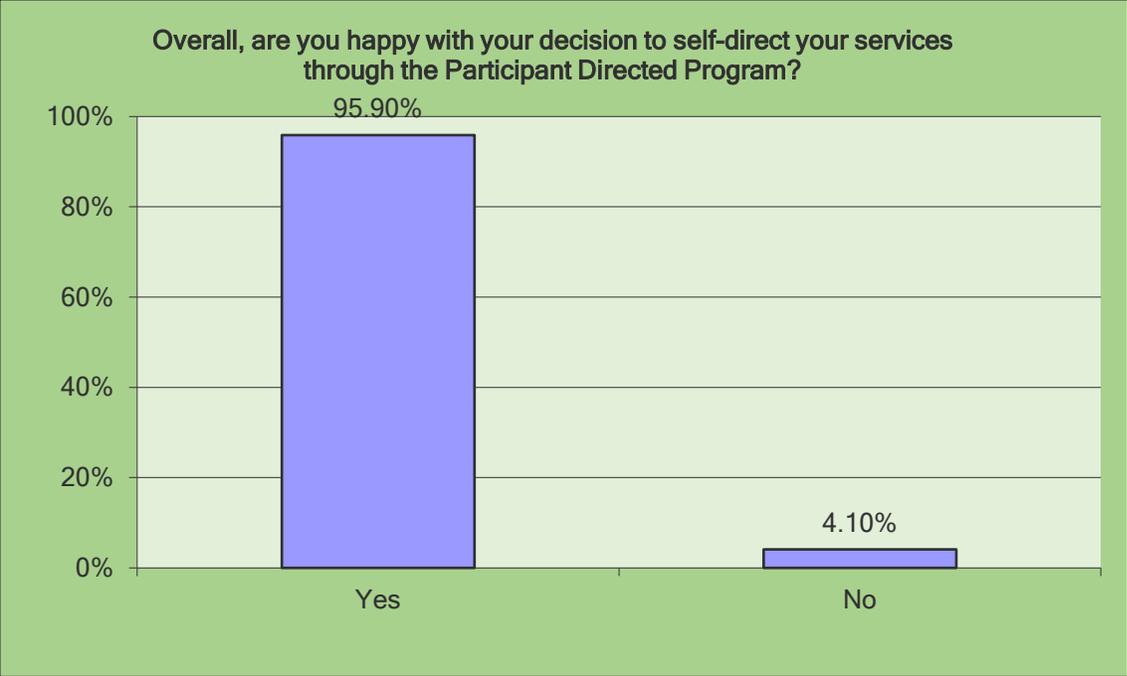
- Getting people on PPL is too long
- Road block at DDS
- My staff is not paid by PPL at present
- Very hard to get the initial employment paperwork completed. They don't specify what is outstanding/still needed.
- Sometimes inconsistency in the answers from PPL helpers
- Onboarding of new staff sometimes goes well, sometimes not.
- Some problems with staff policy
- Service is variable, sometimes good, sometimes not good. They don't always understand how it works.
- problems getting staff with the system
- When there is an issue with a timesheet or forms they wait weeks to inform us and you get tossed around because no one knows what's happening.
- Response time is not always fast enough. It was unclear why they recently failed to pay a bill
- verification got delayed weeks
- Got off to a rough start but things are good now
- never receive the faxed time sheets and even when DDS faxes them they still don't receive
- staff is rude and not
- too slow at staff hiring paperwork
- They did not let me know paperwork for a new employee
- (1) PPL takes too long to check & complete the hiring process. Sometimes they lose forms and we need to re fax. My family even checks candidate references in order to speed up the process.

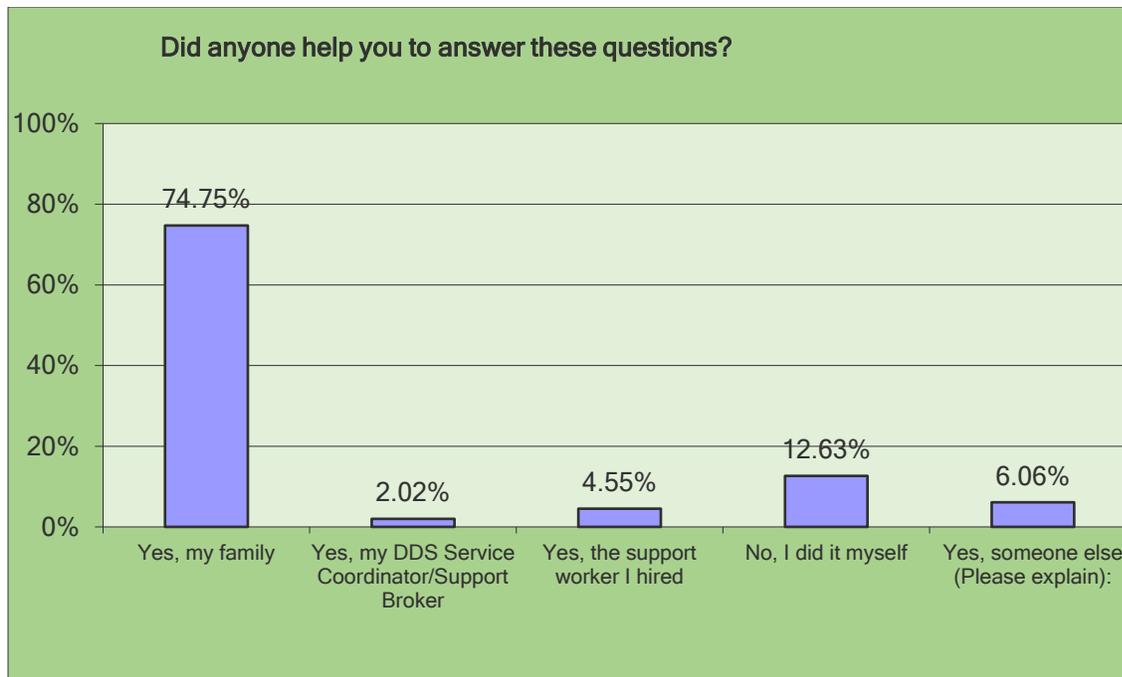
(2) PPL has not paid approved, allocated funds to my RIDE account in the last three months forcing my family to pay up front so that I can travel to my day program. (3) PPL reimbursement of invoices often take months.

- Incorrect error messages during the timesheet submission process
- Their site is non-functional often
- When enrolling a new employee they don't communicate with me. They tell DDS/SC who are slow to pass on info so delays occur.
- Complicated Menu Options
- late reimbursements, confusion with dates
- It is improved but still having issues with an employee's tax problems from 2013!
- still waiting for refund
- Starting out was difficult getting used to the paperwork and getting it processed. Listening to timesheet updates when I need to talk to someone is unproductive.









### Is there anything else you would like to tell us?

- Our DDS service coordinator is outstanding. He knows me personally and cares about me.
- My family help me a lot
- (2 names) have been very helpful they are a good team to work with.
- "PPL rules can be difficult to understand and navigate if you wish to hire someone already enrolled they must complete an entire new packet - this is cumbersome and off putting to staff - it also delays the start of support.
- Several changes to the program are causing challenges: (1) not allowing overnight - unreasonable especially when individual is level 1 and no residential options are available (2) not being able to hire agencies has delayed (even longer) the start of much needed services."
- (name) does an awesome job support [sic] me and my staff.
- DDS does not help me at all to manage my self-direction. No response to my questions or calls for weeks. Way too long.
- From a parent's view, this is a great program it has helped with growth and independence and getting involved in the community, Thank you!!!
- I would like to use AANE life map coaches but told they are not allowed in my DDS office.
- Parent completed form. Our daughter doesn't have the capability to do so. We are completely satisfied with Self-Directed Services. It has given our daughter the ability to have 1:1 time with her staff person, participating in activities that are fulfilling and motivating to her. It is crucial that we have found a perfect match in the staff person to make this successful.
- I pay my staff for mileage but PPL does not reimburse for mileage. It stopped a few years ago so I pay out of pocket.
- I would like to continue doing things in my own way in my own time.

- We went all last year without anyone to take him out on weekends. One staff can only do Tues/Thurs. Staffing is very hard. DDS has contact with the people in the field that would want a position like the Social Assistant. They also have all the info on those in their care who want to make friends and what they have interests in. There should be a network to use to benefit our "kids"/young adults like when DDS holds a seminar and reach out to all agencies. Don't like sitting around at day program. Some people sleep or do nothing. Managers know their population and would help other managers to find friends and girlfriends/boyfriends for those in their care. We were at a seminar and they were asked what they wanted -- they said they wanted to meet others and date and have romances. Managers made jokes about doing speed dating but nothing was done. My son has taken many self-advocacy courses and a course to teach self advocacy to others. We find it hard to get others to listen and help to get what is needed/wanted. They don't have answers to help. It seems there are many problems that are recognized but little is done to resolve - making new friends and social skills and communication, finding romances, dating, jobs, transportation, jobs, and going out. Volunteering was recommended but how to get there? Job required to pay minimum wage but hard to find job and transportation. Hard to get support at job. Minimum wage doesn't help.
- It was hard to get launched almost 2 years ago (very confusing), but since (name) was made our service coordinator, it's all great. Thank you! Self directing has been wonderful for our daughter who has been able to pursue a passion for abstract painting through self direction. Without self-direction I think it would have been very difficult as this is not an activity that is heavily supported in community based day programming. Ps our daughter does 2 days/wk of self direction and 3 days/wk of community based day-programming. This blend has been perfect for her. Thank you!
- My son is significantly involved with autism. He participated in filling this out with me as much as possible. We are very pleased with self-direction and I do encourage other families.
- The enrollment process took us weeks. We lost potential staff during the waiting phase because they needed to work! An advisory committee for Parents serving as caregivers of Adults with Special Needs should provide input into the processes. These Parents love their adult children and want to care for them. The state's inability to help them does a disservice to the adults w/ special needs and the parents alike.
- program has not grown in the last few years -- families need more support
- (name) continues to only have 1 staff -- his father
- Please keep it simple, not too hard to hire people.
- We like the program and the freedom it gives us to get things that are needed.
- Self-direction was the best option for me, however there needs to be more activities created in the community for people who are self-directing to volunteer or work.
- I like the program but it is changing so I can't say much more at this time. It's in flux so no one seems to fully understand what goods and services are covered and what are not. Please set rules and be consistent.
- PPL is terrible

- It would be nice for ages 22-28 to hang out together, share staff, interests, activities, jobs. How to do this when each person has her own staff....?
- "Note from family:  
Very pleased with this program except for the staff issues. When staff leave the family has to become his job load"
- Self-directing has been the most positive experience in my life. I am able to hire multiple staff who I am familiar with and who are reliable.
- PPL is a very valuable tool/resource to manage the budget and pay staff. They are a professional agency that handles all the funds properly and pay all taxes as stipulated by the law. It is in the best interest for the participant/family. Thank you!
- Thank you for funding PPL for me and offering it. It helps to have funding to do more things I wouldn't normally get to do.
- My child is unable to make decisions. I have had no problems with PPL.
- Thank you for letting me participate in the self-directed program
- Just to thank my workers
- I have celiac disease, epilepsy, autism. I need help accepting my diagnosis of epilepsy
- We've been in this program for about 12 years and it has truly changed. The biggest problem is getting straight answers out of DDS. There is more to an individual's life than just support. As far as the sustainability of this program, without an increase in funds, it will not work for a lifetime. When you pay for just care it becomes like a group home. There is more to life than care. There is the social and emotional life that is just so important. "Recreation" is the way to get this. Without the funding for that he might as well be in a group home.
- DDS Service Supervisor and Coordinator are a blessing!
- Need more money to support my gym program so I can lose weight and stay healthy.
- 1. Each year we should get an increase of budget money because things cost more each year.  
2. Do not change much
- These surveys could have question geared towards parents or guardians. The client is not always in a position to answer these questions and may not understand even if explained.
- We are happy with PPL. Our current coordinator is awesome. Not all coordinators are helpful with PPL.
- I live with only my widowed 72 year old mom. It is getting more difficult to do all my direct care, outside activities, transportation, paperwork, medical needs, personal needs.
- Self-direction should be focused on giving families/individuals flexibility and choices to hire the type/category of help. My experience is the ability to hire nonprofessionals only but it would be more valuable get professionals such as life coaches, mentors, job coaches for my son at this time we have been waiting for a male life coach over a year.
- Is there a chance that I will be able to do something I can try to explore my options better.
- Budget money line items have been restricted and capped causing problems with my regular community activities and purchasing clothing and health needs.
- This was a difficult questionnaire because we assumed the role of participant but that person is unable to manage money or make decisions.

- Having this program has made our lives so much better. My adult daughter is able to stay home and live where she is comfortable and happy.
- I just feel this program allows me the quality of a good program. My needs are individually met and I'm not forced to be grouped which limits my experiences and opportunity to learn more. Thank you for this opportunity.
- We appreciate the self-directed option but feel it is mismanaged and there is a lack of professional communication between DDS and PPL and our family.
- Using funds in a way that I want to is very hard now I can't go to "fun" things like fairs, concerts, etc. anymore everything has to be educational or a "learning experience"
- No timely offered written notices of changes to budgets from State Office. No local training or information meetings on changes. State Office doesn't bring caregivers and individuals to gather to educate on changes of their controlled self-direction program.
- It would be helpful to have a step-by-step manual when starting self-direction. We learned everything by going online and trying to navigate the process. It was very hit-or-miss.
- "Support providers need to be able to make decisions. They are really just messengers.
- Family member input:  
This model needs to be departed from traditional models. Too many traditional limitations are being imposed on one model that moves it away from trace self-direction. Support brokers should be moved out of DDS and people can then lure them with their allocation."
- I am pleased with the program
- Everything is very expensive I love to try to learn more things but requires more funds etc.
- Thanks for helping me work towards my goals!
- DDS is horrible. Since I have taken advantage of the program. The good thing is my son went out of the house 2x week with his support.
- My self direction is a full time (unpaid) job for my family member. They do it (sacrifice time and money) because they see a big difference in me.
- In summary, I like the self directed program since I can tailor funds/services to meet my needs, and will continue to use it. I have a good rapport with my service coordinator and she provides me with a lot of support.
- I do like the online PPL site for timesheet approval and for checking my budget.
- However, PPL services need to improve.
- As previously stated,
  - (1) the hiring process takes an inordinate amount of time. It needs to be more efficient and expeditious to become more effective.
  - (2) PPL's invoice reimbursements process is very slow.
  - (3) PPL must make timely payments for approved, essential automated services like the RIDE.
- "
  - Because I have a schedule that I control, I am able to do the things I have been promised when they are supposed to be done. Because of this, my maladaptive behaviors are kept in check. This means I am happier, I can participate in my community, and my care costs less.

- PDP has given me flexibility that my family and I are grateful for.
- No, I feel I am receiving the necessary information to make sure my needs are met.
- my family supplements the PDP program, I do not have a paying job, I need more money in my budget or access to paying jobs or both
- My mother runs my self-directed program and we talk about all of it to make choices.
- My son is non-verbal spastic - filled out by father (guardian)
- Please don't send this to me again. It's a waste of my time.
- This is a fantastic option. I love self-direction!
- Portal is so confusing
- The case load of DDS needs to be reduced so they can give their full attention to each individual.
- "Self direction was a way we went because the safety of our person was compromised in a group home. Additionally we saw issues with general health and wellness on an ongoing basis. There are three needs for those who are individuals and are disabled are not independent.
- 1) Quality Care: This is a real challenge because it is not well paid or alluring to qualified individuals. Group homes can be dangerous, run down, and mixed with individuals who are far from compatible.
- 2) Recreation: Without activity and socialization we are isolating these individuals from society. Additional we are compromising health and well-being.
- 3) Health Direction: Exercise (by way of recreation\_ and healthy food are paramount. Individuals have enough health issues to begin with. Food stamps give ""filler"" foods, toxins that only escalate health issues. Food as medicine should be considered!"
- Yes, do recommend self-direction but its a lot of work!
- There are too many restriction on I can use my budget.
- "I am the mother/guardian of the participant. I am filling this out for my son because he is unable to do this.
- My son is on anti-seizure meds. One of his meds causes an increase in his appetite. My food bills are through the roof. At one point we received \$1,200/month for food. We now receive \$0. This is a huge problem.
- I am an assistance teacher in my city. This is my only salary. My husband passed away 6 yrs. ago. I am keeping my son home with me. I \*do\* need some more budget for food."
- As you've heard through previous questionnaires you've sent. The process within DDS to become a PDP participant is fraught with incomplete and shifting information, an inscrutable budget process, and a too limited notion of what PDP can be. Hiring staff and buying goods shouldn't be the only way someone can use a self-directed budget.
- Self directed employment is one of the best things that's ever happened to my son. It's given him purpose, confidence and happiness.
- I wish there was a list of activities and concrete examples of what to do with the support person. Set better goals and how to follow and build on the goals. More check ins regarding this with the coordinator. Meet with others in the same program and share ideas.
- I'm very grateful for this program. It has made a huge difference in my life. Thank you.

- The self directing wa a good idea in the first place, but wit all of the problem now t get permission buys TV what them think having a TV in your room is luxury?is it because of my problems?they need to be respectful .another problem I known my Dds coordinator for 3\_4 year but never addressed my mother by name,but hi there she had complained but no one listening..
- PDP takes a lot of time to manage but it is the right program for me.
- 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 pass

# MA Real Lives Evaluation

For internal review. DDS Quality Assurance Evaluation  
Real Lives Agency with Choice  
Survey Results  
**November 2019**

Prepared for:

Massachusetts Department of Developmental Services

Prepared by:

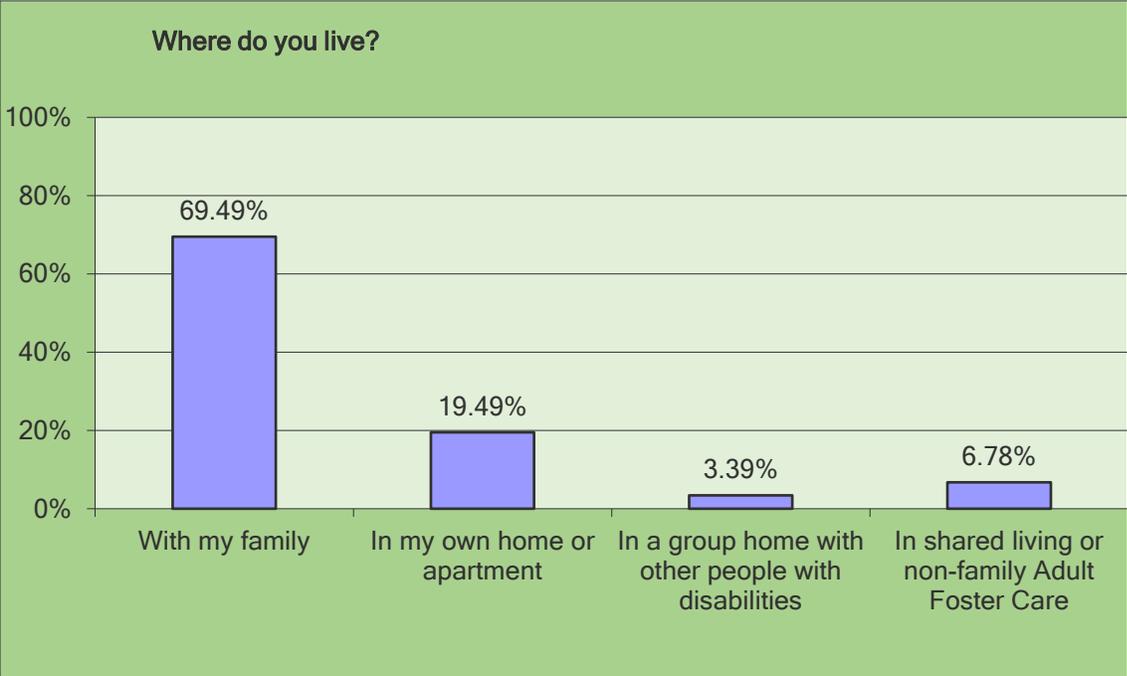
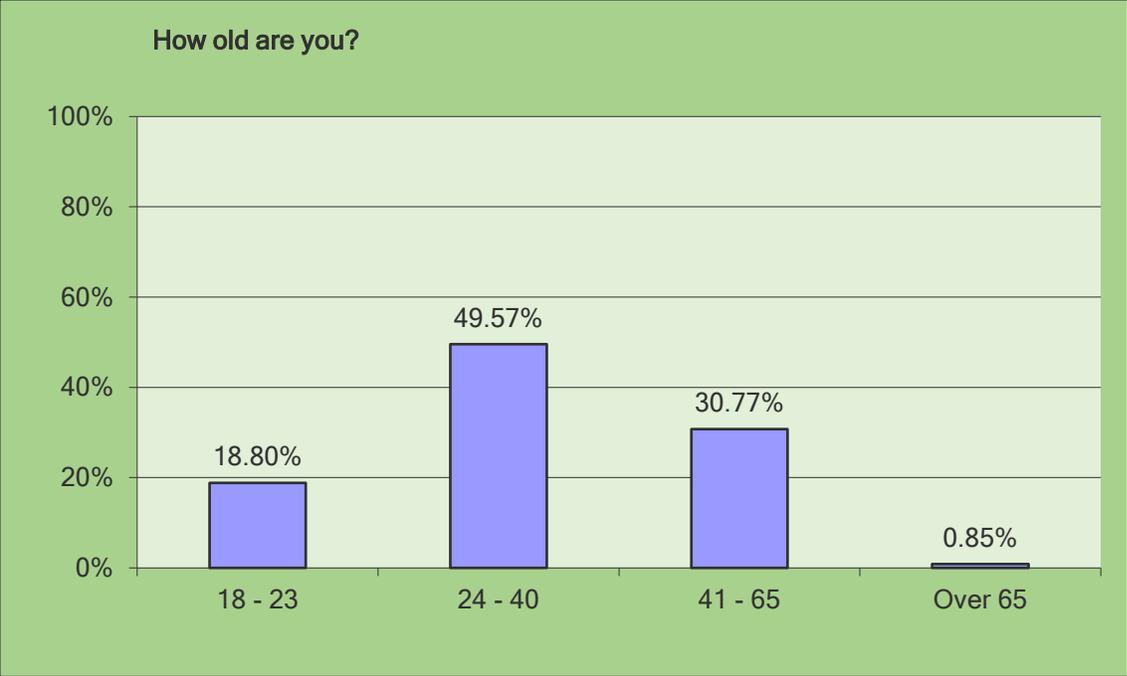
HUMAN SERVICES RESEARCH INSTITUTE  
November 27, 2019

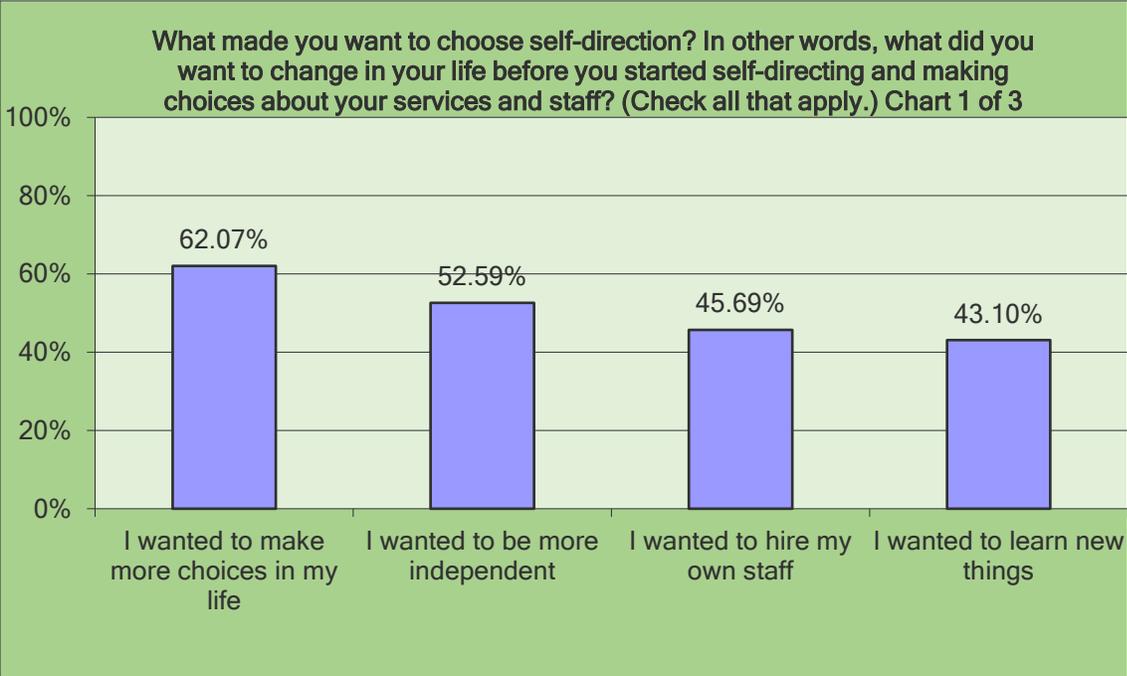
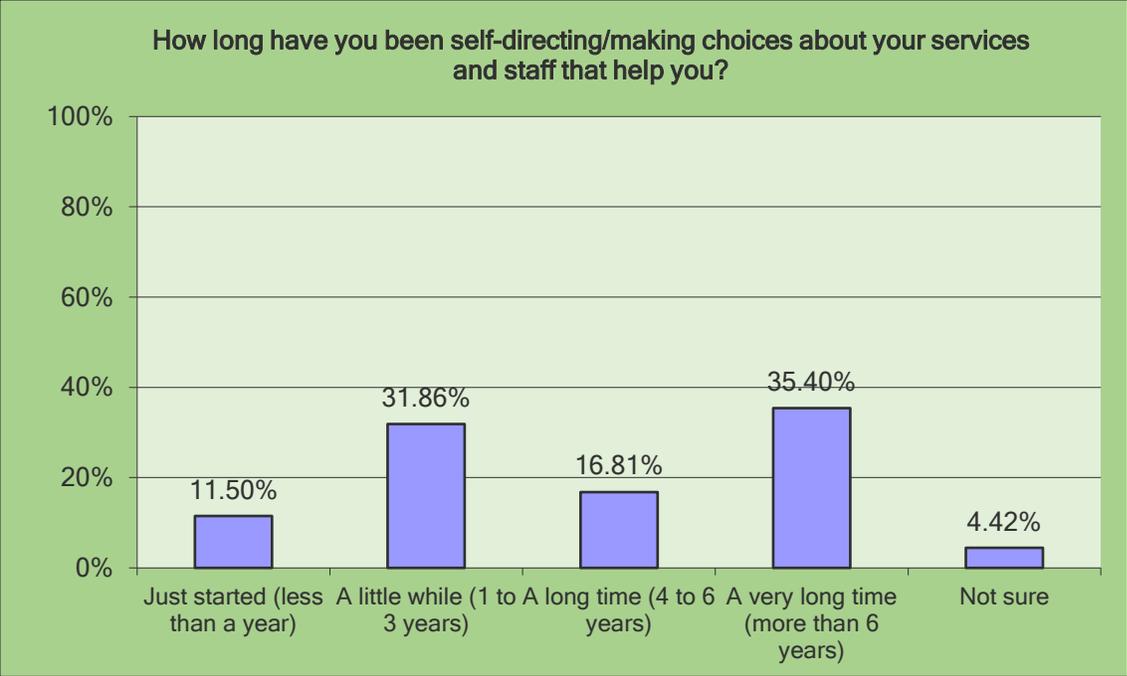
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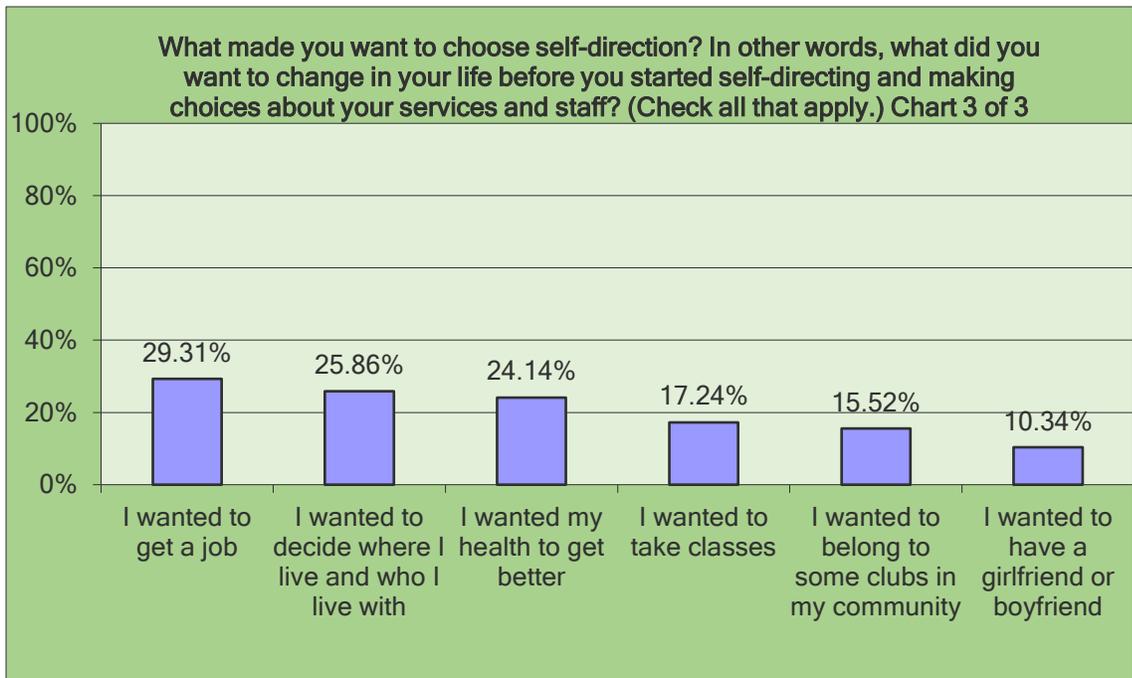
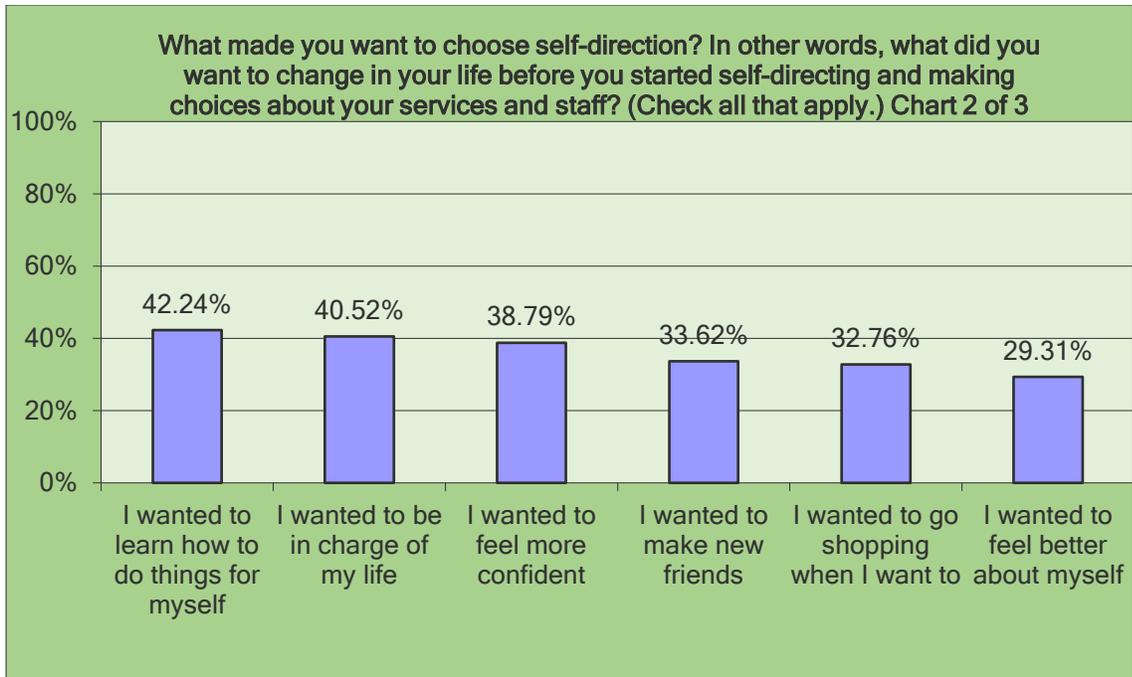
The following data were collected using a survey that was mailed out to 821 individuals who are participating in the Agency with Choice program. Participants were given the option of completing the paper survey or using a provided link to SurveyMonkey to complete the survey online. HSRI received 120 valid surveys between February 18, 2019 and April 4, 2019. Survey respondents were not identifiable in the surveys; however, they did provide their zip codes to allow for reviewing findings by region. However, the responses were not sufficient to make sub state comparisons.

## Results by Question

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



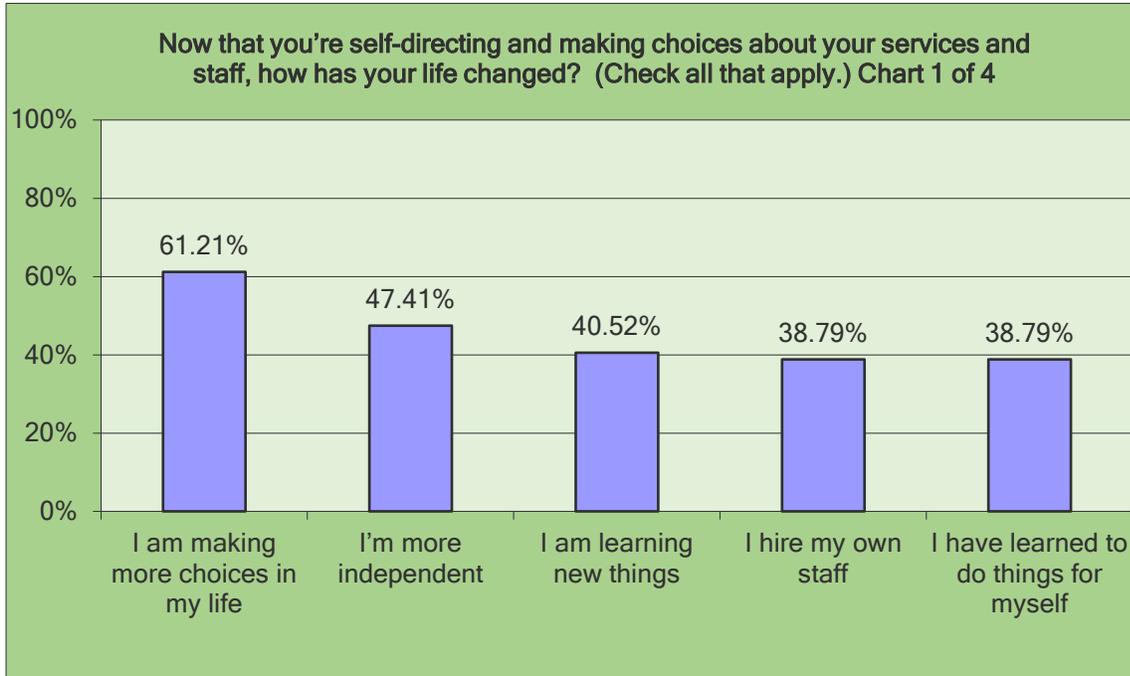


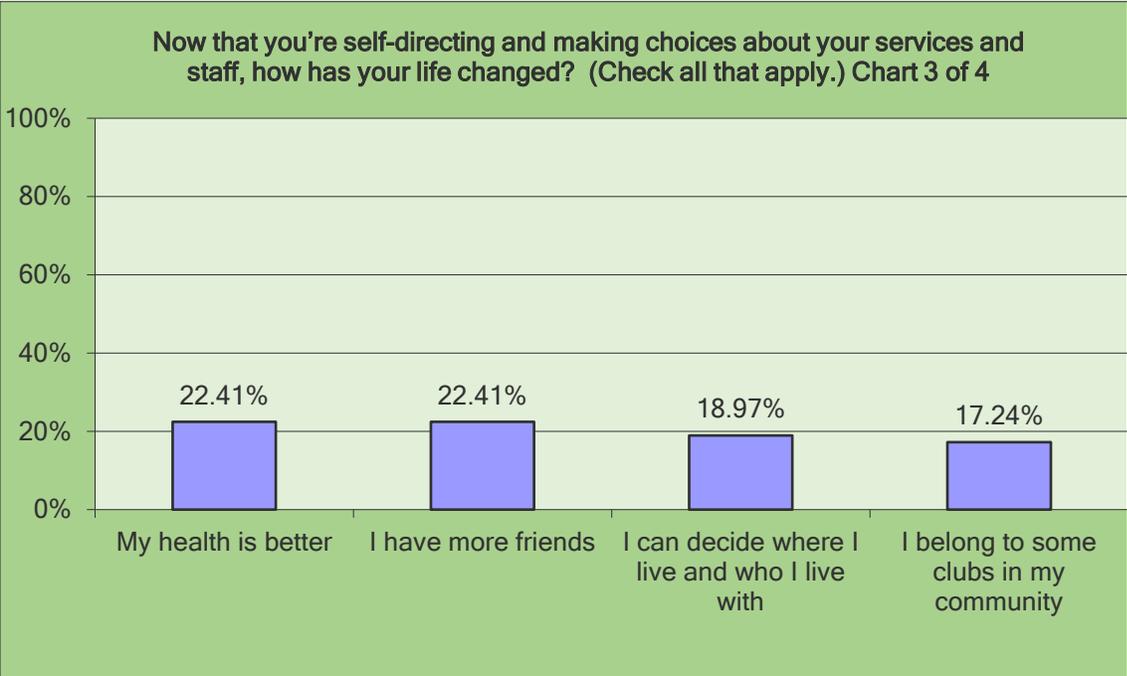
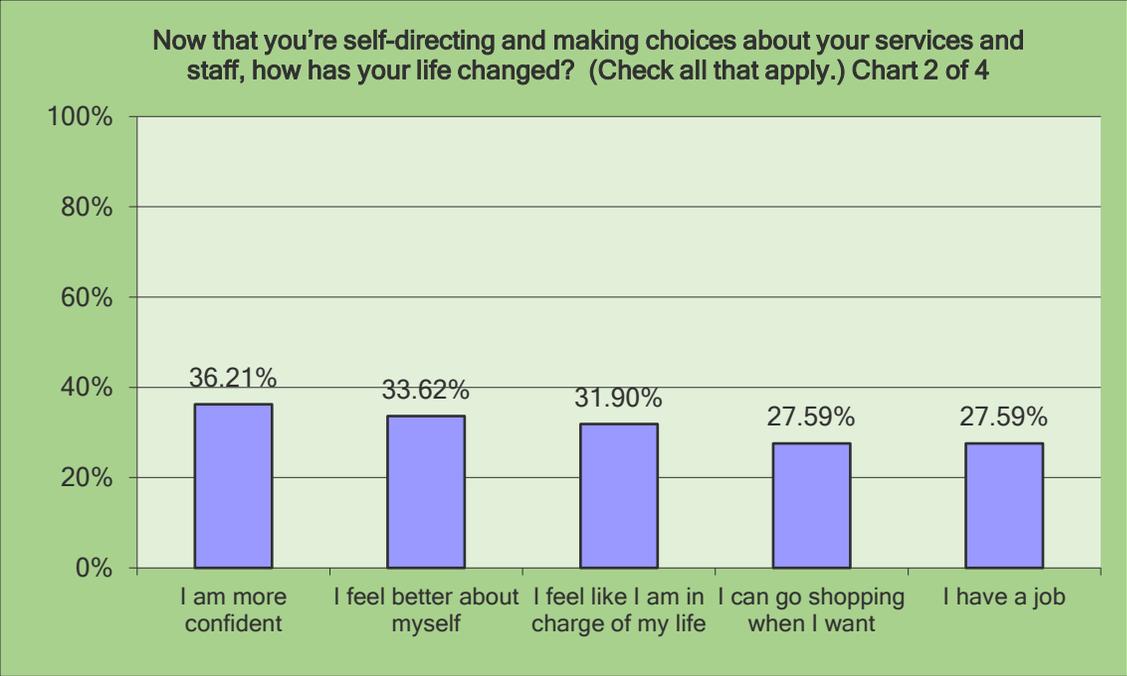


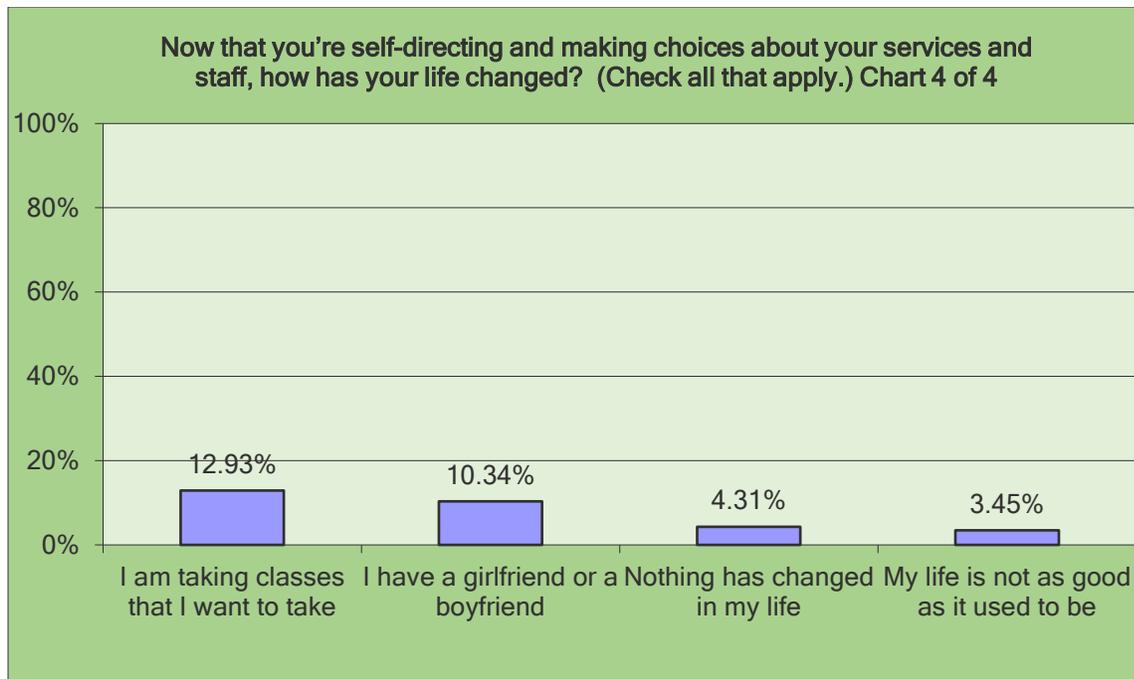
*Other responses (as quoted from survey respondents):*

- Never self-directed
- wanted to control the pace and sensory safe environments to lessen anxiety
- does not make choices for herself. unable to, guardian does
- no program suited me
- I wanted to be part of a involved in my community
- go to church and bible study without worrying about when to get home

- bored with other program
- I've been interested in joining a local theatre group
- There were no food-safe day programs in my area.
- My mum knows the best
- We wanted (name) to STAY a member of her community and continue through our hard work in school. Day had decent(?) offer though(?)
- I wanted not to be abused by group home staff.
- our son did not fit into the previous program under DDS
- I wanted to design my own schedule



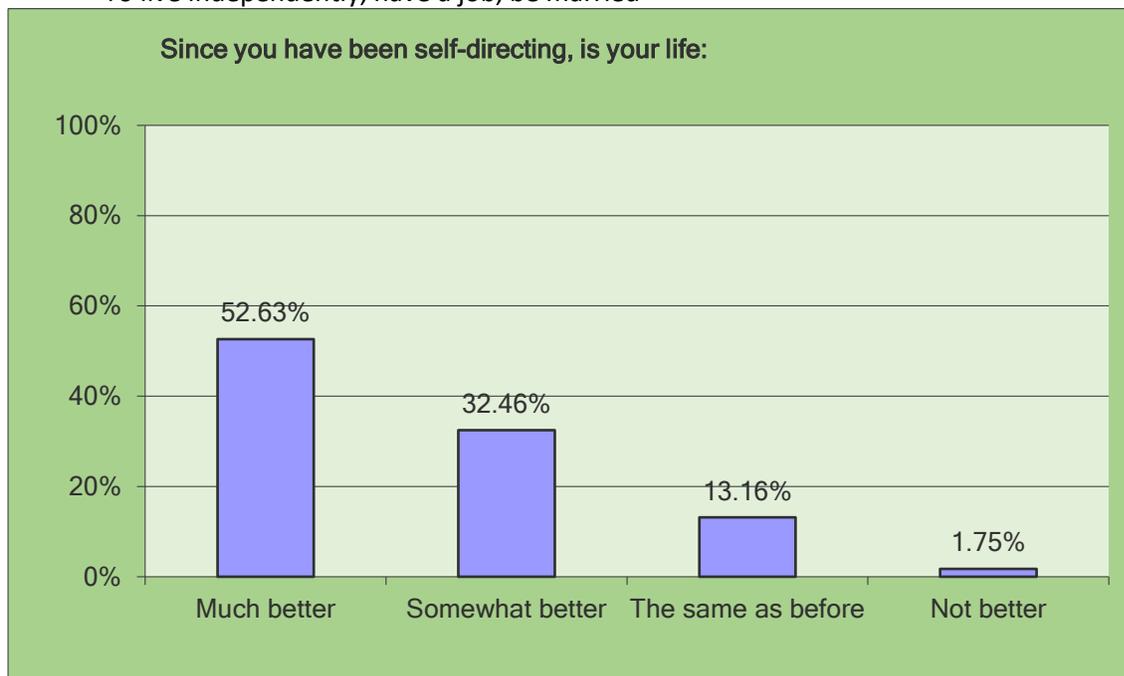


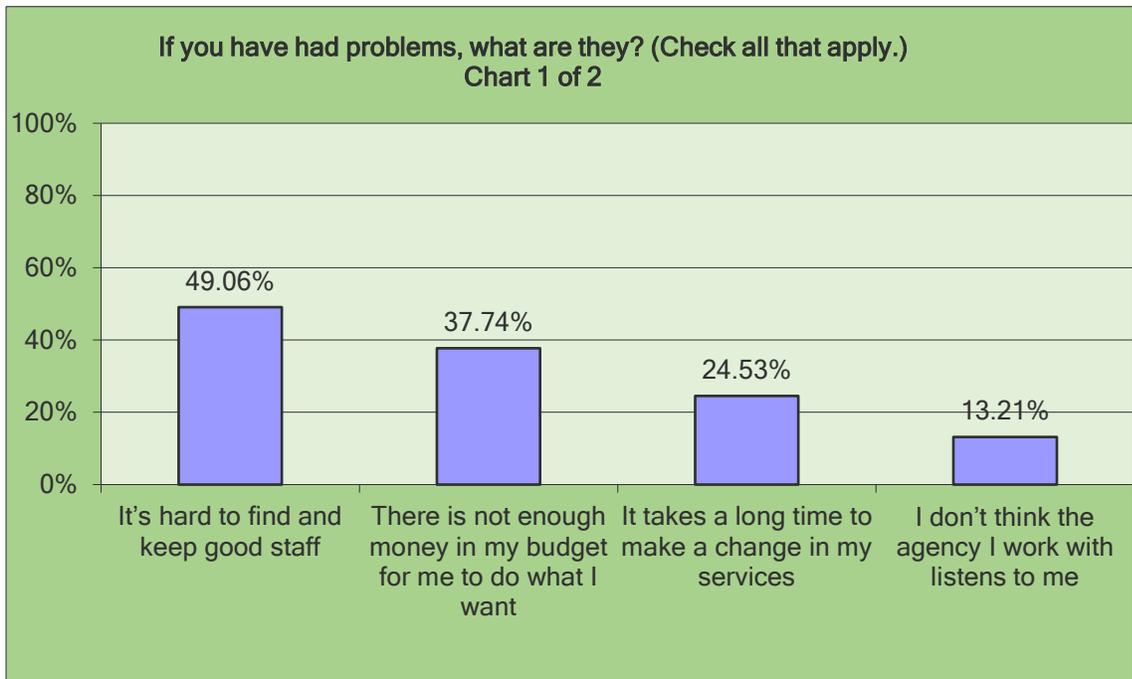
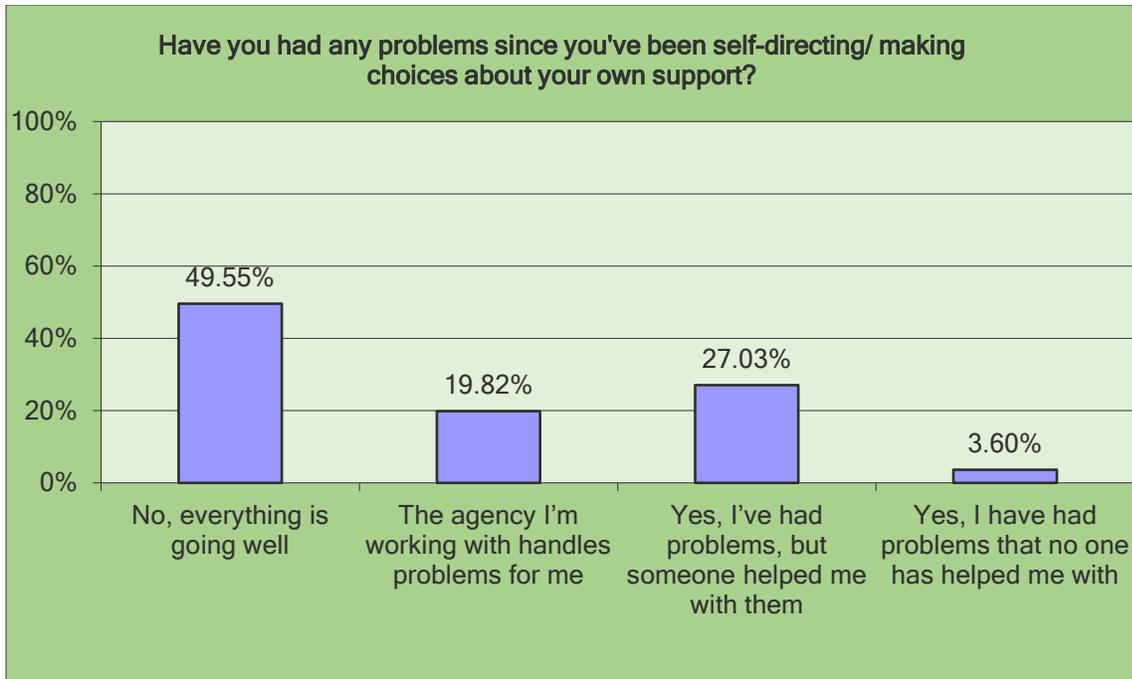


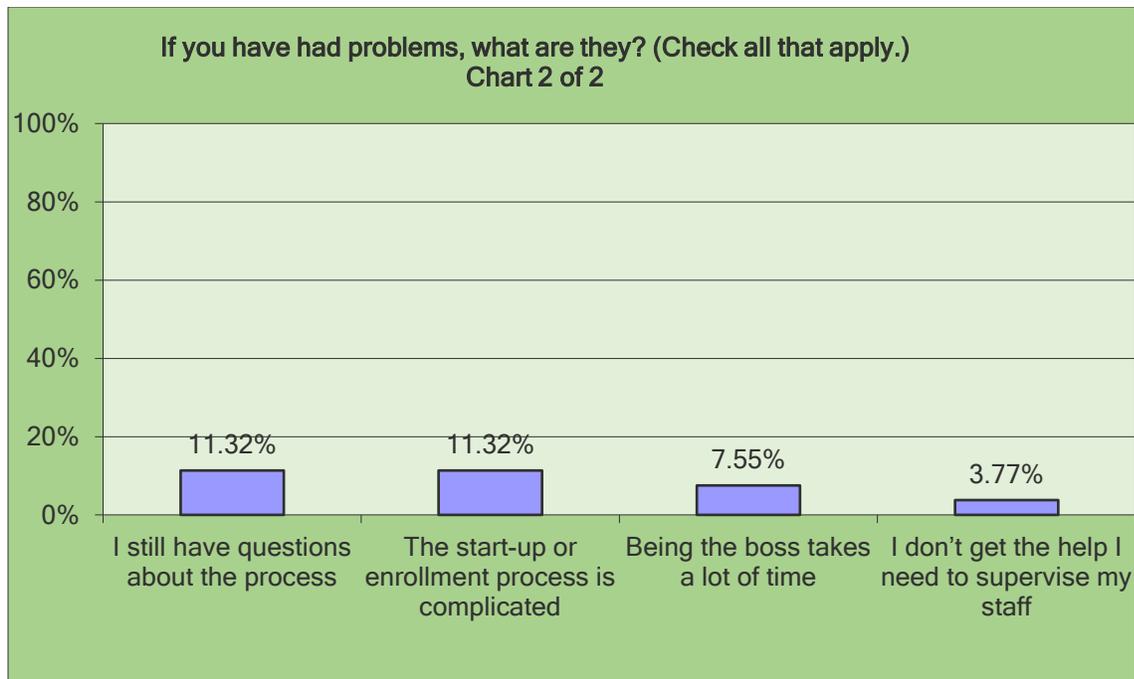
**If there are things in your life that you would like to change, please tell us what those changes would be:**

- Move to a different group-home
- Get rid of (name of program) in (town name). They are truly robbing DDS silly. Awful agency, specifically (name) and her boss (name)? (I'm not totally sure that is their names). They visited our house 4 times out of 48 chances they had!!!!
- I wanted (name). He has been with me since I was 19. He's the only one that helps and really cares, but they won't let him give me more time because will be getting overtime. I wish there was a way that I can have (name) more often. The man they gave me was strange and even asked if he could shower at my place, plus was not around when I went to the YMCA!
- I want to get a job. I would like to make new friends. I have requested to change to PDP at least 9 months ago. However the change has not taken place yet.
- public speaking and storybook writer for extra money
- wish I could speak
- she like to change her behavior but she couldn't
- my anger and attitude
- I need a job so that I can have more money
- (name) still is not participating as much as he could at program, still not transitioning well. With time hopefully he will. The "noises" bother him
- does not make choices on own
- none at this time
- I would like to be more involved in ongoing matters impacting the country
- That places that i volunteer in have no volunteer when place is opened to the community , I am still not being seen
- I want my group home to stop worrying about what time I get home from bible study and not worry about where I go for the bible study!
- I wish that I could share staff with another individual and we could go and do things together

- We are still learning but we feel very good about the self directed program
- I received very necessary and valuable job coaching for my year-round job, however I am only funded for 48 weeks and hoping for a[n] increase to fifty weeks out of fifty two a year. I don't mind taking an earning two weeks off on vacation per year, but four weeks a year even though spread out is a lot to take off with no coach.
- I'd like to be in a theater group and have better public transportation options.
- Opportunities to socialize with others in a self-directed program.
- I would like to live in my own apartment.
- My depression. To find a job faster.
- In-home support staff needed!
- Better Health
- Do bagging in a grocery store with a friend.
- Overcome his debilitating anxiety / OCD
- My sister would like to continue to live in her own family home for as long as she is physically and mentally able to. She loves her "red house" -- her family home -- where she was born, raised, and lived her whole life.
- I am going to live with hyciant.(sic) I want to accomplish my goals for the program.
- Cheaper apartment in the West Roxbury area.
- To have more support in reaching support staff who are able & enthusiastic.
- I would change not having angry outbursts
- He would like to live on his own
- Continue to keep myself busy every day
- To live independently, have a job, be married

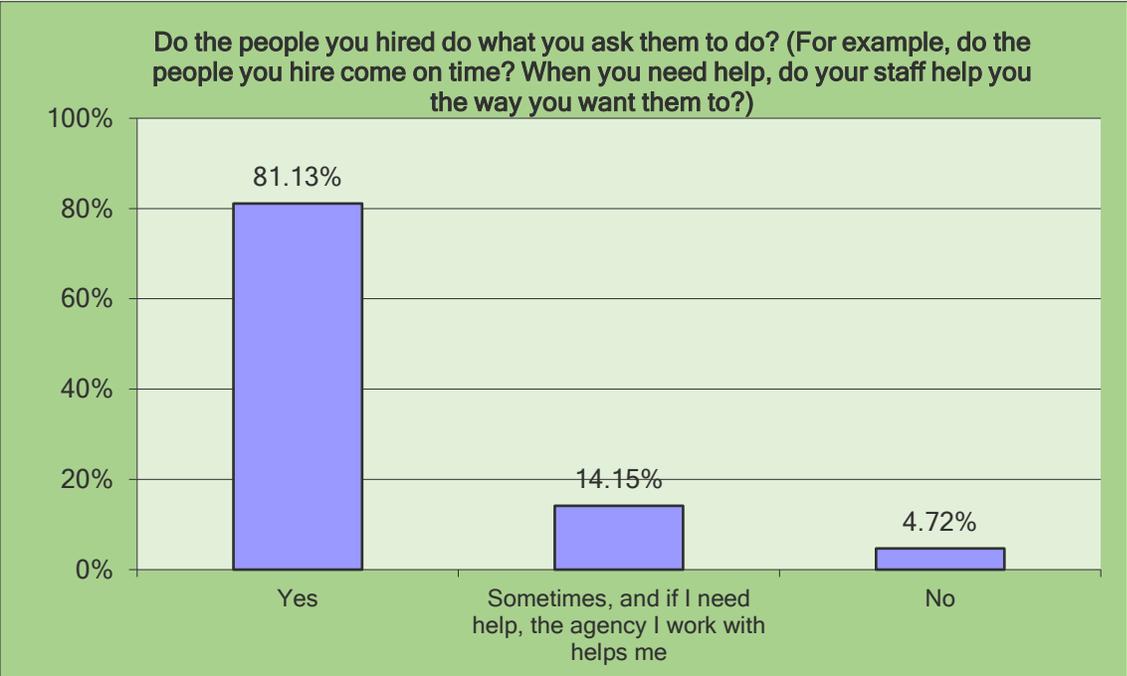
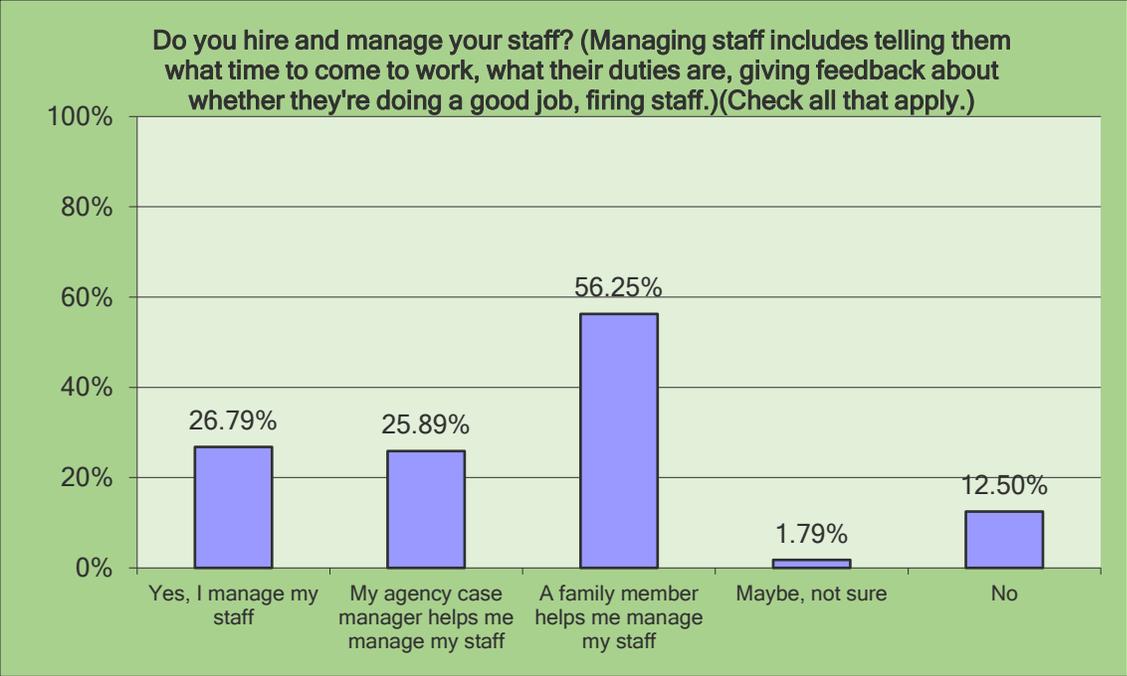


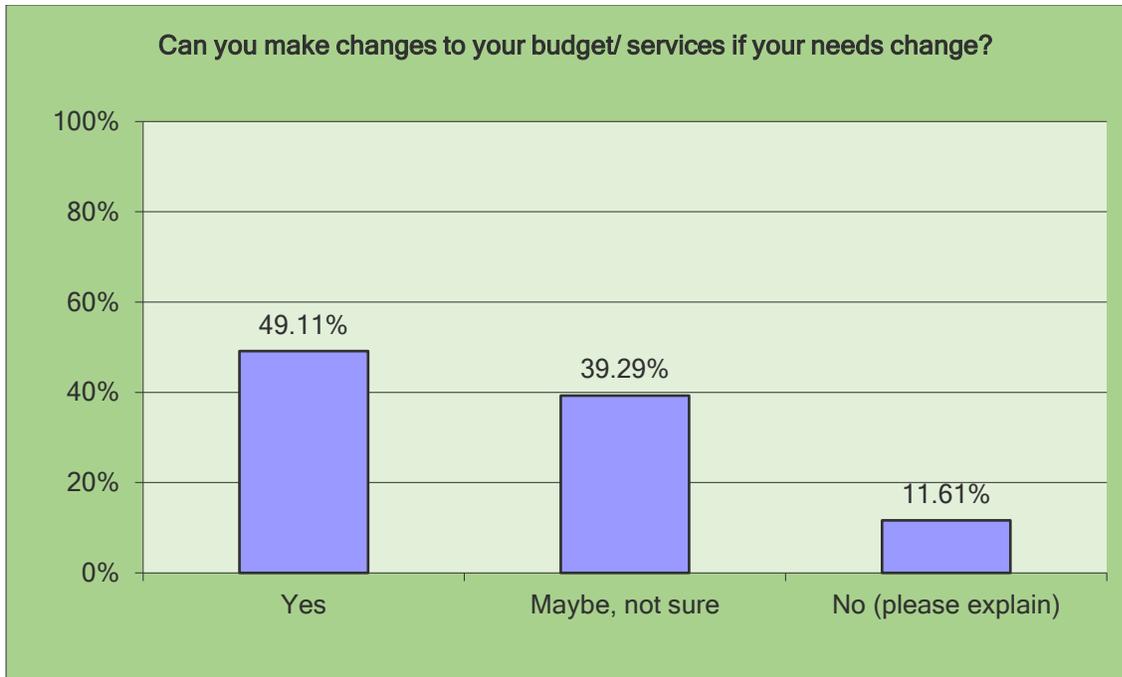




*Other responses (as quoted from survey respondents):*

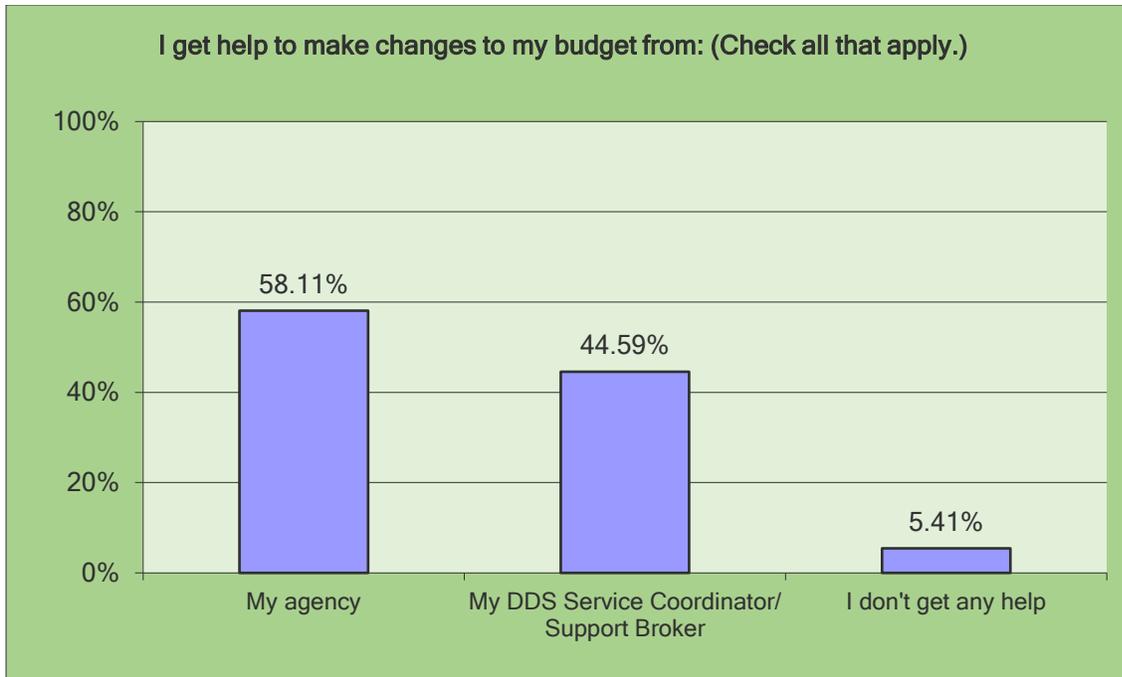
- never self directed
- Using this questionnaire it's really hard to determine between the two agencies I work with. One is SUPER GREAT (name) the other is AWFUL (name).
- The person I want can't do it because of overtime! Current person changed his hours to please himself!
- Scheduling and lack of activities
- hard to find new staff
- cost events /transportation
- not transitioning well with more sever handicapped peers
- Finding places that accept me to volunteer there
- Public Transportation
- AWC was an administrative nightmare
- Find way to cope with stress
- Finding staff to accomodate my schedule
- Transportation
- Not enough money for snowdays, sickdays, holidays. It's also very difficult to deal with Mass Health regarding PCA hours.





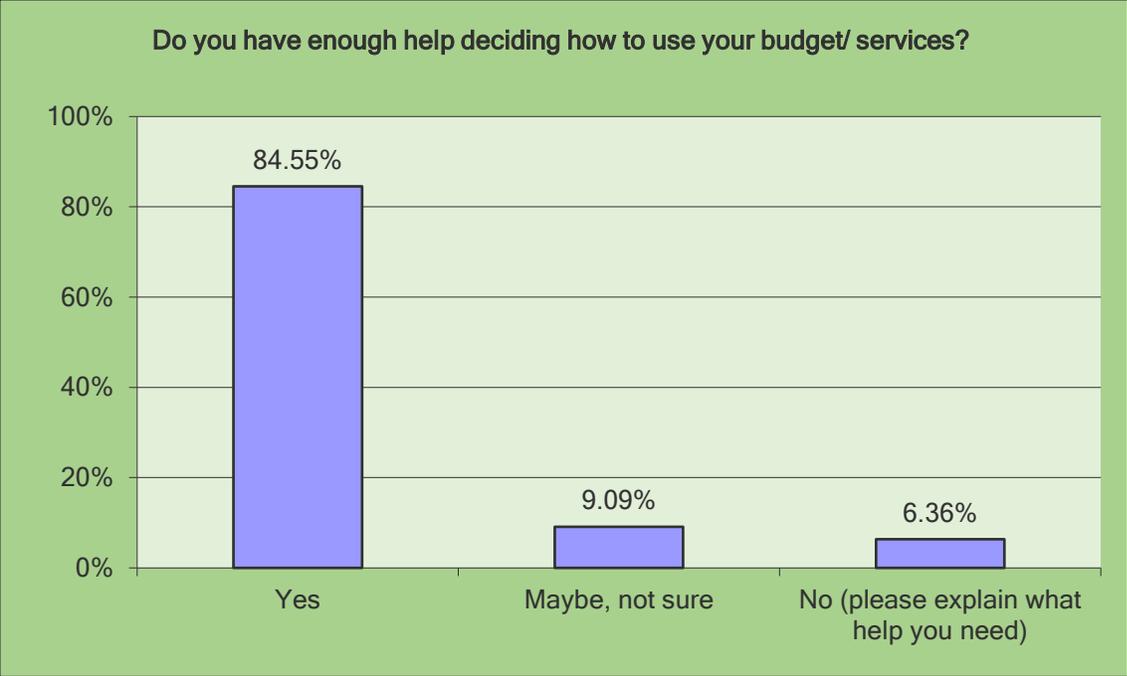
*Other responses (as quoted from survey respondents):*

- I have no choices
- I don't know how to budget, I ask papa
- Family
- I've been told no
- too hard to explain
- my parents help me
- funds are always very limited
- Budget is fixed
- I came to this country as a refugee and I am unable to become a US Citizen due to no documents even though DDS and community providers have tried for years with the immigration dept. No one in my family in Ghana will send a birth certificate to me



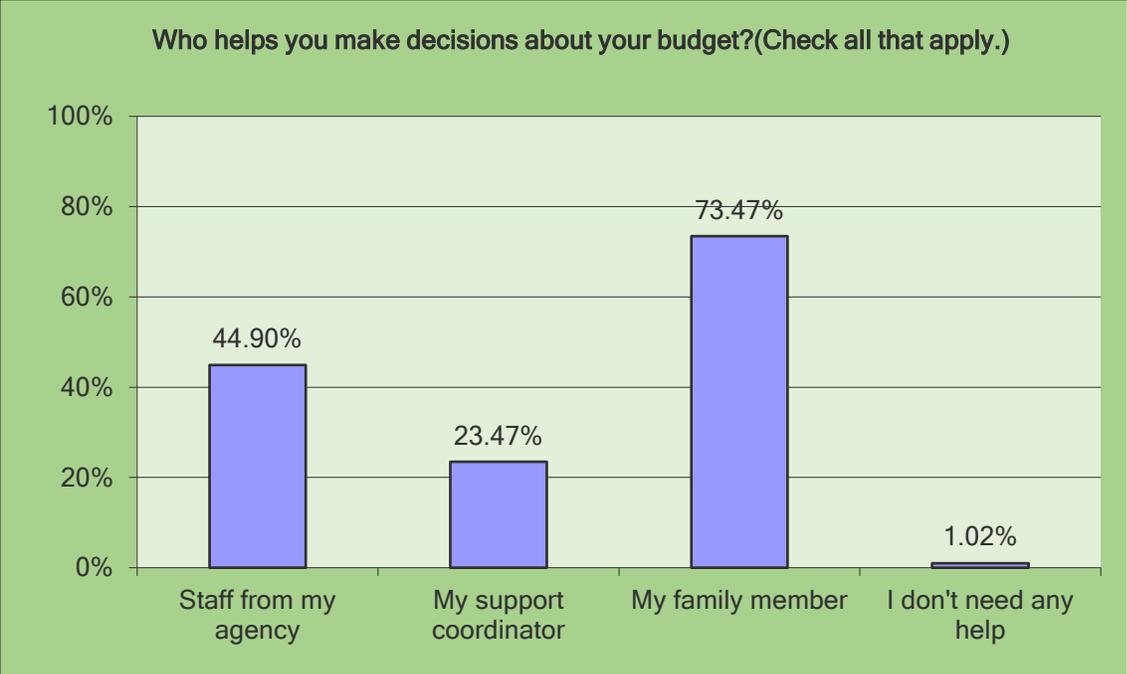
*Other responses (as quoted from survey respondents):*

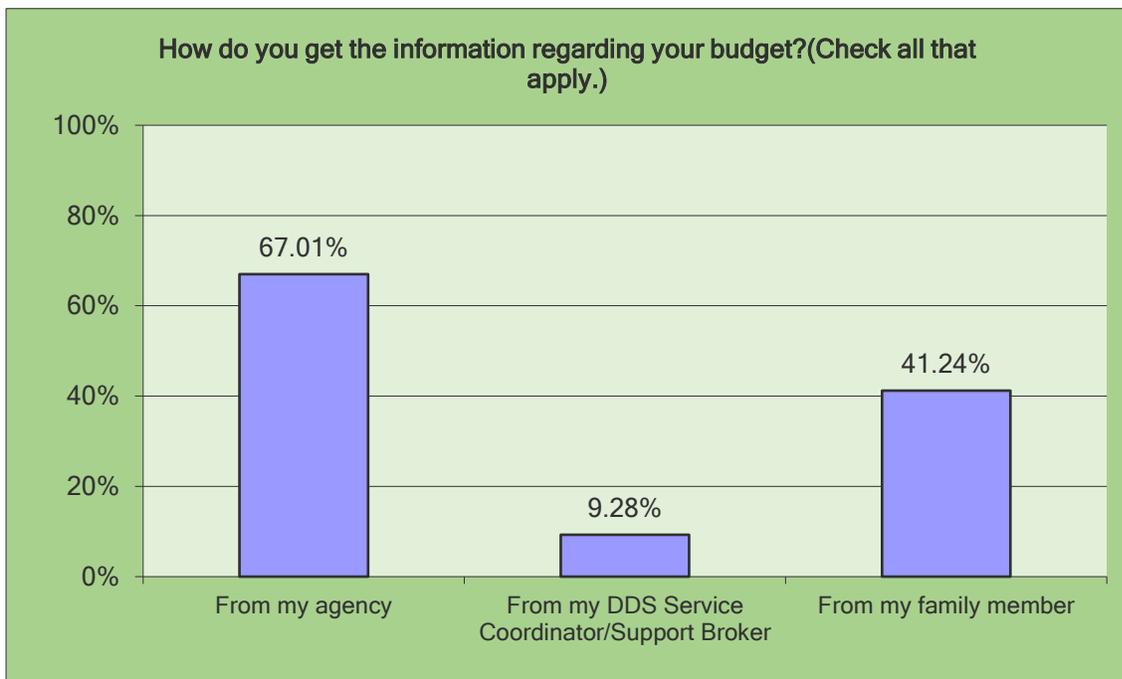
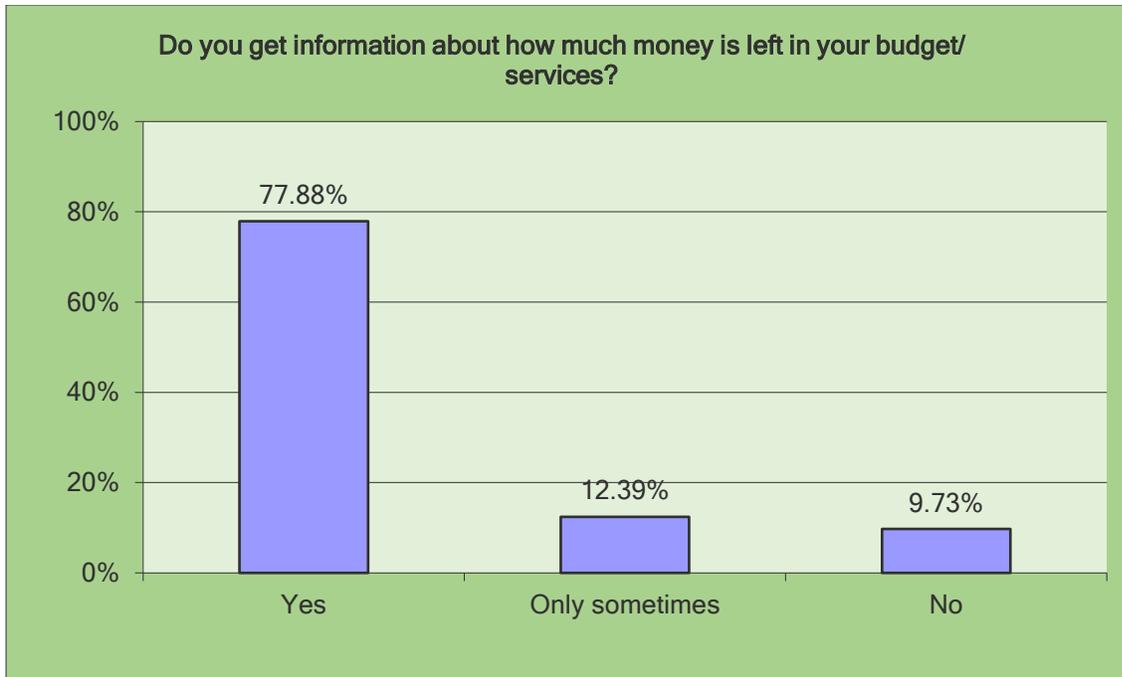
- Family
- Guardian
- Parents
- Family
- I am my own payee but I will reach out to my AWC if I need to
- my mother and agency
- family
- family member - mother
- I do it all myself and by myself
- MCS
- DDS and Agency through mom for me
- My family
- My brother
- My family
- we have not asked as yet
- My nephew



Other responses (as quoted from survey respondents):

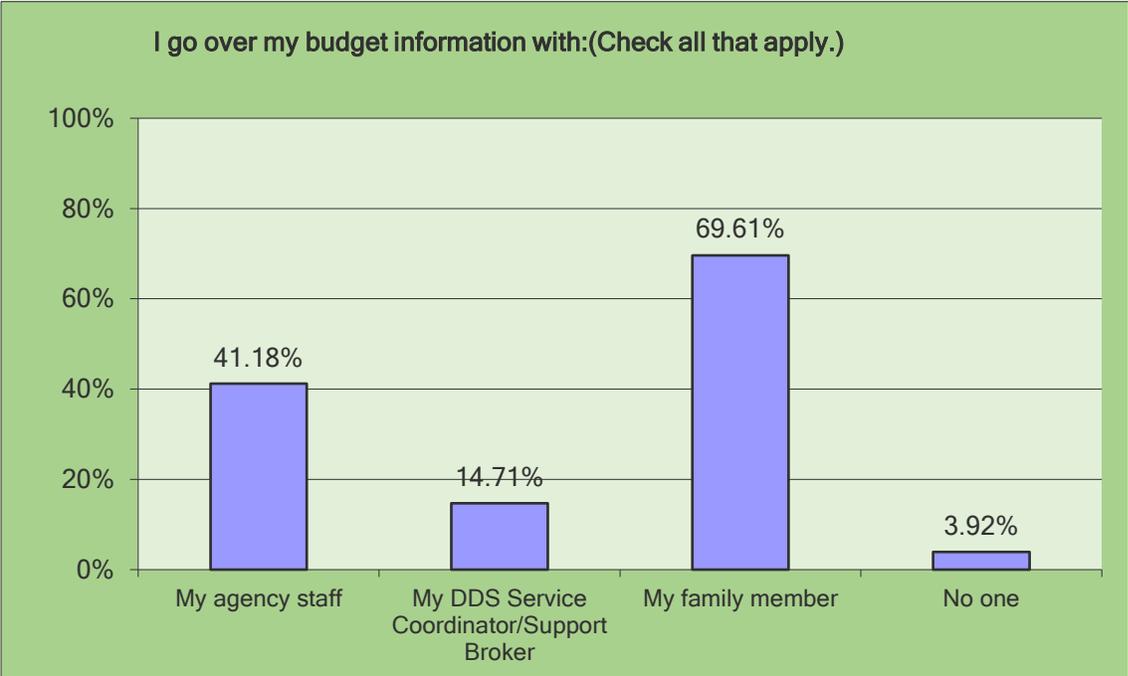
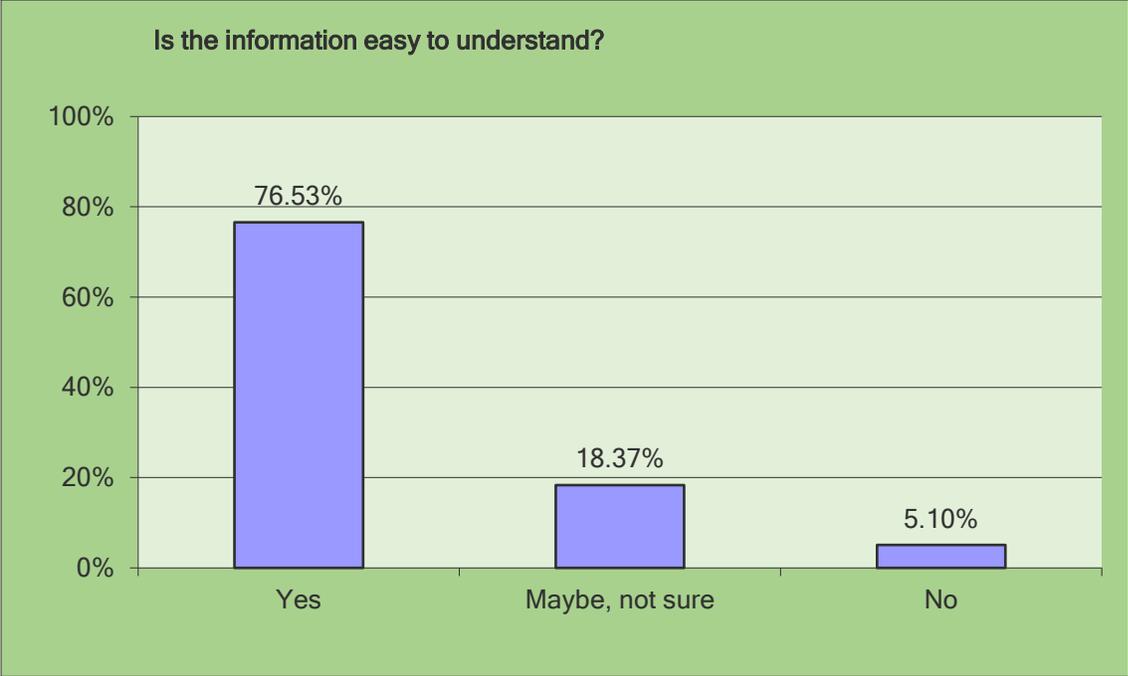
- My mother
- My surrogate grandfather
- support person to write my life story to become storybook writer
- agency turnover
- I do not need it!
- Don't know how much is in my budget
- His parents supervise all financial activities

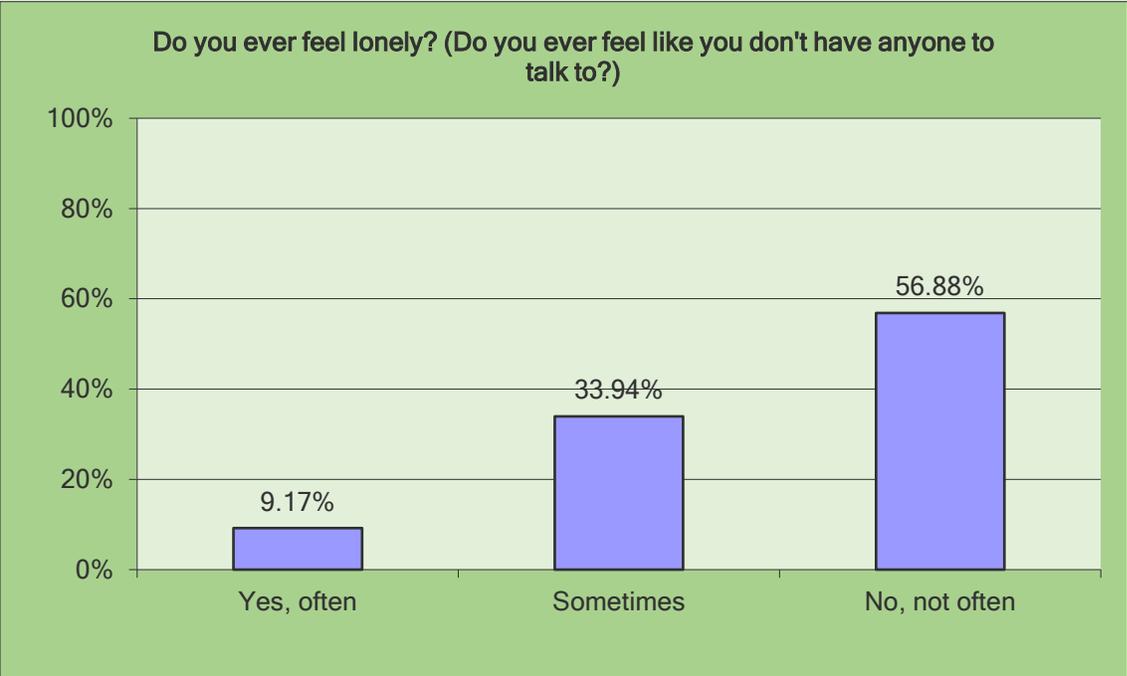
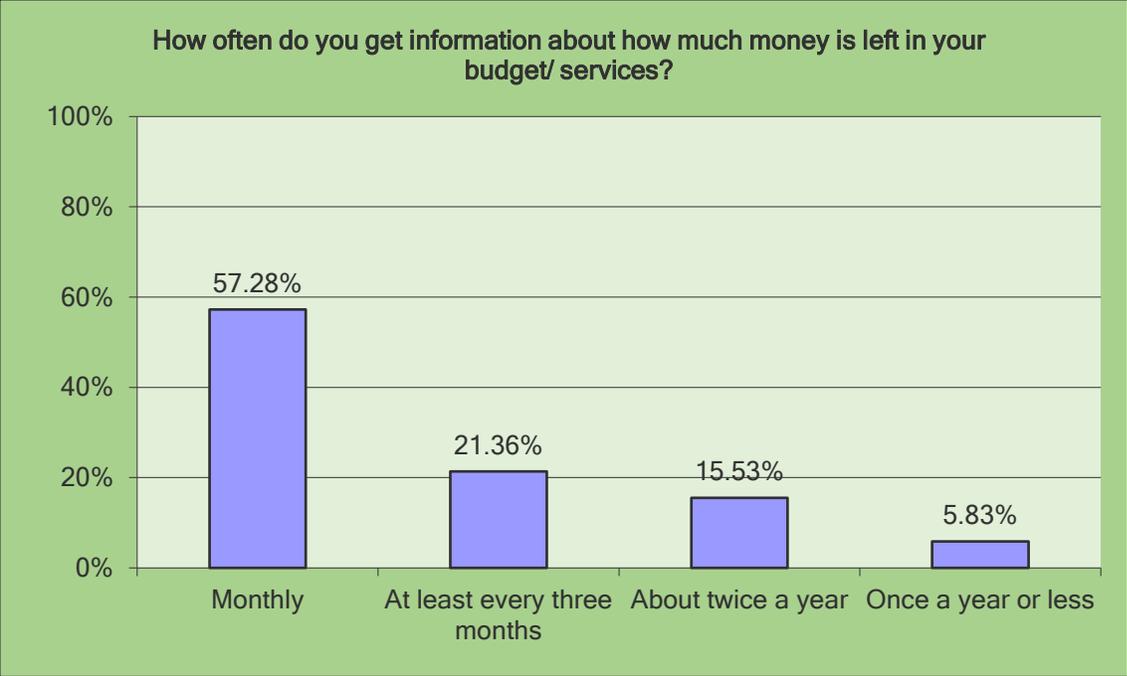


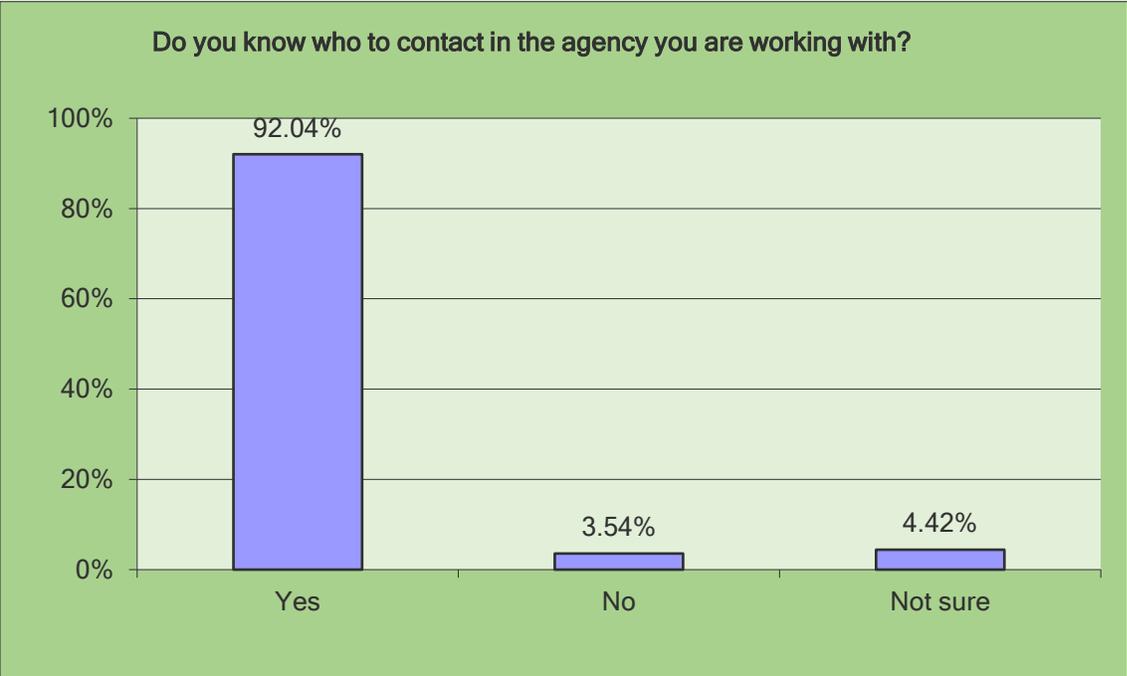
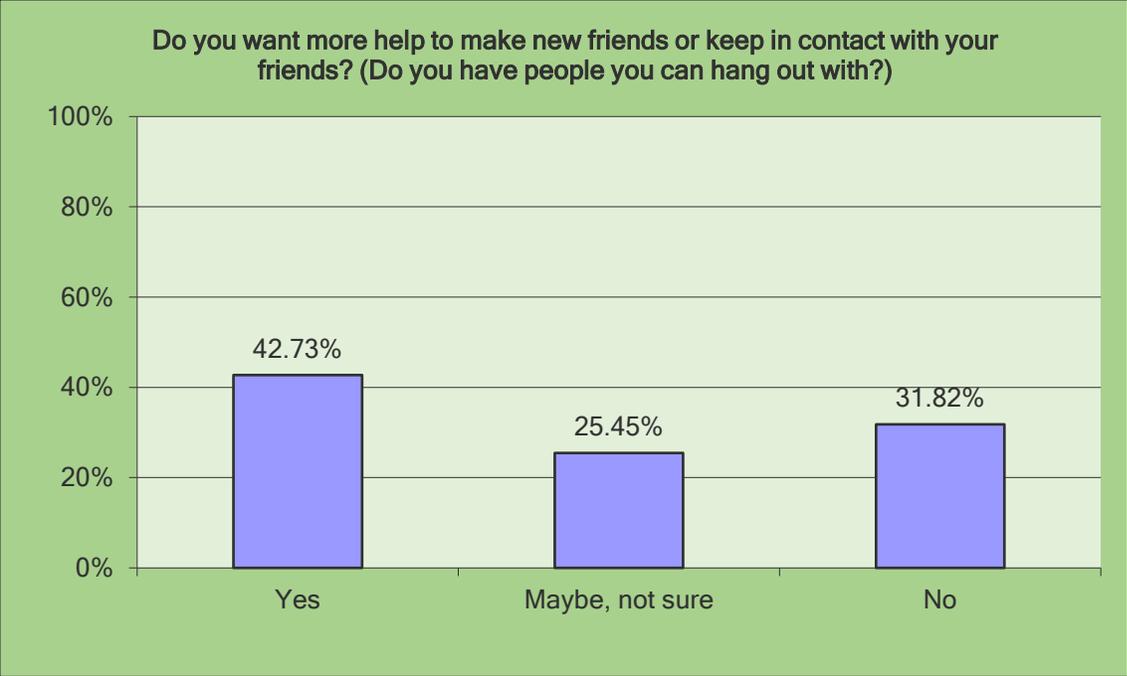


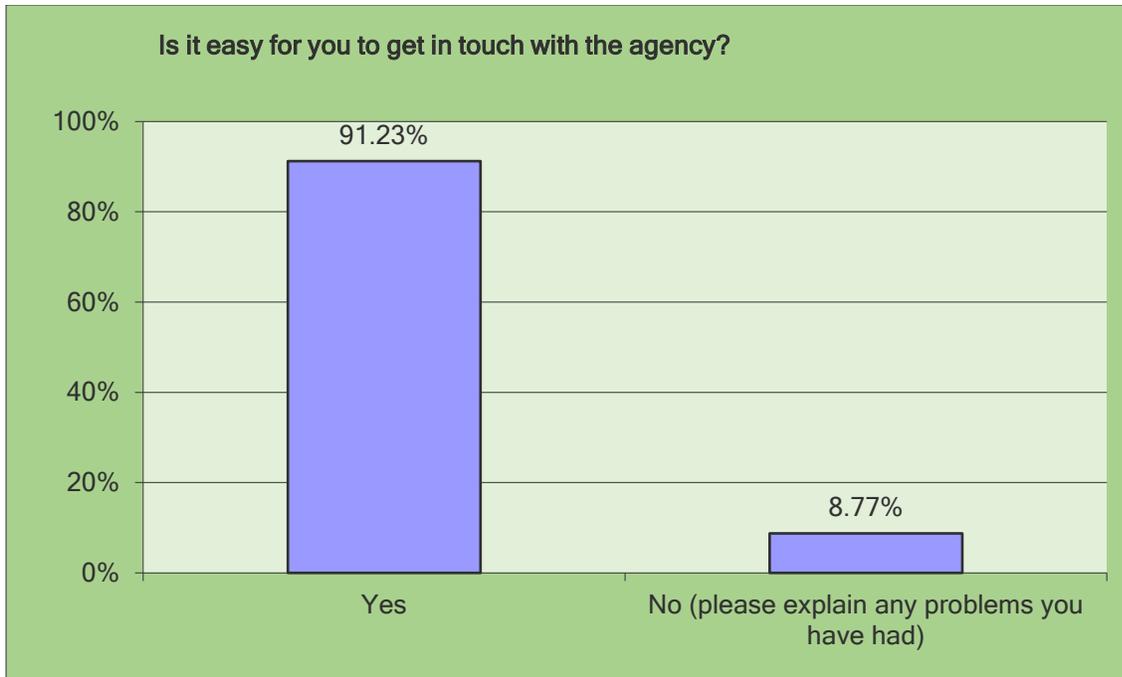
*Other responses (as quoted from survey respondents):*

- my own bank account
- I do it myself and I think before I spend
- agency supposed to send monthly budget updates but don't
- PCA Program
- When we ask



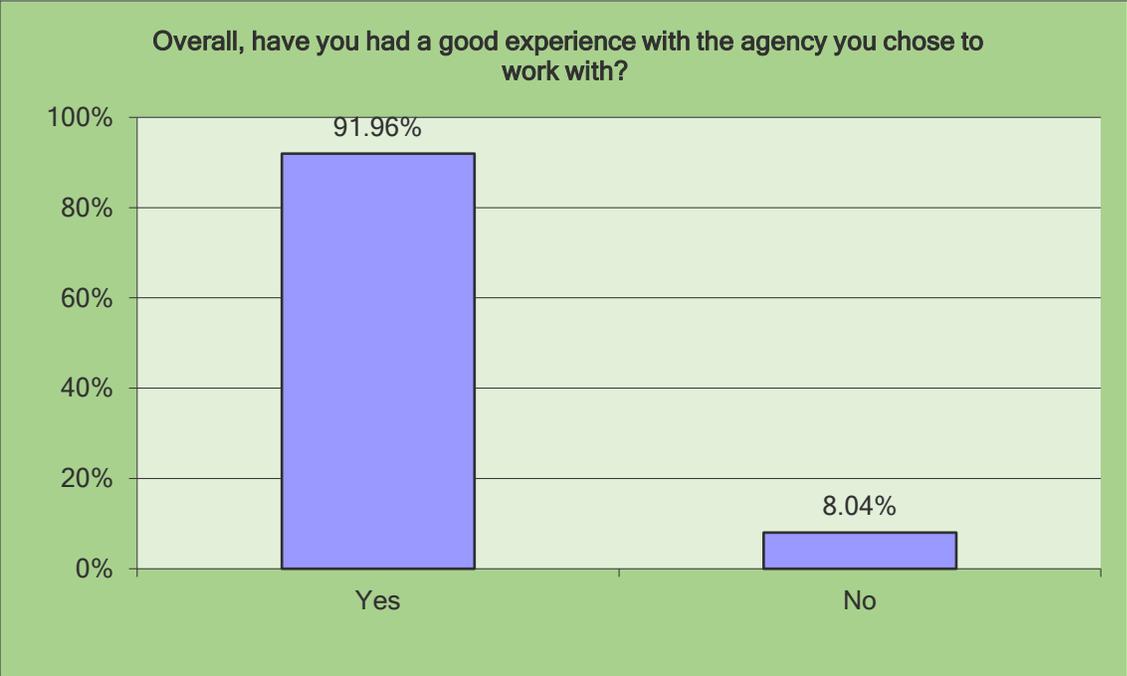
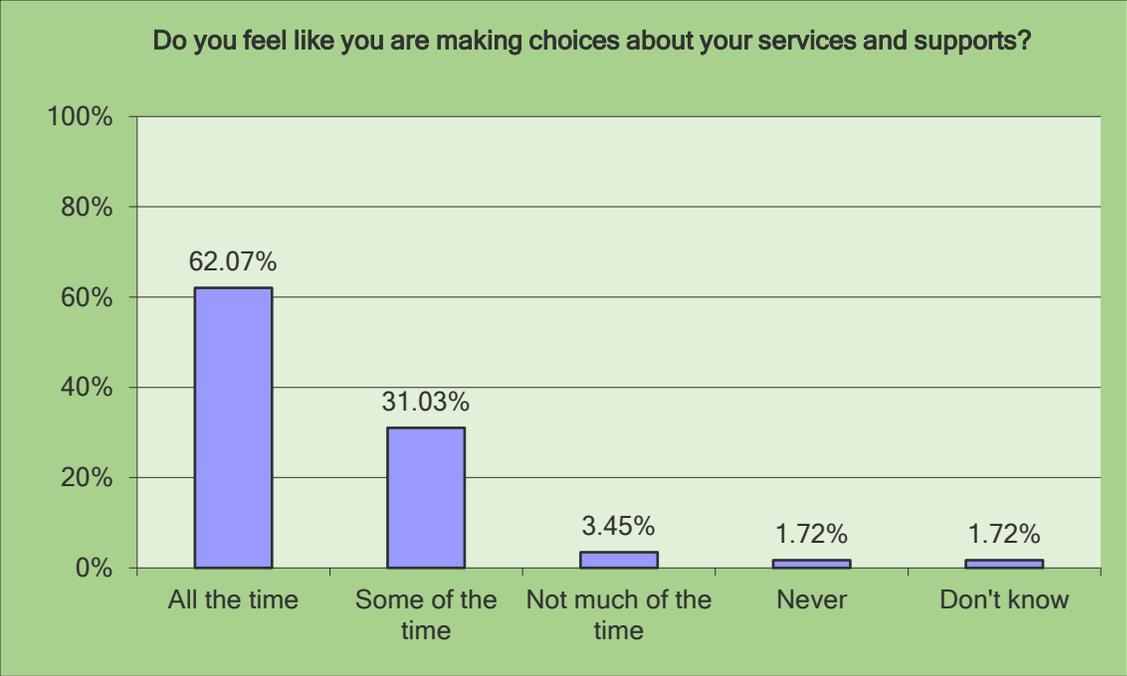


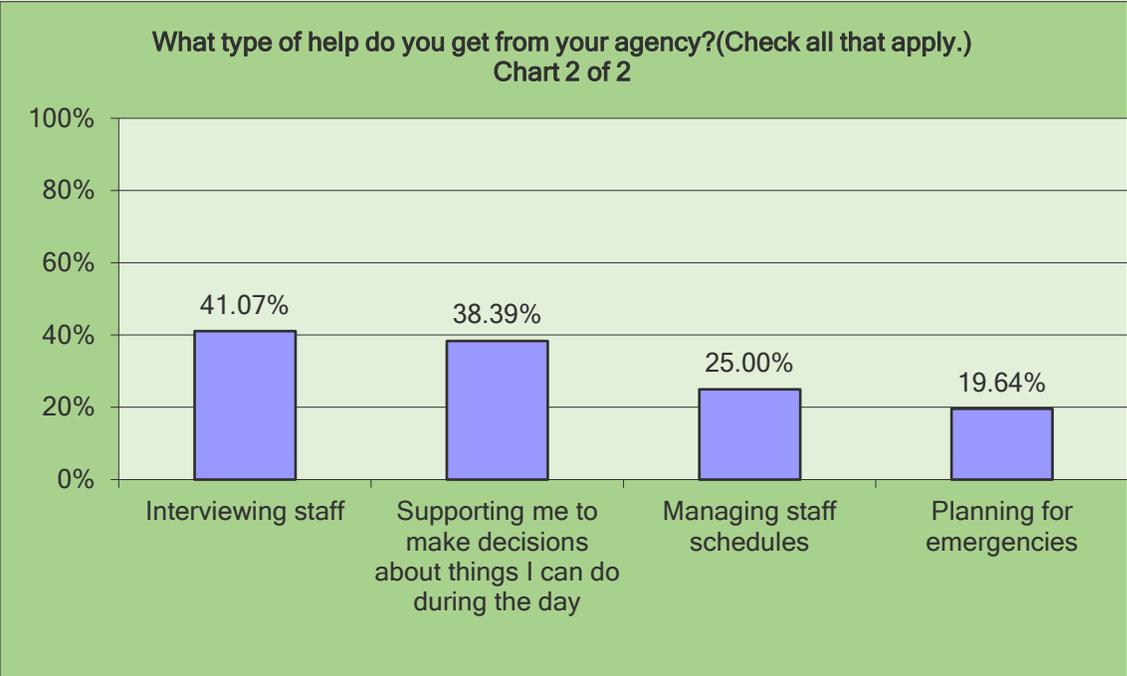
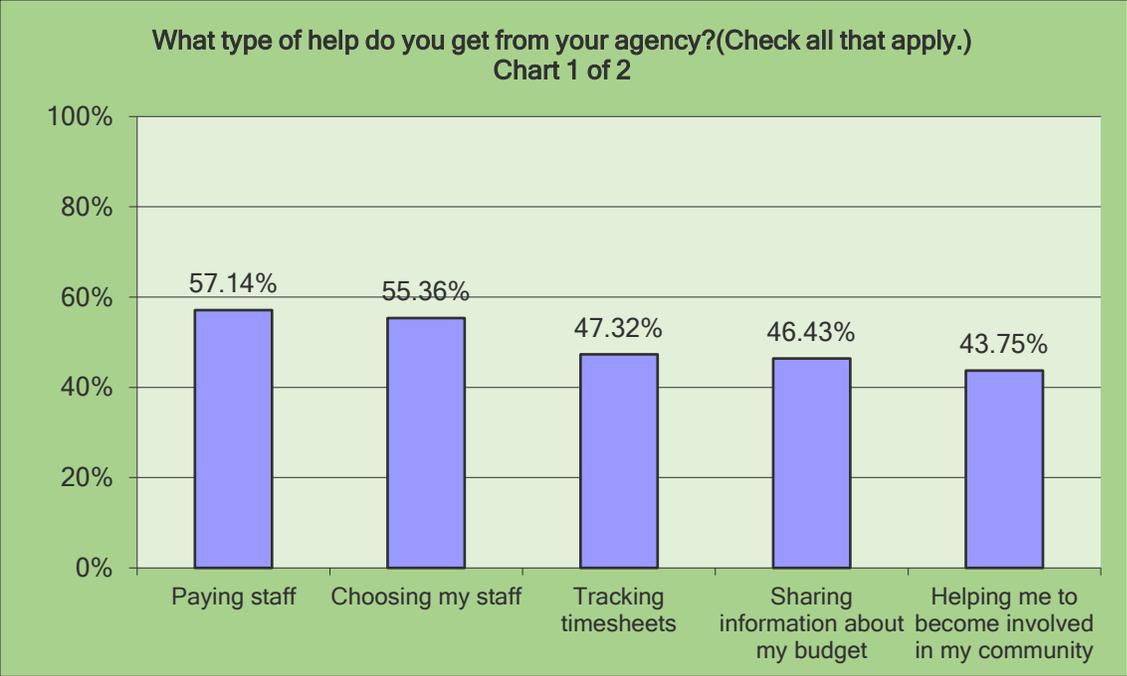


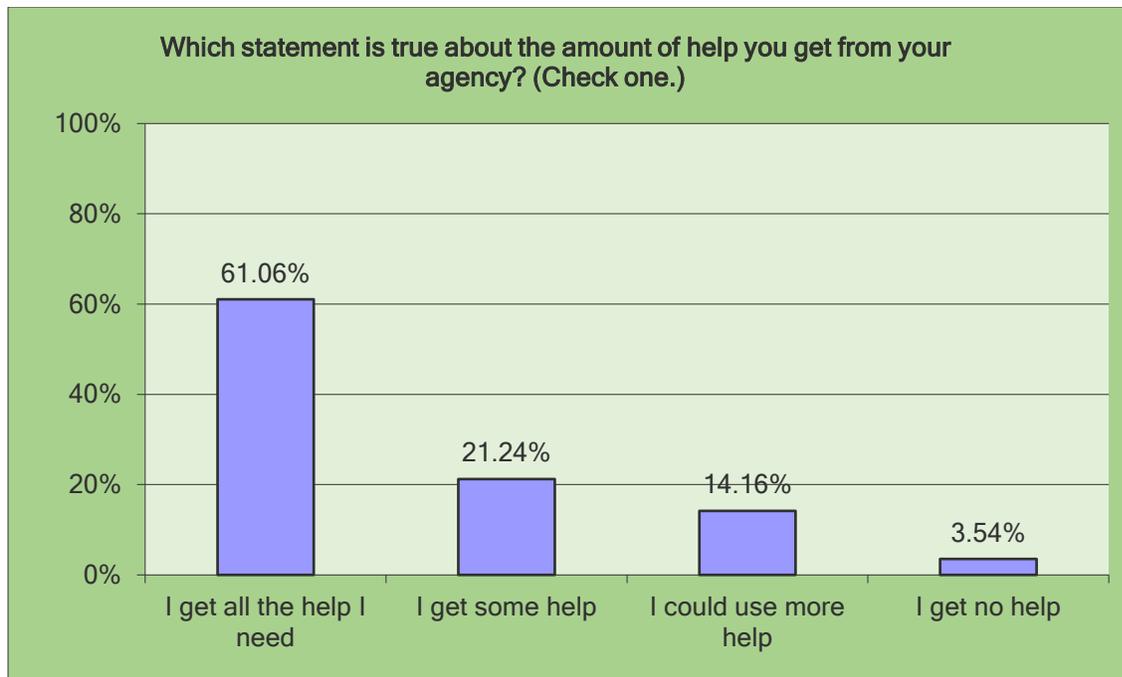


*Other responses (as quoted from survey respondents):*

- Don't have number
- I have to ask papa and my companion
- turnover is often
- sometimes it takes a day or two to get person to call back
- Have to wait a while for a call back
- They don't return my calls
- There has been a great deal of staff turnover. It can be challenging to know who to contact and it took staff some time ot get up to speed -- understandably.
- Get ANS machines



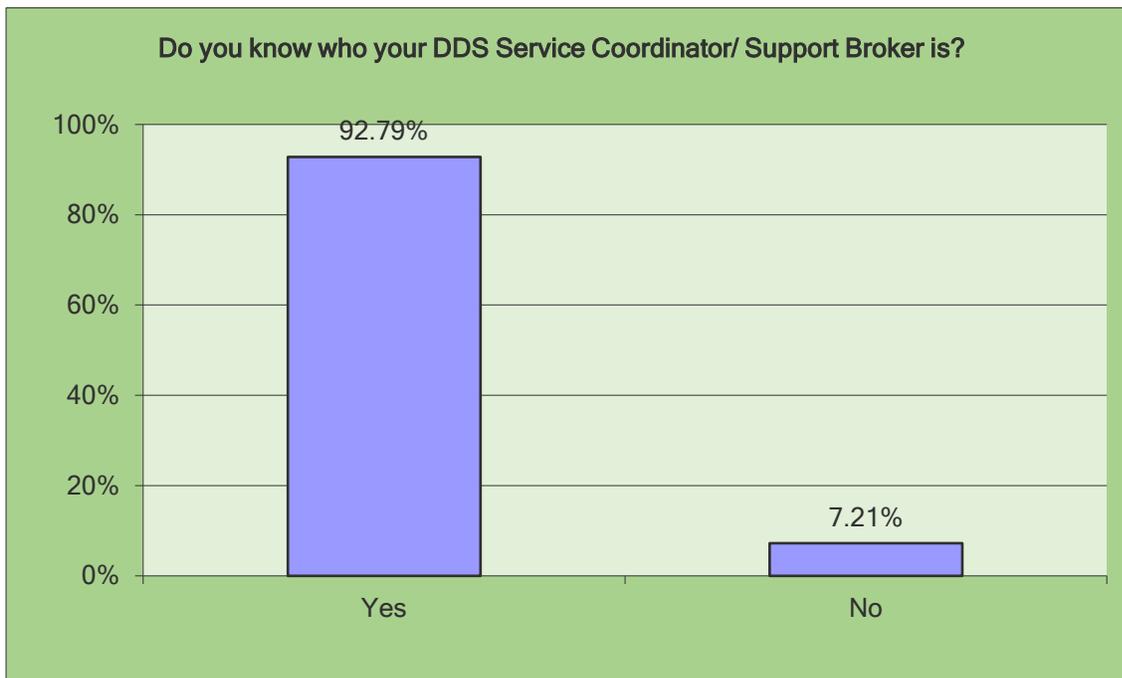


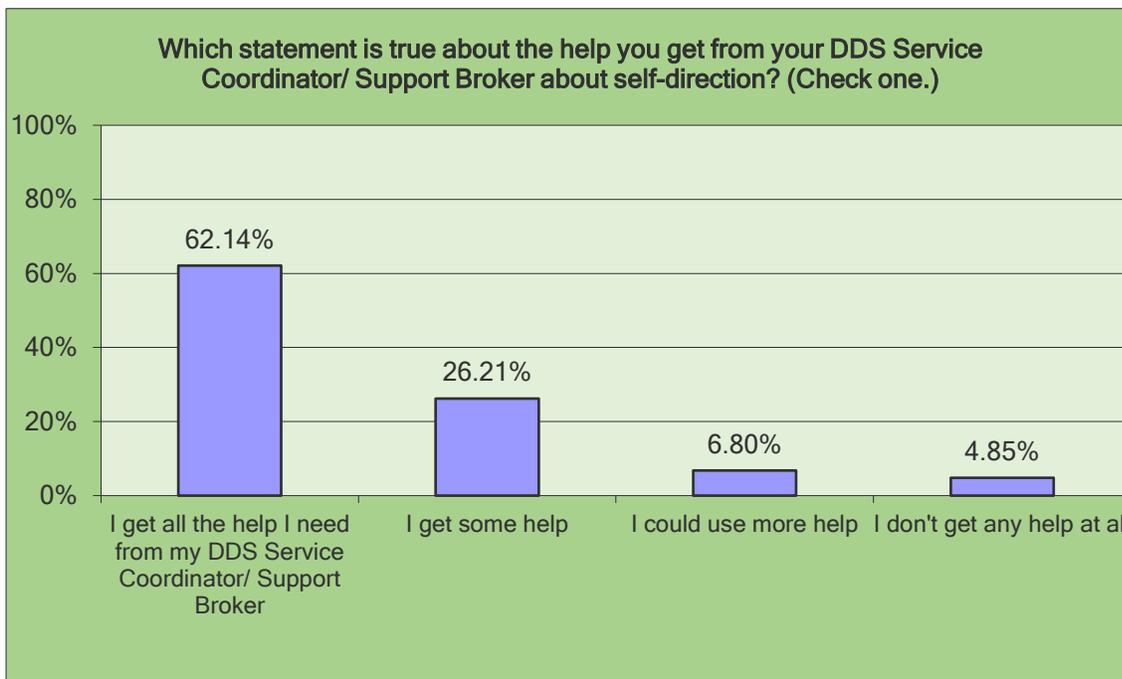
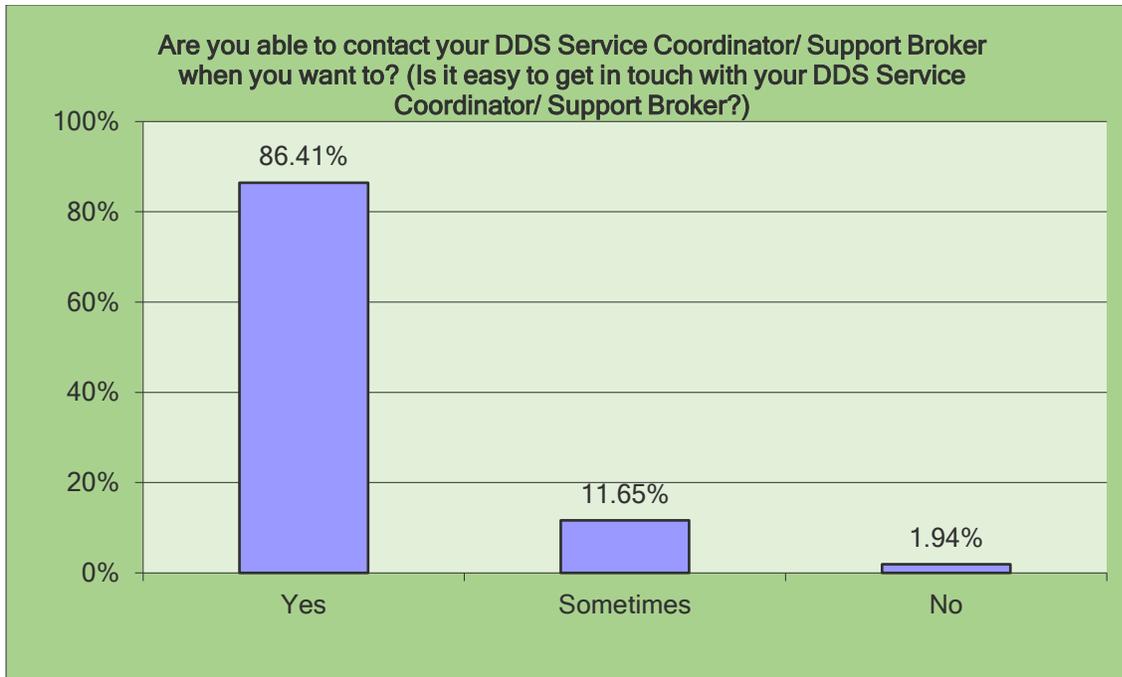


### **If you need more help, what kind of help do you need?**

- I need to get rid of racist people in (name), they are good for nothing!!!
- finding social/recreational activities
- more hours
- I will try anything new for the at illegible
- "1. community activities
- 2. keeping coordinator more than 6 months"
- primary doctor
- I need more money
- filing at home-paperwork
- call to check in more often
- more time dedicated to finding superior work.
- staffing is a big problem. people just aren't committed and staying for a long period of time. (rest is illegible)
- getting things I need at Walmart and they are violating our human rights by doing that
- Another person for Mon-Tue-Fri
- opportunities for education without a high school degree
- I get help when I ask. I wish agencies were more familiar with the area I live in and had more resources. My family sets up all the community and peer things
- Hiring people
- Access to other services. Direction to locate services.
- Staff people - LifeLinks can't provide
- Assistance with recruitment. Timely budget information.
- Explain Options - What is available, how can I spend my budget?
- I need more help with hiring skills trainer. I really didn't see effort made by the agency \*nor\* by DDS.

- It would be good to be able to raise extra money for what to do with their helper, a non-profit organization
- Running errands, cleaning, and helping prep meals just to name of them.
- To receive monthly statements.
- Hiring. Where to find transportation--reliable, safe.
- More dependable workers. Reimbursement on time.
- A budget, Social Security, skills training,
- How to secure a budget to provide 24/7 care (excluding Day Program). As meds reduced issues increase. How to deal with Mass Health regarding PCA hours.
- Finding staff
- TO get my permit. Cooking classes. Going back soon to get my GED.
- None. The agency is great!
- Connecting with others who are self-directing/Agency with Choice program. Unable to get contact info of individuals or parents.
- budgeting money
- We need to fill in more hours around his specific needs

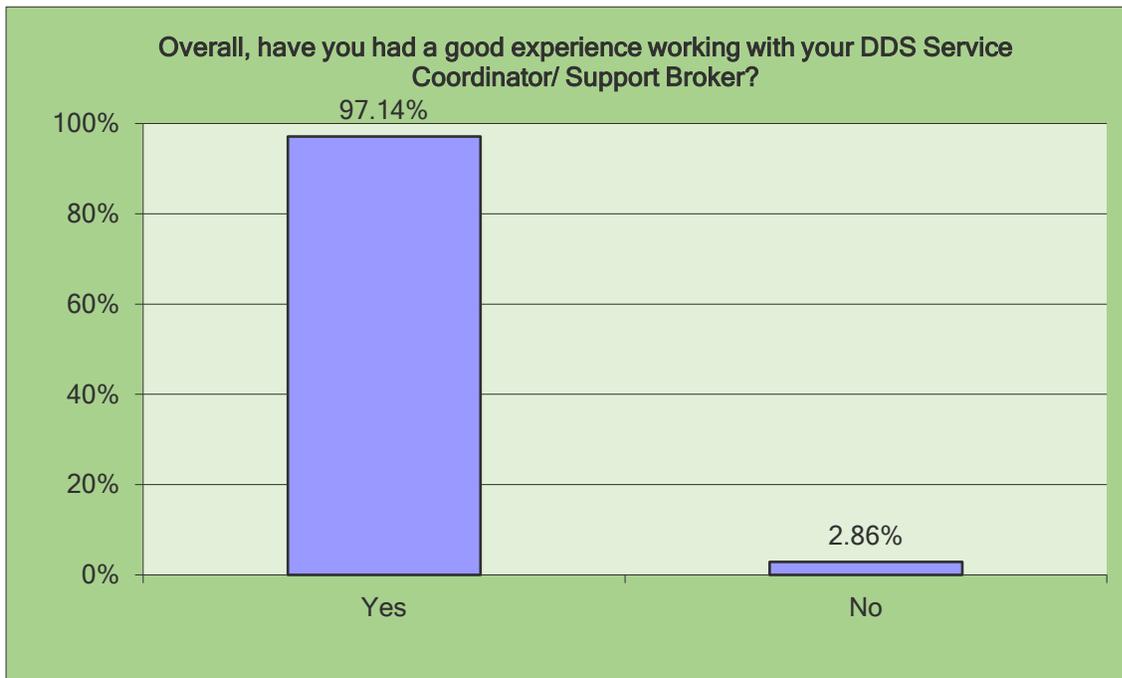


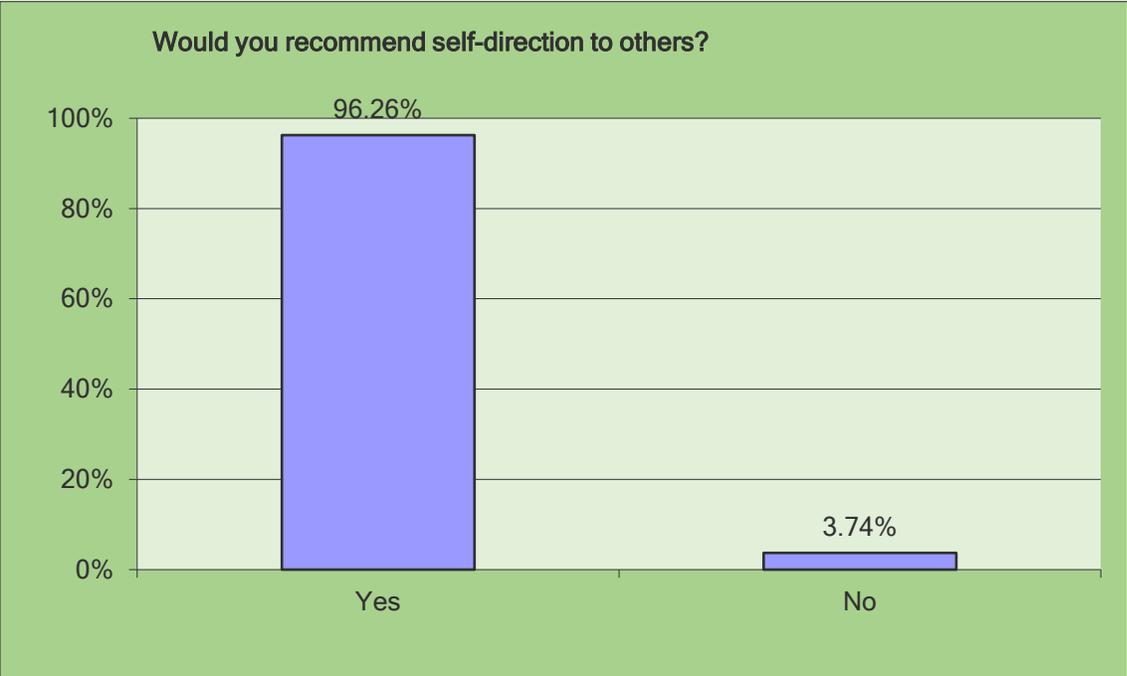
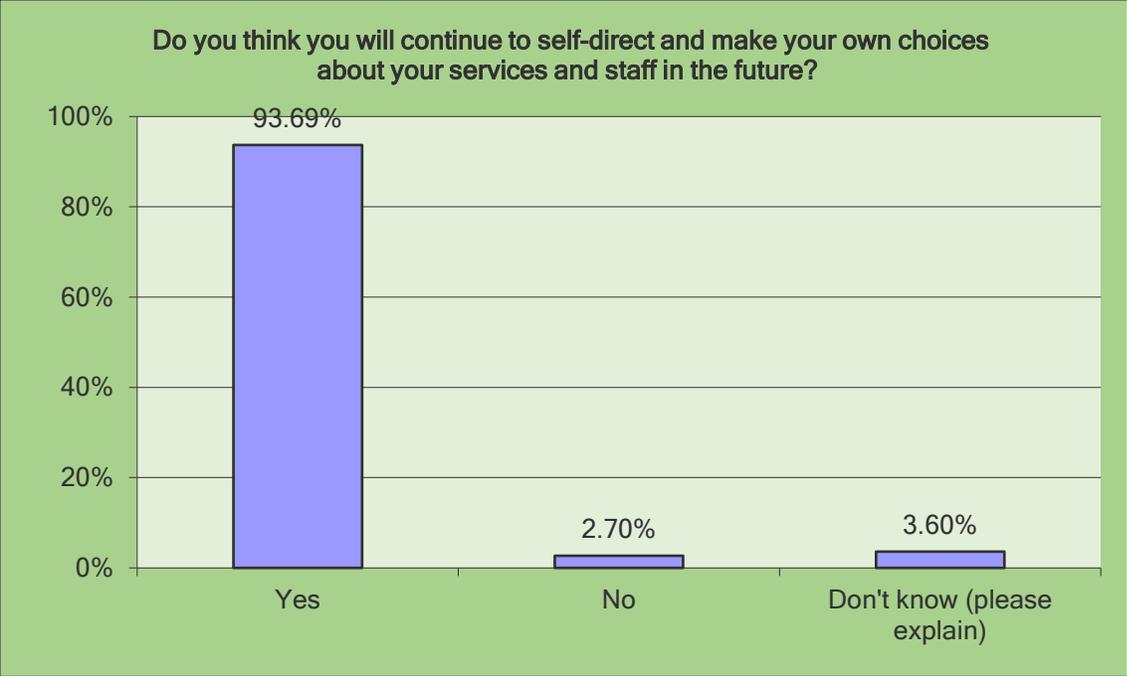


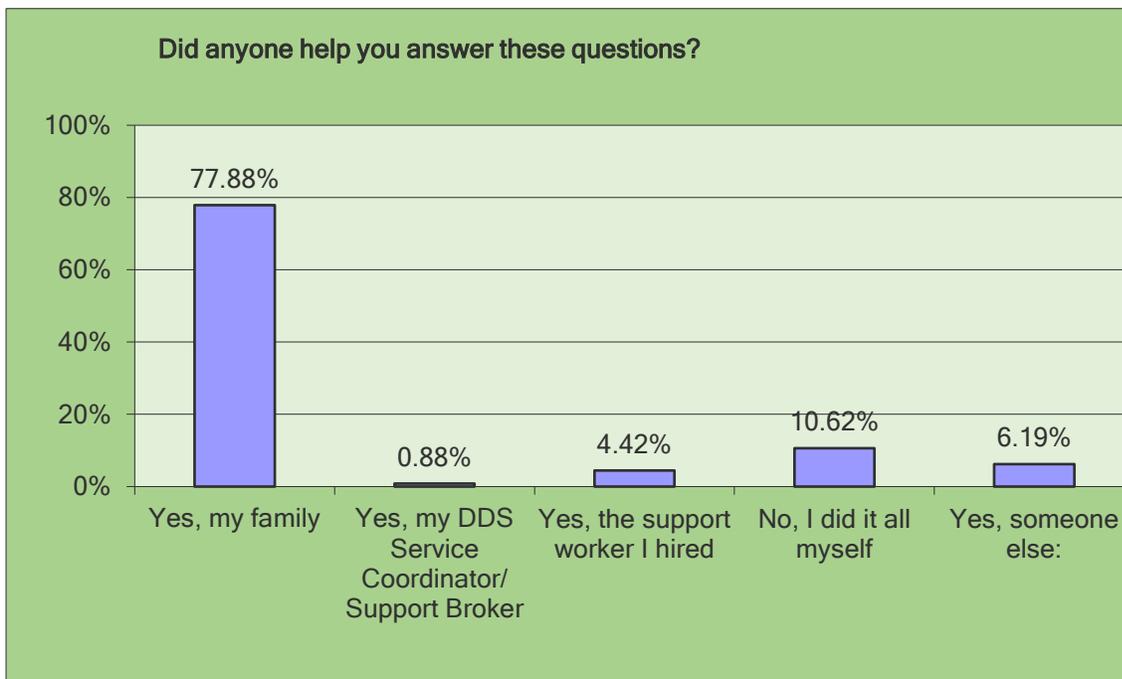
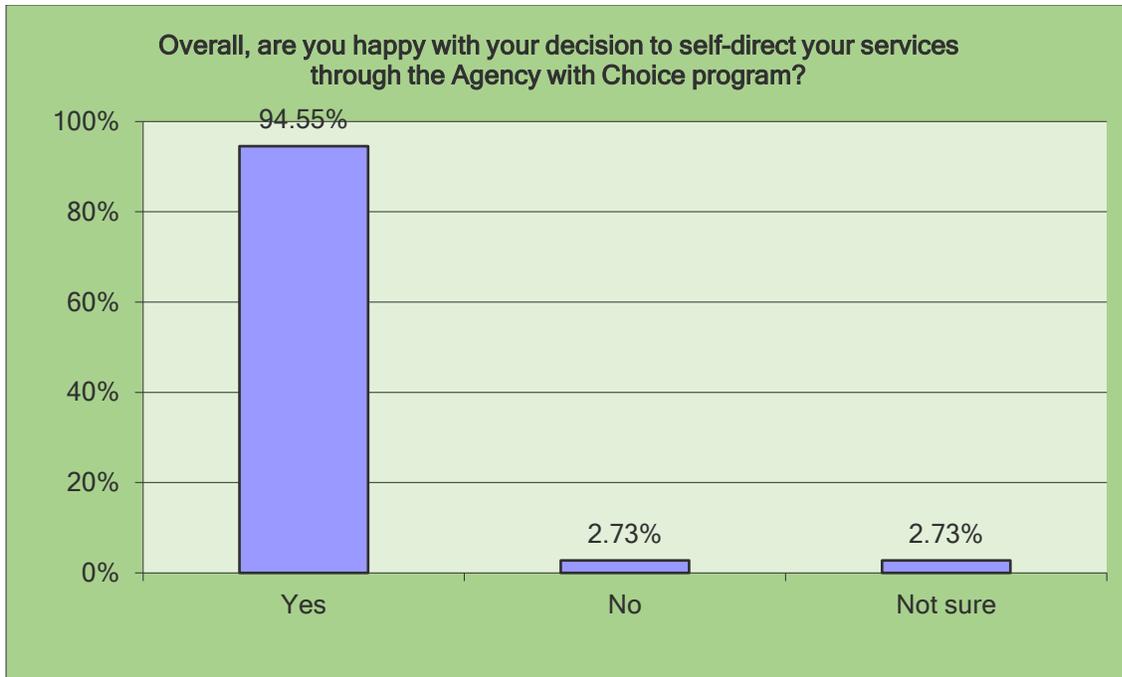
**If you need more help, what kind of help do you need?**

- I want to move to another home
- need to work with DDS re my budget
- I see him for my ISP or ISP update only. However I have never really called him other than to change to PDP
- transportation to meeting and supports to class to improve my life
- a new service coordinator, no longer have one due to relocation/transfer

- not sure
- job search
- the entire staff is very good
- better responses to emails- better time
- I would like more work that is in line with my abilities
- Help with staffing
- he needs to get me out of my group home and do it now! ASAP or I want a new one
- information about services available to me
- Staff - We have 1 staff. If she can't make it there's no one to take her place.
- Intervention for: \*Speedier onboarding \*Speedier reimbursement \*Help with finding candidates
- To meet with my coordinator
- I call for my daughter. I get mostly of the help from (agency name). When we call DDS they usually look into something but we don't really get anywhere.
- Organizational skills, interpersonal skills, money, finances, bill paying, grocery shopping, time management, understanding social situations
- Transportation - If program available
- Social Security, AFC, skills training and a budget
- Dealing with anger
- We are at a critical point in planning name's future







**Is there anything else you would like to tell us?**

- It is hard to answer all these questions when there are two agencies diametrically opposed in efficacy. One is a really awesome group and the other one is truly terrible. Their director should be running a penitentiary instead of a service agency.
- You guys should design a questionnaire that allows me to grade two or more agencies, plus DDS.
- In my case it's just not fair to put together a grading for both agencies into one. "

- I feel that they can't find the right person for me. We waited a long time for (name) and he didn't encourage me or know the rules!!
- Hope to hear from you and that my problem is resolved."
- I am happy because I don't have agency with choice anymore. I have self-direct services and a new coordinator / support broker.
- support to fundraise for SABE conference, public speaking and storybook writer funds and more staff persons
- I am (name) father. She is nothing to do and she need help for everything 24-7 myself and mom and sister helping her
- I'm having transportation issues to get to the day program I go everyday. I wonder if there are some resources about transportation covered by health insurance
- right now everything is good with the program
- "thinking about art or music classes at (name) but still might have to work out schedule now at name and job.
- Administrative Staff wonderful. "
- DDS Service Coordinator we meet with once a year for ISP I do not know who or what a support broker is? Mother
- this form filled out by client's mom-she filled out answers based on what she would say if she understood questions
- need more friends
- self direction is great but the local DDS employees need to provide more info and support upfront when people are starting
- Like self directing- the only draw back is finding good help that will be committed and staying past a year. (rest is illegible)
- Agency with choice has improved my life considerably especially the quality of life
- there needs to be more money for the individuals in this program. Not all clients are, able to work . Activities in the community that interests me are expensive. Activities like joining a gym , working with a trainer , working with a music therapist, taking classes like yoga. My SSI check only stretches so far. Elderly parents have to help finance my life
- I want to request a new DDS Service Coordinator cause he is not moving me to shared living and I wanna move there right NOW and I mean NOW!
- Mom wrote "this does not apply to my son, he does not have choices!"
- While self direction is great it seems to lead to only being with my staff. I don't have friends to do things with. Also, sharing staff with someone else for say recreation would be great. No one seems to be doing this. It would be a great way to stretch hours/budget.
- I'm happy with who I have become so far with the help I get
- The program provides vital supports for me to live a meaningful, productive life in my family home and community and have social and recreational activities that I would not otherwise have.
- I am so grateful for HMEA job coaching because without them I would not have my dream job and be a successful zoo keeper. My job description, animals, safety issues, are always changing and I need their helpful direction sometimes. My DDS service coordinator is outstanding, genuine, caring, and dedicated to helping. He is a great person!
- Transportation - Public transportation in rural areas is Extremely difficult, if not impossible.
- When we signed up for self-direction it was not clear to us that our daughter's priority, group home status, could not be accommodated. She qualified for priority status due to her diagnosis. When a placement became available where was no way to support her self-directed program.

We were not counseled that group home placement and self-directed are mutually exclusive. Our daughter's needs are great. We have developed a wonderful day program for her; but no one to support her in our absence, and no long-term housing plan.

- We are most grateful for our services. There is always for improvement. I little more "hands on" assistance would be a big help. Not just saying yes/no/or "here is a number to call." But ... and their time is limited. Maybe if they had more resources and help.
- Unable to hire skills trainer because salary is so low (\$13/hr) and hours allotted are too (2 hours/week)! Have been told repeatedly by my DDS case worker that the hours cannot be increased due to NO money available!?!
- The biggest concern going forward is a way to increase the budget allowing us to give raises to the staff. As minimum wage increases so should the staff's wages and at this time we have been ""level funded"" for three years allowing for no increase to staff that has been committed for the three years."
- ...the last three years becoming more independent, making [illegible], looks forward each time I go with staff and is up [illegible] ...of what like will be [illegible] for name, when we are not here. Thousand thanks!
- Very happy with self-direction, with the agency, with my wonderful helper, and with my DDS service coordinator.
- Historically, when there are changes with the DDS coordinator it is not always communicated to the consumer and family in a timely manner
- "Mother would like to say People Inc. program has made a positive situation from a problematic one, from depression to increased interaction.
- Also, our autistic adult son does not discuss much, so his thoughts as we did this survey were helpful to me too."
- Why was my severely disabled son turned down for Social Security???
- , her DDS worker has been extremely helpful accommodating. We appreciate her help. my sisters coordinator from The Arc is wonderful -- she is great help and a wonderful advocate. She is a MIRACLE WORKER!
- my sister's previous DDs worker was the best. We really miss him. "
- This survey didnt allow me to answer all the questions under Agency with Choice. I dont know who my DDS coordinator is. He/She has never contacted me therefore he/she is of no use to me. This is my second Agency that I chose to work with because the first one never provided services to me. This current agency still has not found staff as of July 1st. It is now the end of September.
- Great Service!
- I am the parent of Autistic Adult ages 18-23. I am the one filling out [the survey]. We are very happy with services so far. Thank you!
- Very grateful for AWC & DDS support. Much appreciated!
- The freedom to choose is amazing - as is the cause. However - difficult to fund excellent caregivers who totally get it -- far and few.
- ""Completed by parent/guardian, son who is nonverbal""
- [Re: #8, It's hard to find and keep good staff, added ""and have them understand it's about true choice""]
- "This has been the worst program for us to start. My child has had no program started since March. We have paid out of pocket all summer to work with a college student. Started with agency with no results. Now we have been waiting 5 weeks for agency to start. They just received the referral this week. We were told it was sent in End of July.

- I'm very happy living on my own
- Very happy with services.
- Agency name is doing a great job with AWC.
- I am 35 years old, living at home and would like to think about alternatives for my future given my strong likes and dislikes
- We appreciate our AWC program very much!

# **MA Real Lives Evaluation**

## **DDS Staff Survey Results**

**November 2019**

Prepared for:

Massachusetts Department of Developmental Services

Prepared by:

HUMAN SERVICES RESEARCH INSTITUTE

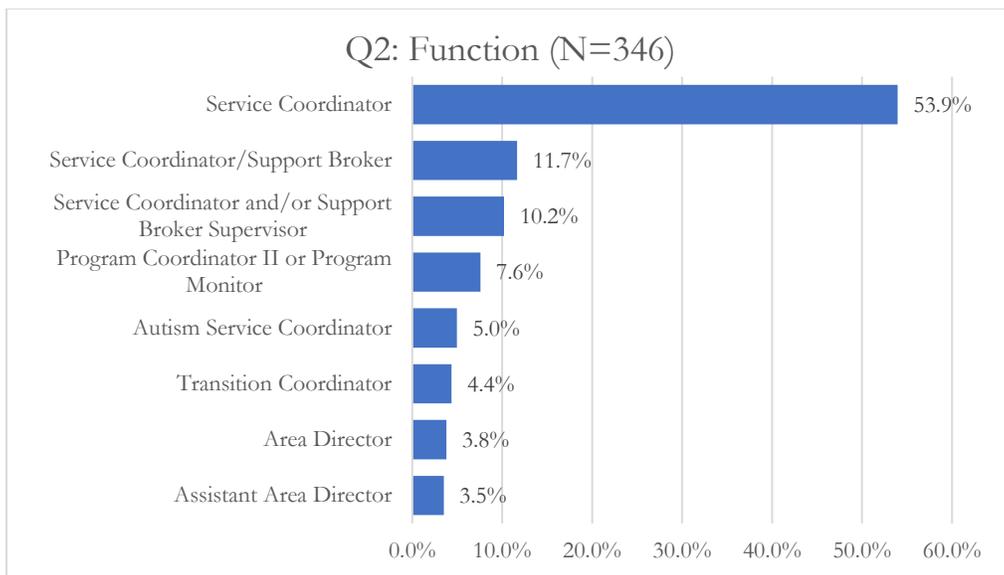
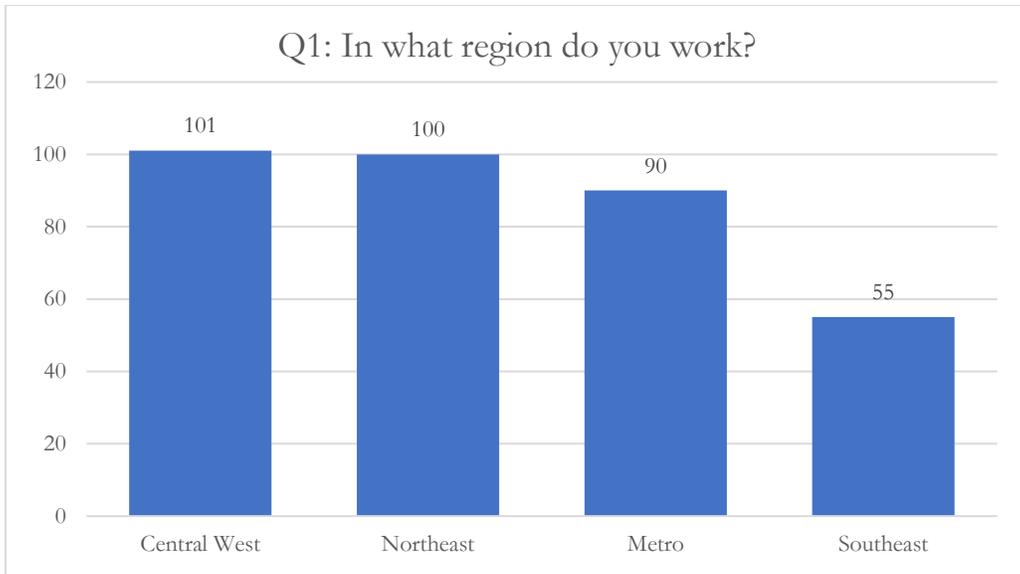
November 27, 2019

### **Background**

The following data were collected using an online survey that was designed to be taken by DDS Service Coordinators, Support Brokers and their supervisors. The DDS central office sent an email and link to each of the regional offices who forwarded that message onto their respective staffs. HSRI received a total of 346 survey responses between September 1 and October 13, 2019.

### **Results by Question**

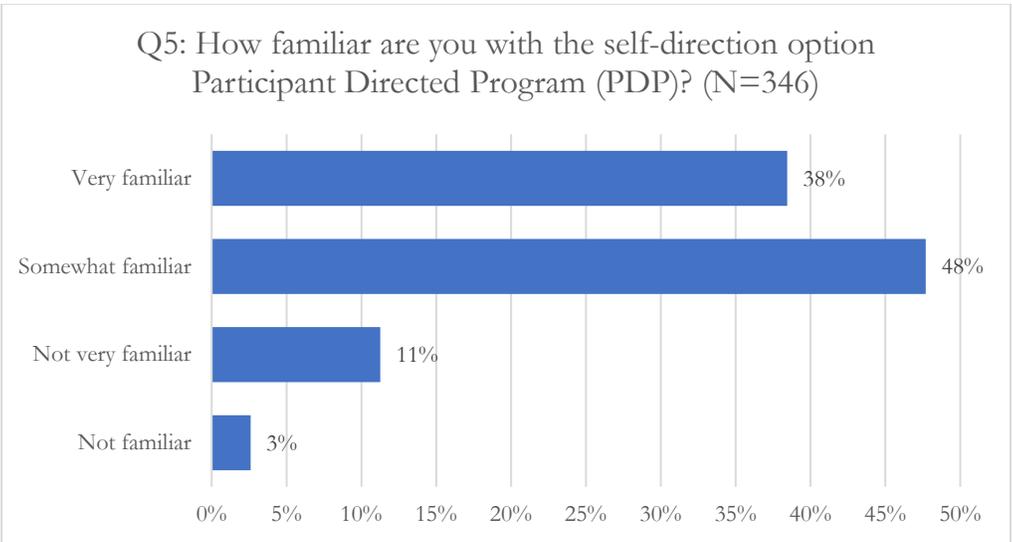
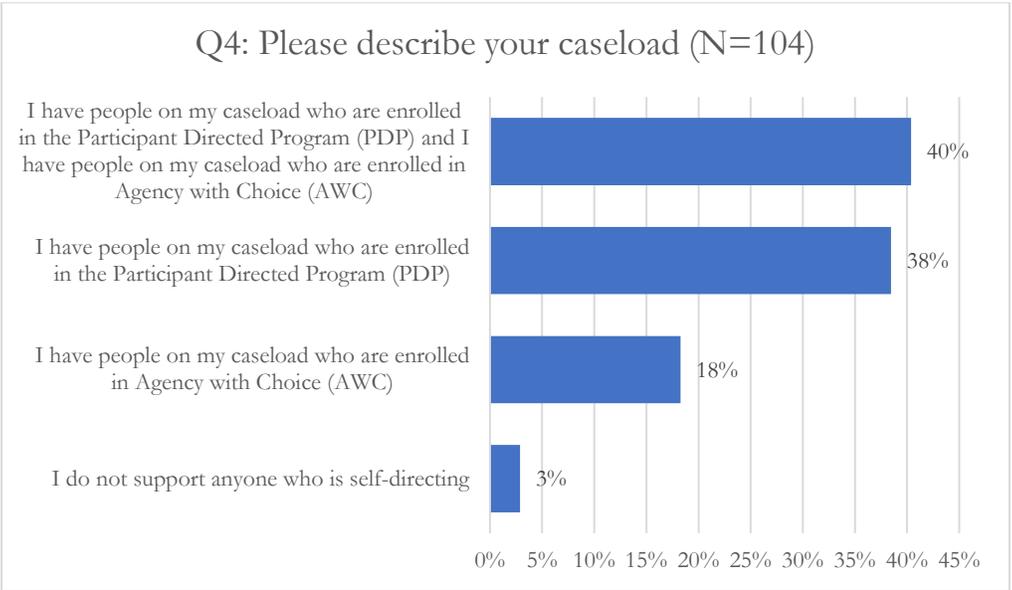
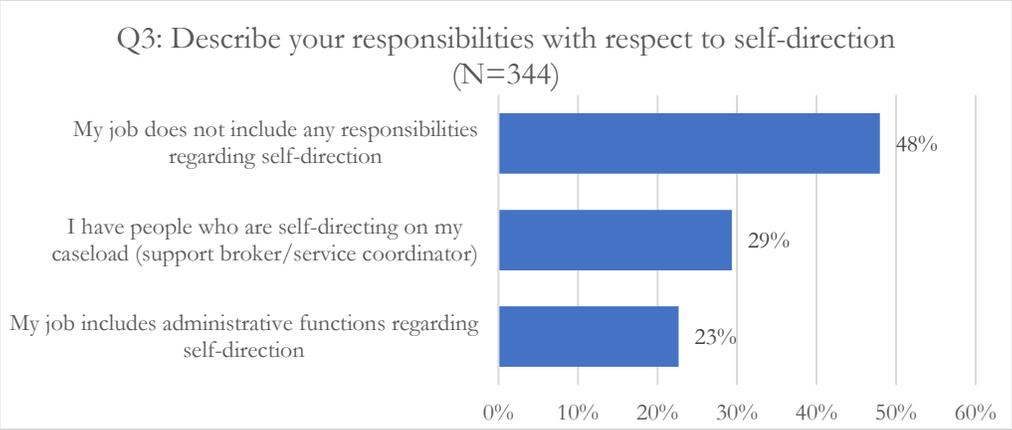
Detailed results and graphs for each question on the survey are presented below.

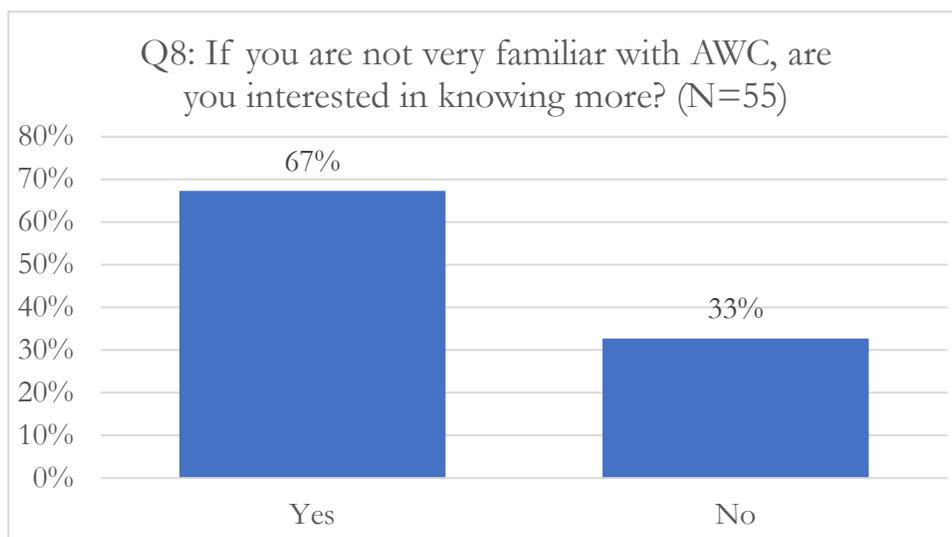
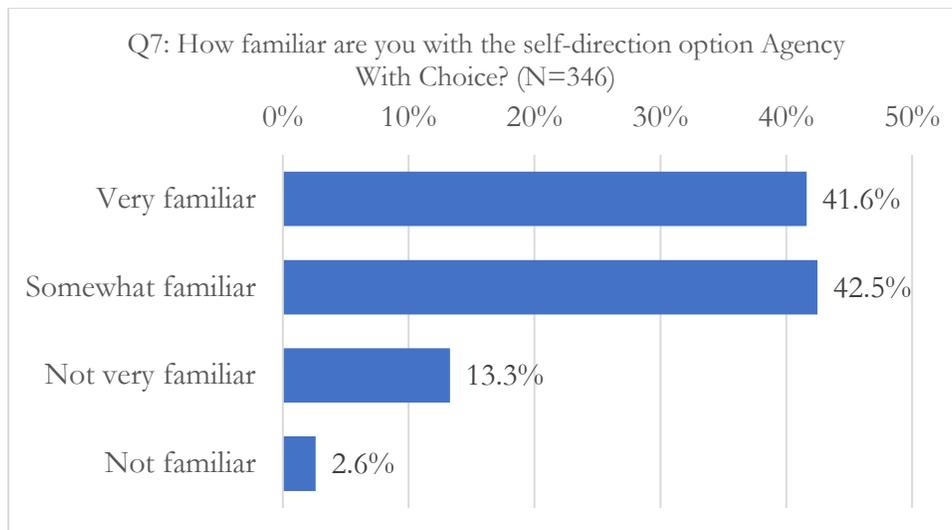
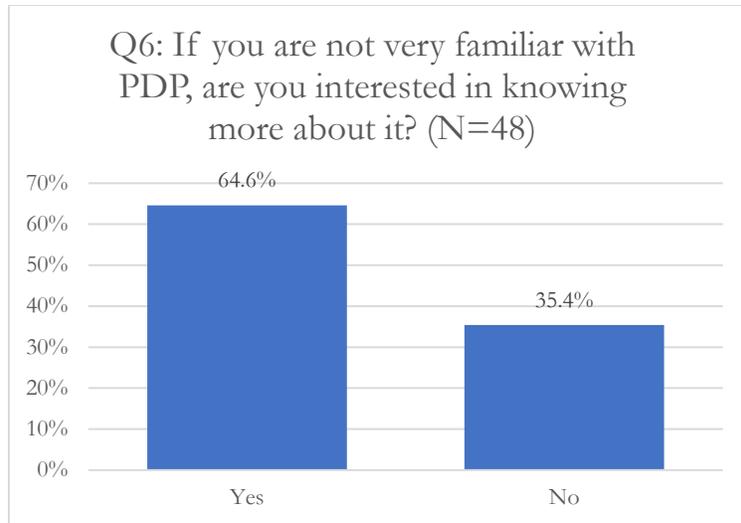


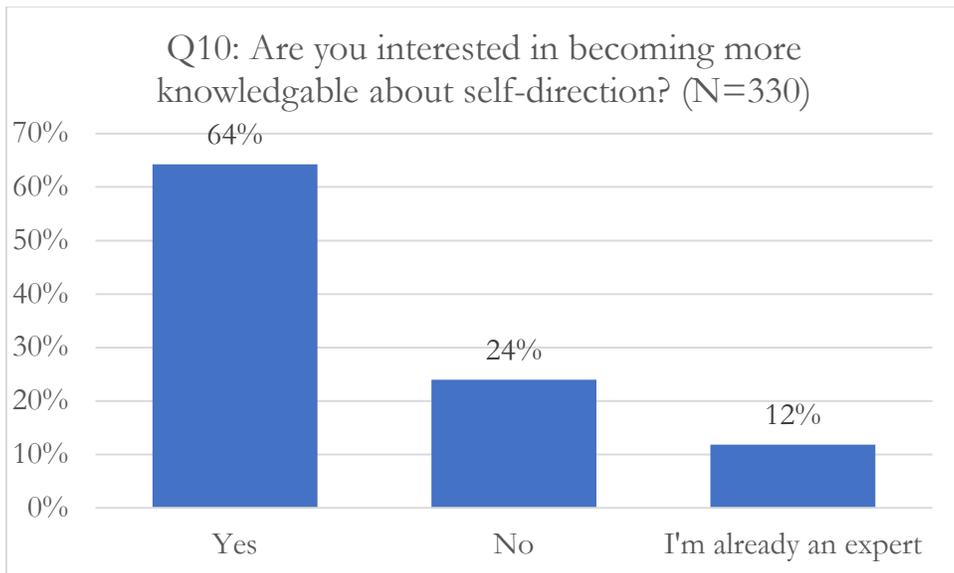
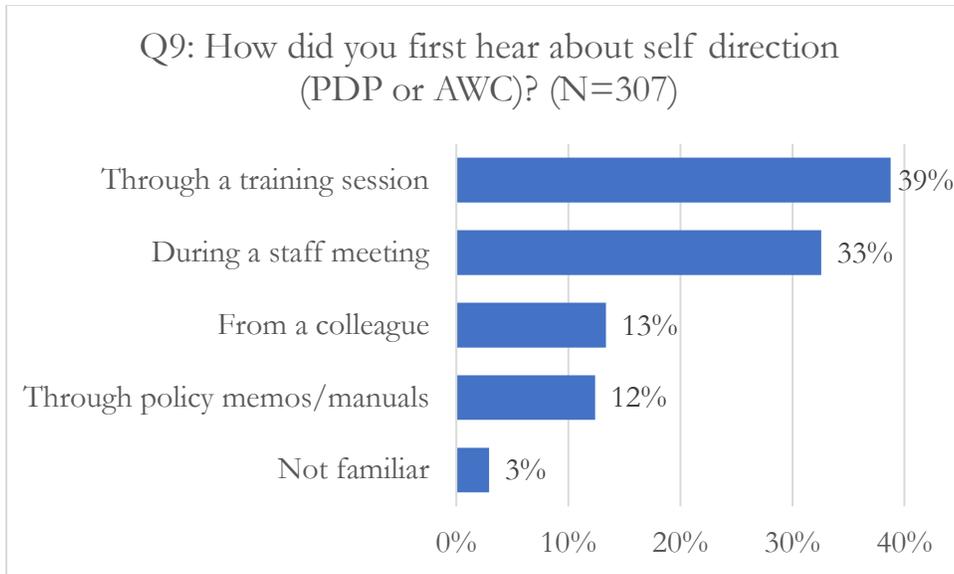
“Other” Responses:

- ABI MFP Director
- Active Treatment Specialist
- Admin.
- Area Office SD Liaison
- Area Psychologist
- Children's
- Children's Coordinator
- Children's SC
- Children's with DESE access
- Clerk
- Clinical Director
- Clinical Director
- compliance
- Fiscal Projects Manager and support to SD Advisory Board
- Former SC
- Healthcare
- I am a Program Coordinator, but I am considered our office's Support Broker
- Metro State Op Director
- Nurse
- Office Support Specialist
- office support specialist
- QE

- Quality Enhancement Director
- Regional Director
- Regional Director
- Regional SD Manager
- service coordinator supervisor
- Service Coordinator Supervisor
- Service Coordinator Supervisor
- Service Coordinator Supervisor not directly involved in Self Direction
- Supervisor
- Supervisor
- Training





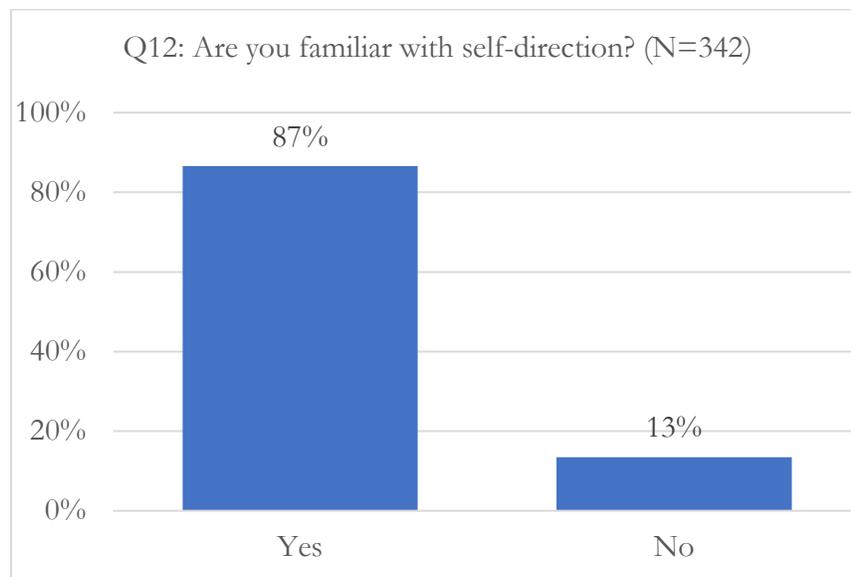


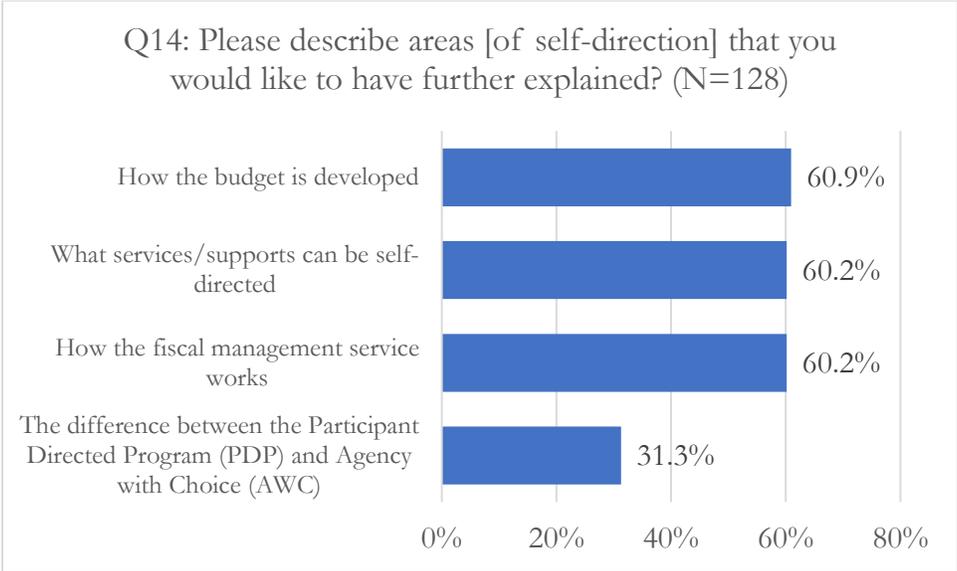
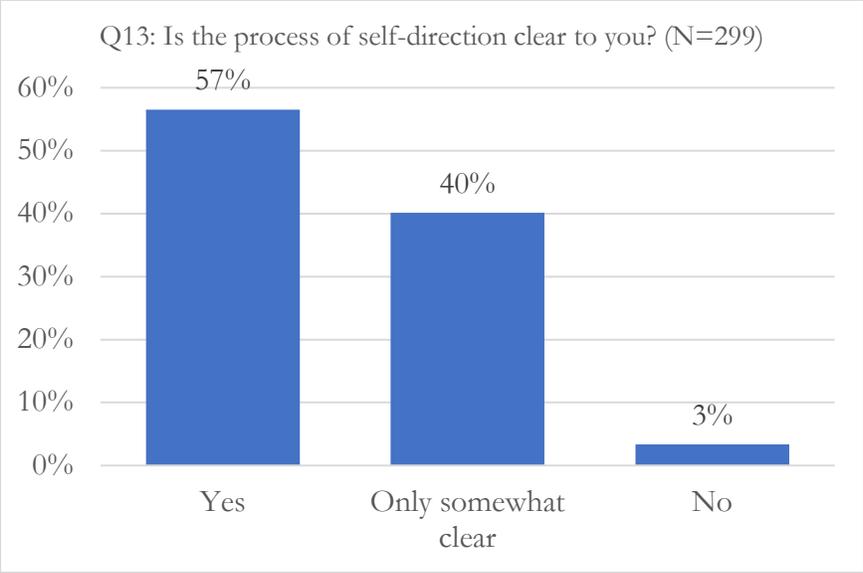
“Other” Responses:

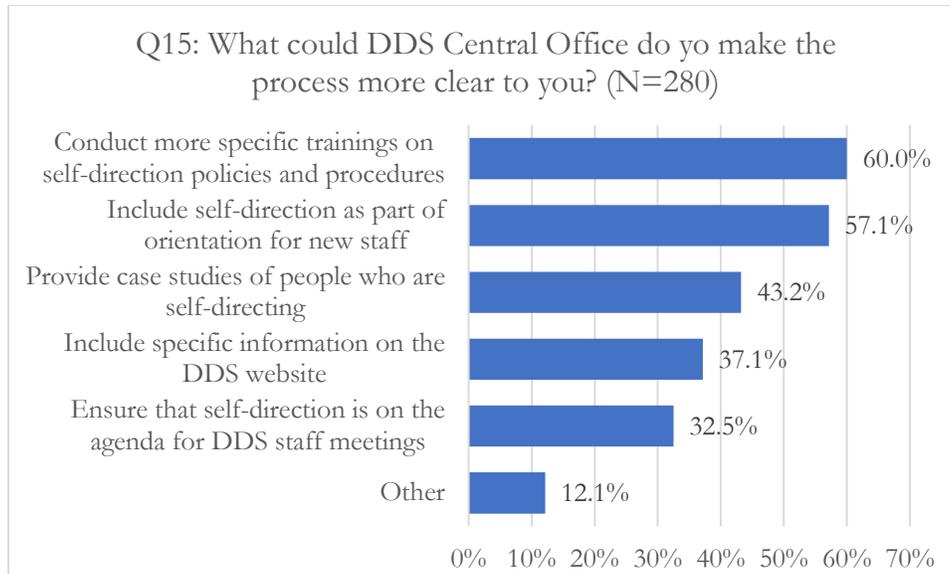
- ABI MFP Does not currently have the option for self directed supports
- Agency with Choice as one of my individuals wants that service
- Agency with choice day
- Always want to know more
- Can always become more knowledgeable
- I am familiar with the PDP process and consult with supervisor and support broker.
- I can always be more knowledgeable
- I feel knowledgeable already but I'm always open to new info.
- I have experience
- I have sufficient knowledge and know where to go if I need more information.
- I like to participate in monthly Support Broker meetings to stay up to date on any changes
- I wouldn't say expert, but I have lots of knowledge of self-direction

- If I need to
- if self-direction was available in traditional service model yes
- I'm knowledgeable enough.
- information available suffices
- Maybe
- my role isn't directly involved but we discuss the option
- not if i am not going to need to implement it.
- Our office has a specialized group that focuses on self-direction. I could learn it but then I would never practice it so it would be pointless.
- The Metro Region has great informational sessions, Regional Meetings, etc.
- This evolves; knowledge expands. Nobody is so expert that more knowledge would not be helpful.
- updates- DESE training for self and vendors
- Yes, always. Experiential learning as well as learning through ongoing analysis of the system, the tools, the process and participant feedback.

**(Q11: Is an open-comment question, see the end of this section for those answers.)**



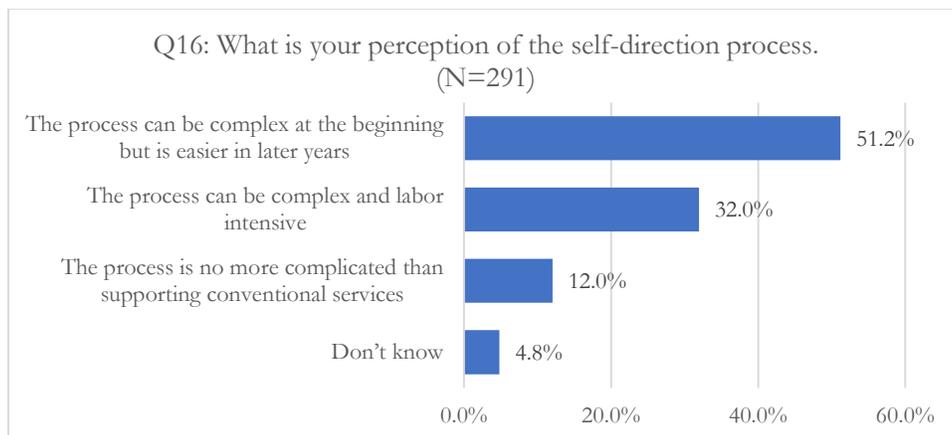


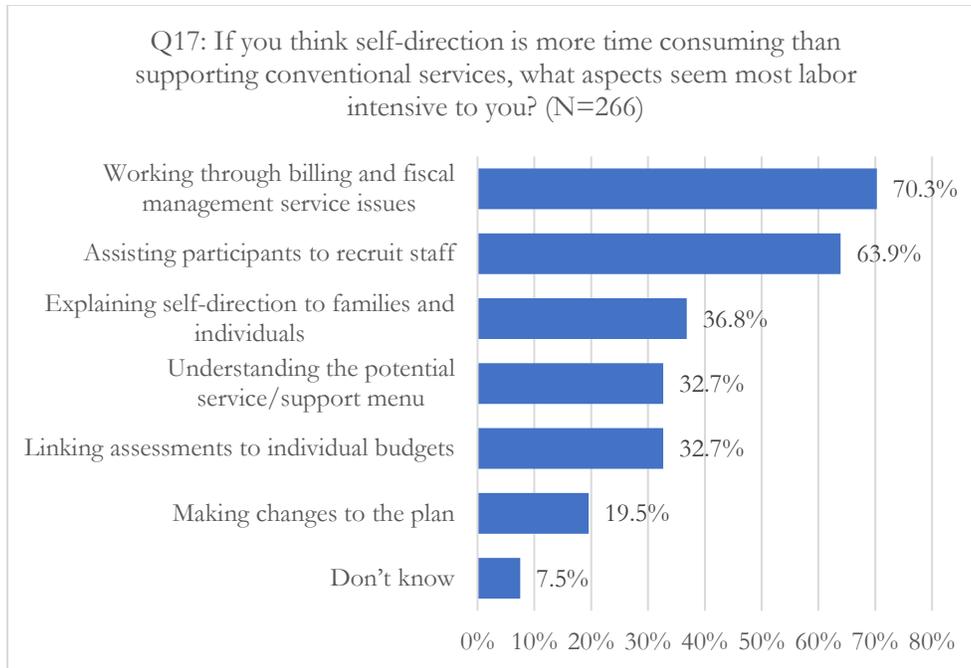


“Other” Responses:

- all the above
- Better oversight so that self-direction is consistent across area offices
- Case studies both positive and negative, so we can learn from both.
- Change the perception that Self direction is a process that is leading to the privatization of Service Coordinator position/services.
- Clearer guidance and direction for families seeking policies and operations guidance
- Consistent and concrete guidelines for support brokers to adhere to when approving/denying invoices. Provide step-by-step trainings from start to finish when completing credentialing packets, EIN packets, etc. Provide trainings to support brokers to navigate the Portal through the participant's perception (filling out timesheets, etc) so that we are able to train them.
- develop comprehensive training manuals that are standardized across the state; provide additional individual friendly documents across the internet about self direction; develop training videos for individuals/ families instead of delaying this idea; make all PDP systems more user friendly for all users (Hsc/ families) ;
- Ensure a clear, consistent curriculum is available to train the workforce. Staff rely on peers to learn PPL Portal. There should be formal training available like DDS ensured with Meditech, HCSIS, etc.
- Expand the audience of DDS staff receiving in depth training. ie. Transition Coordinators, Adult SC not in a support broker role, etc. SC supervisors
- Have Support Broker Quick Reference Guides
- Have the service area reviewed on a regular basis within area office management meetings. Review funding in budget, consistently receive updates on available funds for new cases. Our reach from the supervisor of self directed services.
- Help to get 509 on board with SCs taking on these cases.
- I believe Central Office provides the needed information - It is just a matter of me walking through the steps of someone going through Self-Direction for me to get the full understanding.
- I think it is helpful to ensure that it is part of new orientation for our staff. Updates are helpful via email for me to use.
- Identify the components necessary to make SD successful. (Example, network of support, Individuals' level of functioning, what factors must be present)
- Include it in during the eligibility process as part of any other DDS support service.

- Increase PPL consistency and accuracy when processing
- interactive trainings of case scenarios developing budgets and entering items in the portal as it is very prone to issues. How to deal with different pends and what expected timeframes are for resolution. What is a processing error on PPL side versus incorrect entry by support broker. What is a good use of a certain code or what would be an exception for using a different code
- It is always on the agenda for our staff meetings!
- Mix self directing individuals into every SC's caseload, not just one designated person
- More details regarding specific functions and how-tos.
- More frequent specific trainings on PDP areas that are challenging
- Posted case studies could help generate ideas for all support brokers.
- Provide clear, consistent, and concise guidance for families
- Provide support in starting up a new self-direction budget
- SC Institute
- Self-direction needs funding and positions
- Stop changing the rules every day.
- The best training is to have a knowledgeable person walk you through process and help you troubleshoot your first case
- Training on policy/procedure will only be as useful as the policy/procedures are clear. There seems to be little consensus on how the SD process works between area offices.



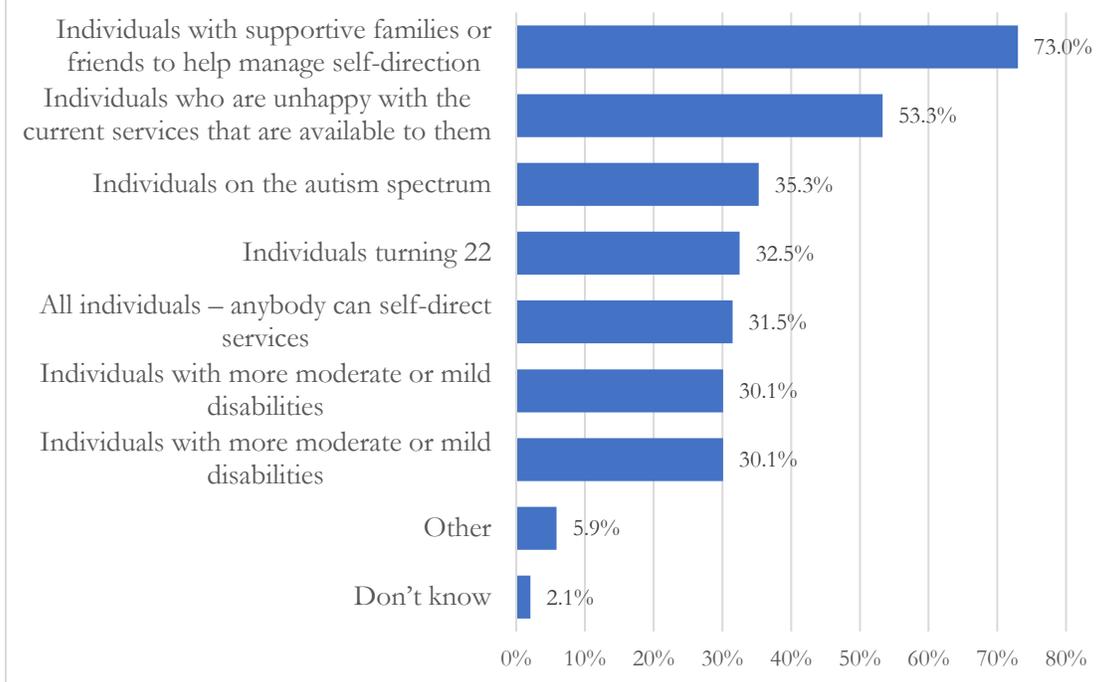


#### Other Responses

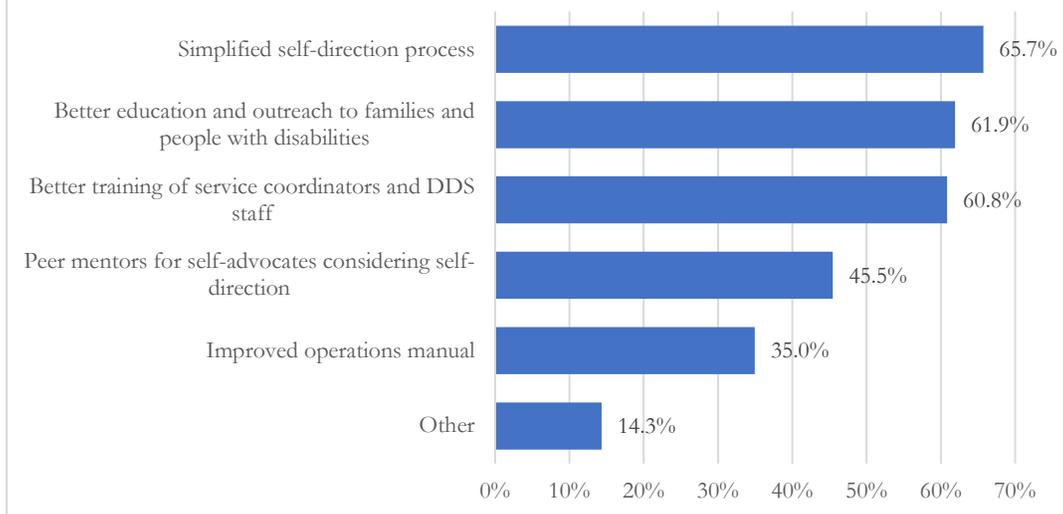
- 1) making sure clients spend their budget is spent on time so clients don't run out of money; 2) helping clients with an excess of funds because they couldn't find a worker; 3) re-explaining the ever changing guidelines about how clients can spend money 4) ISPs are off HCSIS and we need to do all assessments/goals/etc.
- All of the above
- All of the above
- All of the above
- Also, submitting receipts for reimbursement is time consuming.
- assisting individuals and families by explaining it and navigating the choices.
- Assisting participants on other languages than English
- Checks & Balances, making sure services are no being duplicated elsewhere
- Explaining and justifying what services are covered and not covered and making sure families stay within the new caps without being told to do it one way but then having upper management change how to do it afterwards.
- Explaining the PPL portal, EIN paperwork, EOR/on-boarding documents, workmen's compensation documents, etc to families, and fielding their questions about these documents.
- Families tend to need the most assistance when first setting up self-direction. Once the program is set up and staff identified, Families are able to manage independently, unless they need assistance in re-evaluating their budget or finding staff. Some families also need assistance with accessing and understanding community resources.
- finding an agency of choice
- Finding staff can take a long time. Credentialing staff and submitting EOR paperwork can be time-consuming if you are not already familiar with the paperwork/portal. I perform those functions, instead of the Service Coordinators, for the sake of time.
- For PDP families need help when glitches come up on employee phone apps for billing
- having the individual take the lead with directing their own services.
- Helping individuals and families to understand the budgets and policies

- Hiring/onboarding of staff (acting as Human Resource Departments), especially to families/participants who are not familiar with technology to access the information themselves.
- I do not feel it is more labor intensive
- I don't think it is more time consuming.
- If issues arise it can become time consuming to address the issues at hand.
- initial paperwork issues and interacting with customer service when Pends arise. Explaining to families that group homes cannot be supported through self direction as different regions have explained things differently.
- It is not that difficult- with the exception of submitting the invoices to be paid - that takes some time.
- Many of these apply as being difficult, especially financial and finding support staff
- Monitoring services to prevent fraud without the hierarchy of something like (a hopefully unbiased) human resources department at an agency.
- Monitoring the service for appropriate use and expenditures
- n/a
- NA
- Paperwork Training to the employer
- processing invoices, helping with the employee/employer paperwork
- providing training to participants on how to navigate the SD process
- re-educating families who receive inaccurate information about self-direction from vendor forums
- self direction staff are the point person for services and supports that can not be answered by PDP customer service.. agencies have multiple staff to spread out the work. PDP is time sensitive. Individuals and families expect that their DDS PDP staff are always accessible due to the time sensitive nature of PDP with timesheets, credentialing packets and invoices.
- Some requests are not allowable and families/participants do not always accept that somethings can't be granted under the regulations.
- Sometimes changes to the plan cost more and the funds are not there. Also some individuals want to hire family or friends and that is not always the best choice because challenges always come up and some people find difficulty in separating personal from work.
- Start-up process with paperwork
- Supporting providers and participants more due to no agency involvement.
- The biggest issue I find, is that families who support individuals who would benefit from Self-Direction, don't have a knowledgeable person with enough available time to implement it.
- The registration and credentialing process (start up), inputting receipts, trouble-shooting Pends
- There is a specific person in office who manages this
- We need additional brokers due to amount of referrals.
- Would emphasize that the recruitment of staff, during a statewide staffing crisis is very time intensive for the families and DDS staff.

Q18: Which DDS individuals are good candidates for self-direction? (N=289)



Q19: What could be done to enhance growth of self-direction at DDS? (N=286)

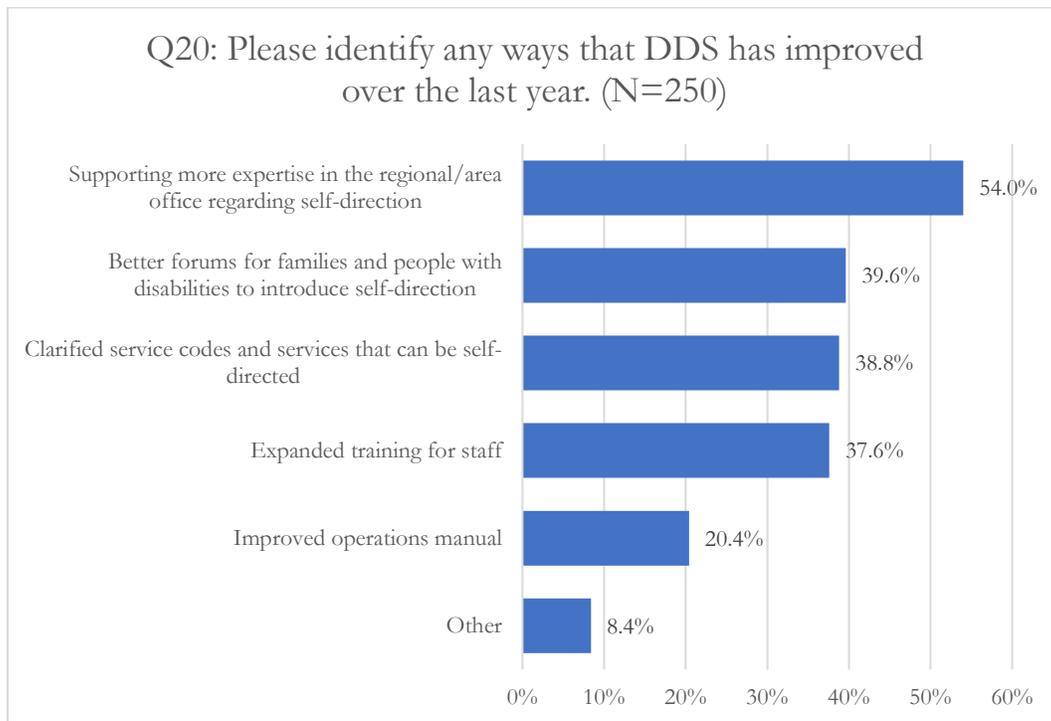


“Other Responses”:

- A training/orientation for all parents going into PDP discussing policies of staff, benefits or lack thereof, payment system or app training for using PPL etc...
- access to funding allocations to develop program
- Additional Service Coordinator Positions

- Additional staff
- All the helps, manuals, regular trainings and in office trainings are great. Anything can be better though:)
- Change our caseload sizes so maybe more SC could assist.
- Consistent procedures across area offices
- DESE participants should have greater access to this support WITH APPROPRIATE CO, REGIONAL, OR PPL SUPPORT. This might allow families to begin to learn the concepts, efforts, benefits and limitation of the model. Potentially expand to Family Support, particularly for large allocations. Work more closely with schools in the years preceding transition to not only provide the general education, but perhaps to begin more specific training on what a self-directed set of services may look like. This would require a better formula for determining 688 allocations for potential participants. At 22, families are already leaving one service for another. This may be the group most open to exploring this option, but it takes considerable time and would need support beyond the Transition Coordinators to do this well.
- develop back up plans and staffing pools for individuals
- Educate the public about work opportunities in this field.
- Education and outreach to school program transitional staff beyond what the service coordinator has time to provide. Availability of agents for those individuals whose families are not able to support them with self directing services.
- Families need help recruiting and keeping staff. That is the biggest concern for families considering self direction.
- Getting 509 on board, still push back on SC's taking PDP cases.
- Glossy Marketing materials, strong connections with schools and young people, stop calling it "non-traditional" and "unconventional," create an expectation that SCs ought to know this program as well as they know all the others
- Guides for individuals with resource information in the following areas: Where can I find an employee? Navigating the PPL Portal (simple language, pictures, and step by step instructions), Writing a Job description,
- Having enough funding available for staff training that work in the self-direction model.
- I do not know, I am not involved with this program.
- If there was more support for the families in implementing this, it'd go over better. When we explain the type of work and amount of work involved on behalf of the families, most people I speak with shy away. They can't make the level of time/energy commitment in the midst of working multiple jobs, and supporting the rest of their families. If support brokers had substantially lower caseloads and could put in a higher degree of assistance to each family, this would be more feasible than it currently is for a great deal of families.
- Improved communication at the area office level in regard to budget and availability for new referrals. Over view in staff meetings.
- Increase in the number of SCs in the office
- Increase staffing pool
- ISP developed for those that Self-Direct. Current ISP does not work for those in that service.
- It is so complicated, it just doesn't fly! I need someone holding my hand the entire way, which does not give confidence to the individuals and families I support.
- It seems very cumbersome to keep up with the constant updates
- Maintain / increase "flexible" part of Self Direction
- Make it a mandatory function of all Scs
- Make it part of Service Coordinator EPRS to have at least one person from caseload Self-Direct
- Making the entire process more accessible to individuals with developmental disabilities- NOT necessarily their families.
- More implementation support for families, supporting them in becoming employers and how to supervise, support in developing schedules and activities etc

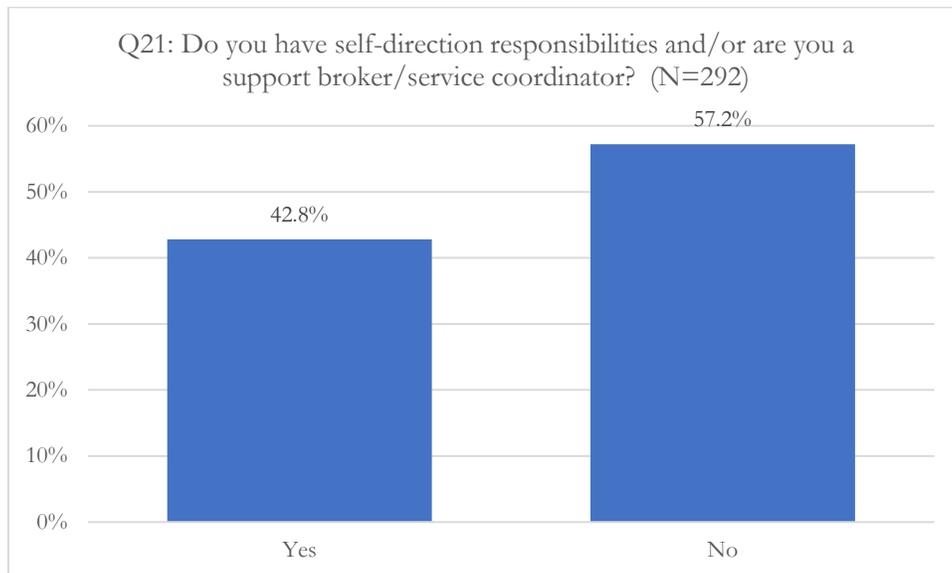
- More resources, easier ways to recruit. I have the impression that it's much easier if families should hire people they know, which is not at all easy in most cases.
- More staff, lower caseloads
- n/a
- Needs its own funding and positions. It's too big a process to fit within our current system.
- On-going training (offered quarterly?) should be available for professional development in this area
- Provide assistance with finding qualified staff
- Success stories from peers
- This should be pushed at the 688 level, at IEP's, etc.
- Unsure
- Unsure
- Videos about how to use PPL portal and other aspects of self direction for clients and families, they could posted on YouTube
- When approaching families with PDP/self direction services, they should be aware they will need to be assigned an EIN through the IRS (sometimes families are taken aback by this), understanding they will ultimately be Human Resources for their staff, technology requirements, understanding that the program is Day Support and staff/service delivery driven. Understand staff turnover and recruitment. Finally, families should have training on the ISP document and the documents necessary to be completed every year/6 months. Training in Goal/Objective writing, progress summary requirements along with data tracking, proper assessment reporting (and what assessments are mandatory annually), etc. Families who are not aware of these topics up front oftentimes become very discouraged and agitated with this service delivery option. Families and participants should go through an "orientation" with the realities of PDP/self-direction prior to choosing this option.

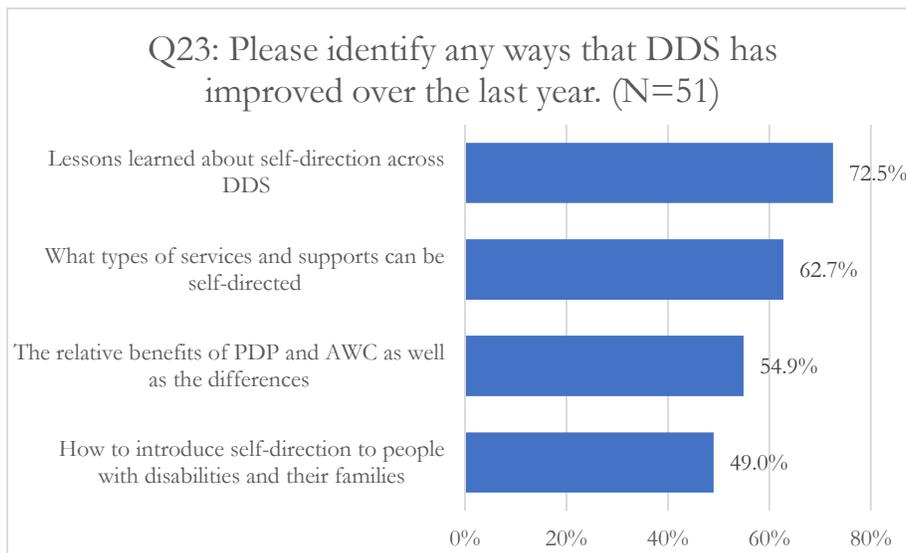
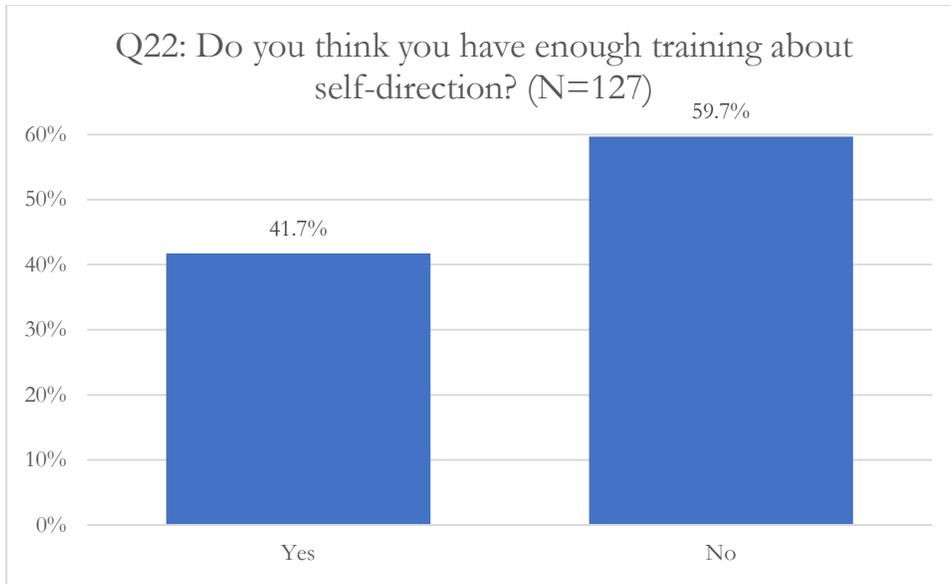


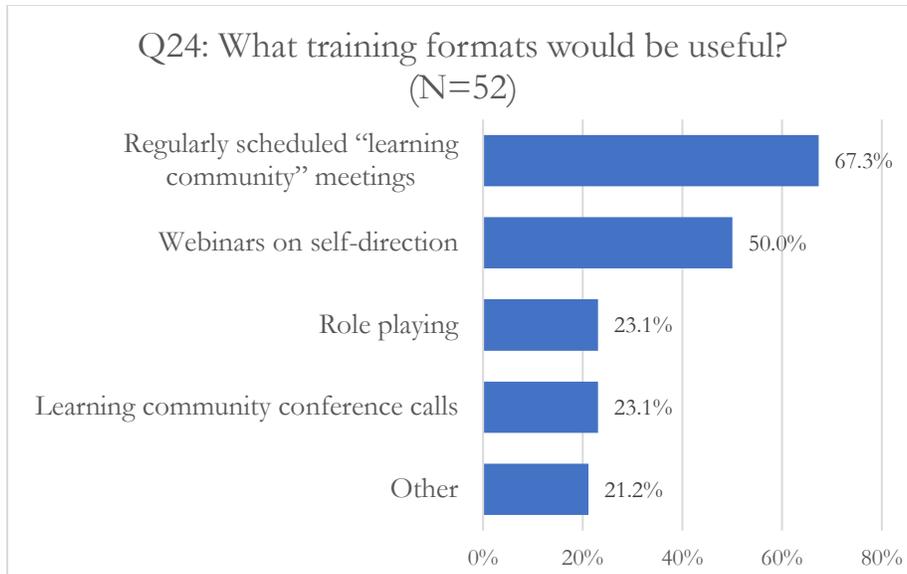
“Other” Responses:

- Access to Pam Hickey
- Can't speak to forums as I've not attended

- Dont know
- Have not noticed a difference between this and last year
- Have not seen a change
- Haven't been employed for a full year
- Having New Guidelines out is great
- I am a new employee
- I have not had the opportunity to work with self-direction
- I have not noticed particular improvements.
- I'm not sure.
- It has become more in the fabric of our thinking.
- Limiting codes was a huge help. However, still too many options.
- Making individuals and families aware of the PDP option
- Managers assuming more of the responsibilities because the process is slow or makes no progress because it lacks clarity.
- No improvement. Too complicated.
- none
- none
- None of the above
- Provided an amazing Support Broker Staff Person in our area office
- Slightly clarified service codes and services that can be self-directed. Summary guide for self-direction has some clearer guidance.
- There is a specific person assigned to manage cases
- unk

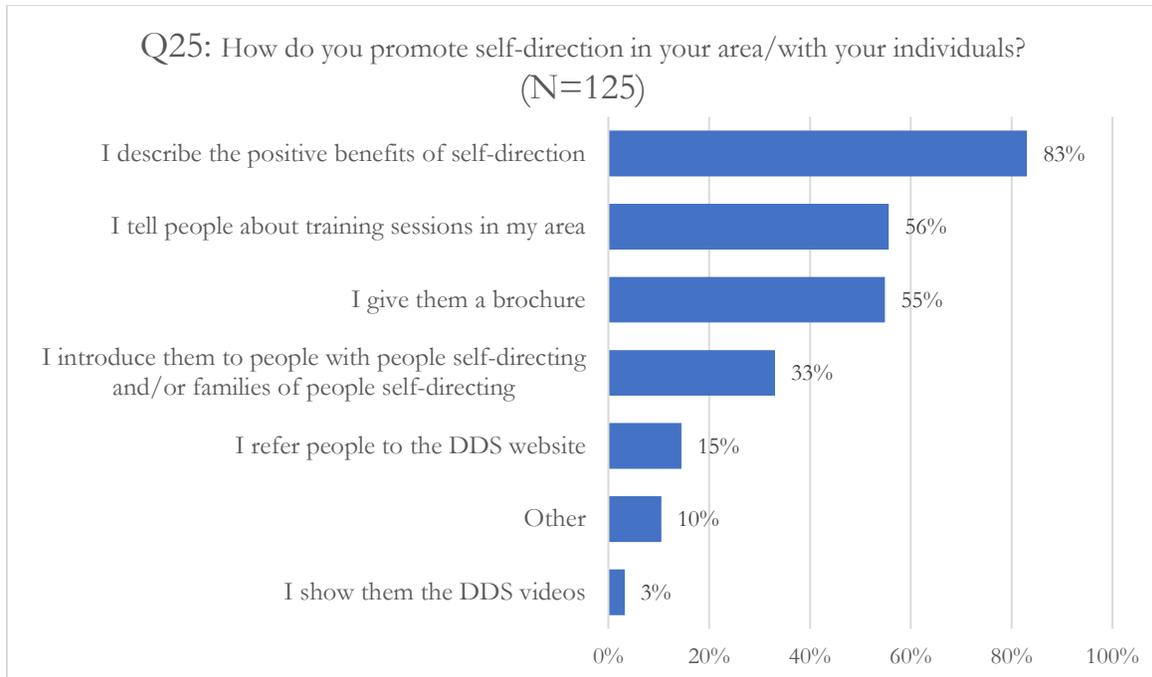






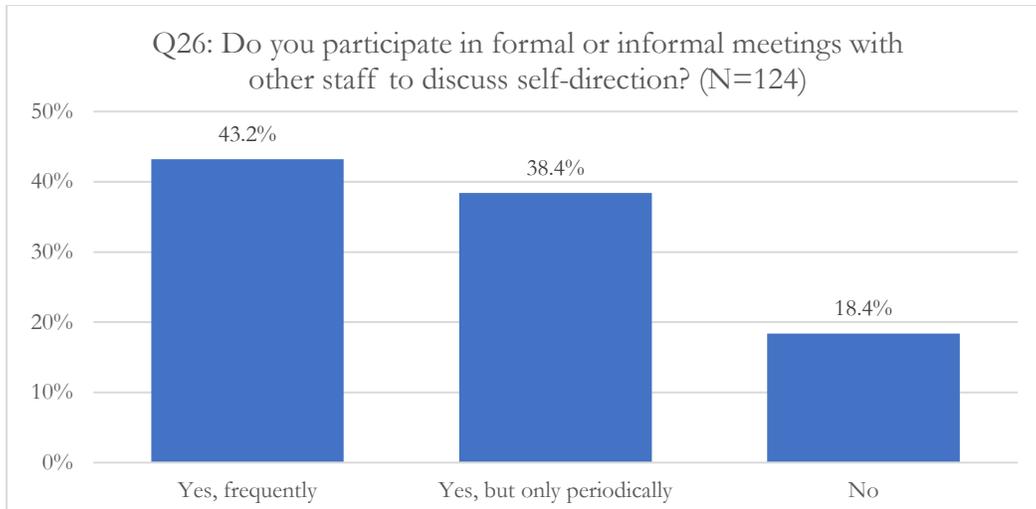
“Other” Responses:

- A formal curriculum
- Hands on practice with PPL site in a test environment
- Interactive entering items into the portal, interactive budget development
- Interoffice Meetings
- It's not about the format. This subject is complex and there are few experts.
- More guides, written checklists, etc. At the area office level, it is important to have written material to reference and as a source of finding answers to the everyday questions. A checklist of sequential steps for orientation, forms associated with start up, steps in Meditech, steps for the contacting the waiver unit, etc would be extremely helpful for day to day problem solving and getting through the most difficult part of any self direction work: start up.
- Quick Reference Guides
- Staff meeting
- Trainings off site
- Videos on Youtube; twitter, and other social media platforms
- Walking through the steps of self direction



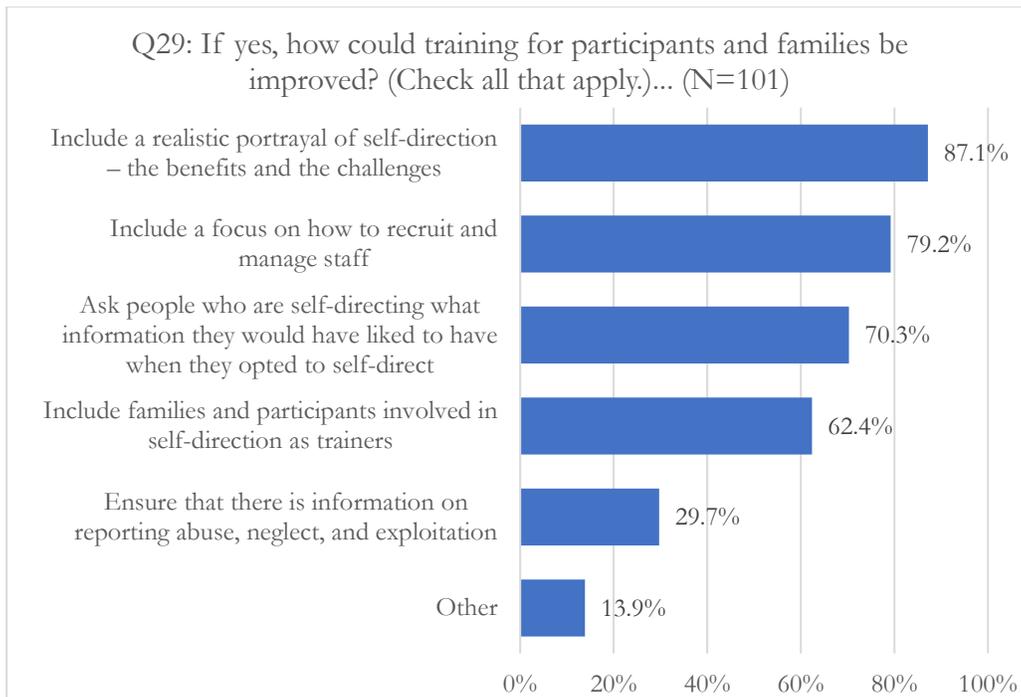
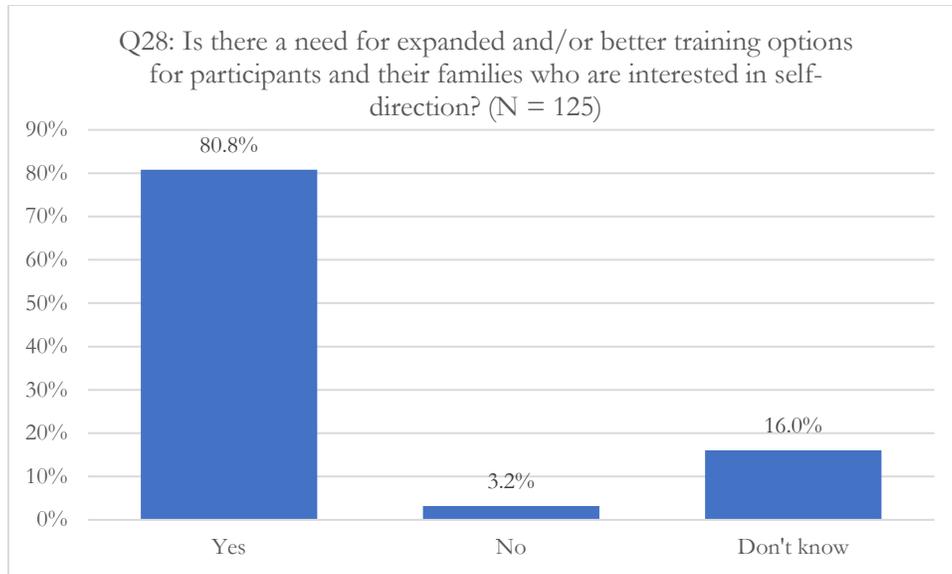
“Other” Responses:

- Cookies and Chat in Fitchburg!!!
- Discuss in initial visit and again if/when financing of services become available
- Face to face meeting with families/individuals who have shown an interest in PDP or have expressed disinterest in more traditional models of service delivery.
- Have them meet with expert in the office or region.
- I am mostly trying to promote SD among staff in my area office (SCs and SCIIs). SCs must see SD as a viable option if they are going to talk to families about it
- I bring our Support Broker Staff Person to visits and meetings for people who have expressed interest
- I clearly present the pros and cons of all services including self-direction and let client decide
- I give info sheets from the DDS Transition Manual. I email the Self Direction PowerPoint presentations. I give examples of how other individuals are using self direction. I include self direction materials and an information poster at high school transition fairs.
- I hold info sessions at the area office for individuals and families that are interested in learning more about self direction.
- I sit with them and explain the service
- I work with families turning 22 and Individuals with ASD
- Invite the program monitor / program coordinator to meetings with the family so they can explain
- Only recently given self-direction duties. I'm working to develop training materials for SCs, and solid internal processes for my area office



“Other” Responses:

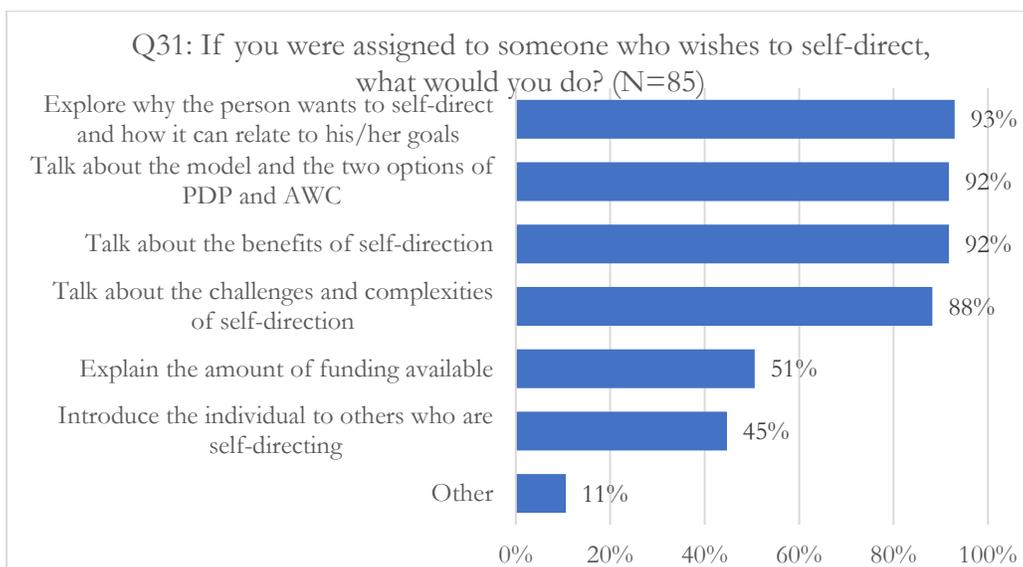
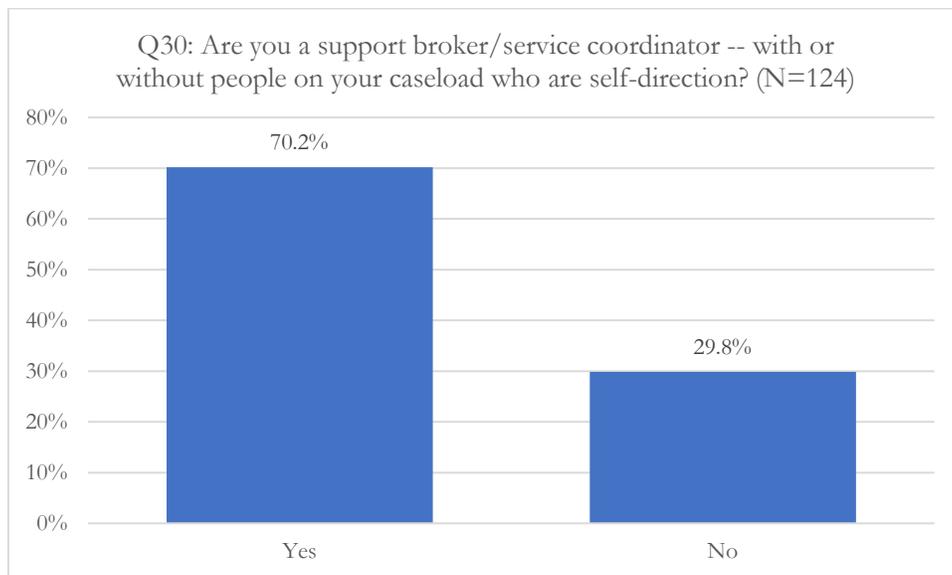
- Having other support brokers in the office is beneficial to bounce ideas off of, and see what other's would approve/deny for invoicing. Helpful when needing staff credentialed or when families have questions.
- I luckily have an expert in self-direction in my office. I can't imagine how I would promote self-direction without that.
- I share problems and get suggestions at Regional Support Broker meetings. In my own office, I have an open door to any staff that want to learn about how SD might benefit their clients
- Need more time/open-ended discussions/group think/brainstorming/case studies
- Our DDS Regional point person is excellent
- Receive updates on policy/procedures, provide feedback regarding PPL
- Updates from a regional and statewide perspective.
- We've been working on the structure in our office, so those meetings have been pretty focused on broader topics, not specific case issues.



“Other” Responses:

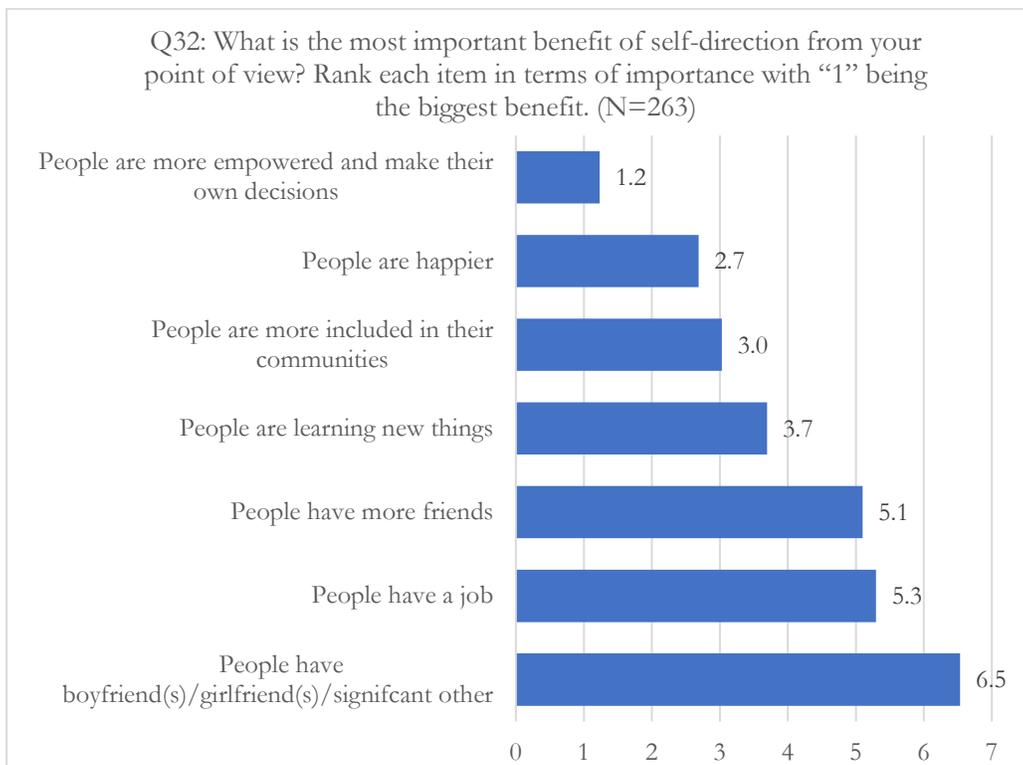
- A formal curriculum on accessing the PPL Portal and how to navigate.
- A lot of this is already happening, but needs to continue to help improve and expand the self-direction services/options.
- Biggest issue is finding staff.
- Create a progressive training track, that is not overwhelming to families. For instance offer the following over time- an overview presentation in a group , followed by a video watched
- Create information that individuals can understand that do not have family involvement; create opportunities for PDP individuals to teach/ train other potential PDP enrollees
- Fraud prevention training, ISP paperwork requirements

- If more SCs understood the program, they'd be great ambassadors for people on their caseloads.
- In depth review of things NOT allowed (group home/residential)
- Include a staff training component for families with regards to working with individuals with disabilities so that families can provide this for staff they hope to hire
- ISP responsibilities
- Managing staff is a needed training topic, especially when it comes to providing training to staff, and evaluating staff performance. Families are not used to being the "boss" and are at times uncomfortable in that role/unsure of how to navigate disagreements that arise. Families have also asked for training resources to use with their staff (ex: introducing ASD to an unfamiliar staff person)
- Online videos where clients and families can refer back to for information and refreshers after learning info from support brokers
- Simplify the information in layman's terms, information should be better organized when meeting with families

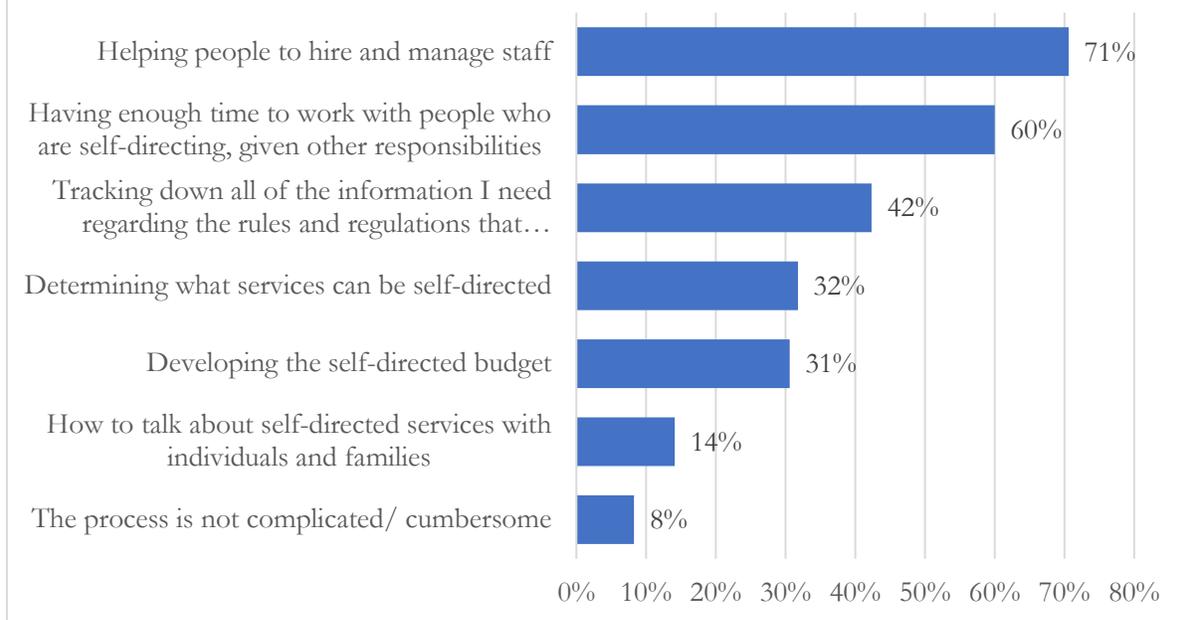


“Other” Responses:

- Connect them with our Area Support Broker Staff
- Discuss goals
- Discuss with Supervisor
- I do not discuss exact funding at the beginning
- I do not discuss specific funding amounts with a client until I know exactly what their needs are and what DDS can commit to funding. I do however explain that funding decisions are based off of our conversation about Vision and that changes to funding can be requested and will be discussed as part of the team process as needed.
- I would explain how the funding works, budgets, the process of applying for an EIN, who can have the EIN if the individual can't/doesn't want to be the EOR, how salaries work for support staff hired, how many hours of support they may need and how much they may like to pay the staff (these meetings usually take several sessions and several hours)
- If I know how much funding could be available.
- Support the person in defining their vision
- We discuss the individual's needs and allow their needs/preferences to help develop a plan/request for funding to the Area Office management team

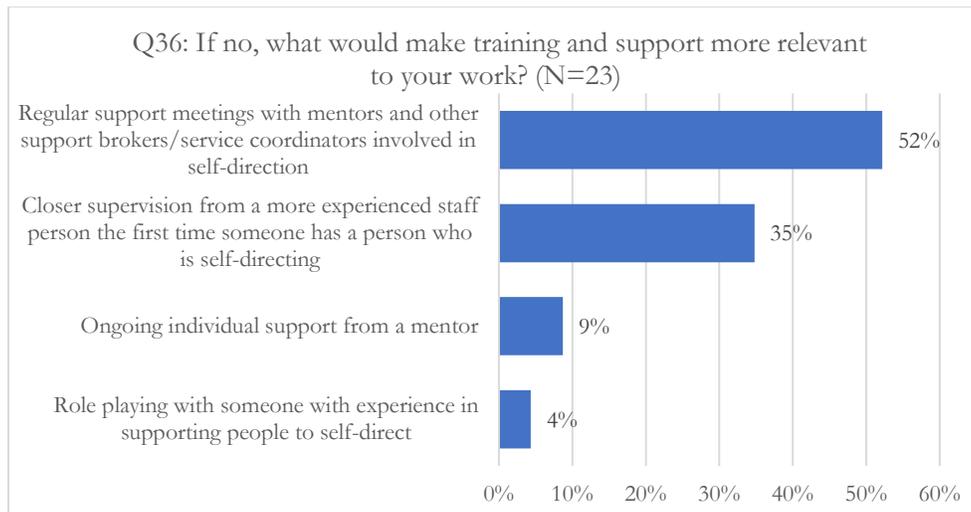
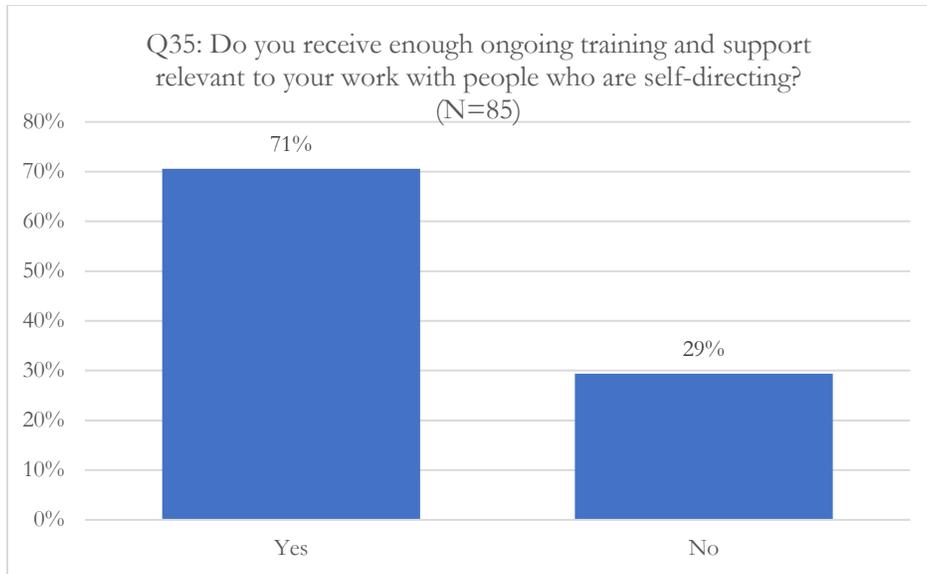


Q33: What is the most complicated/troublesome aspect of self-direction for you as a support broker/service coordinator? (N=85)



“Other” Responses:

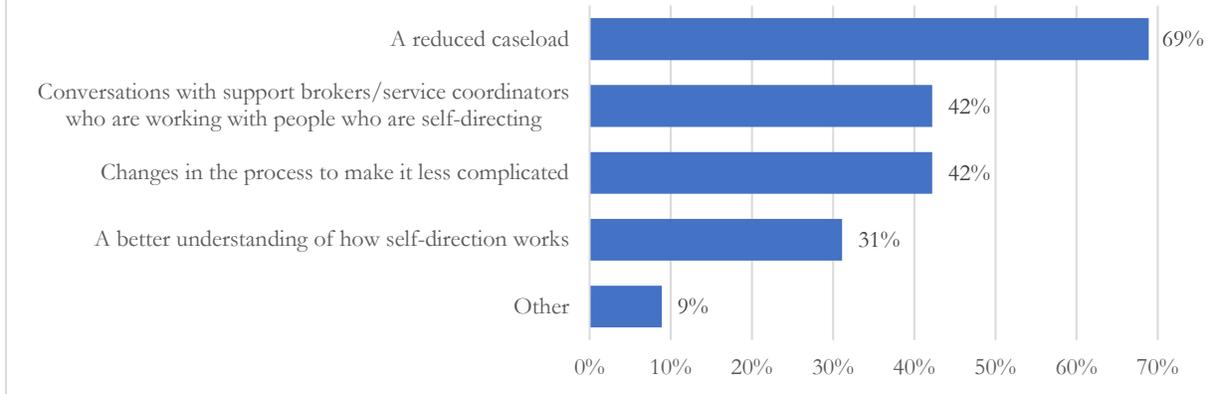
- Finding and keeping staff is the biggest worry for families. Families are often uncomfortable advertising for and hiring staff from the community (without having previously known the staff person). We often recruit staff from existing provider agencies, which comes with other complications (ex: pay rate considerations given that AWC can pay more than a regular agency contract would pay)
- Finding staff, ensuring community integration, cumbersome start-up process
- Funding for ASD Folks is a huge obstacle
- I am the ASD coordinator with a caseload of 81 individuals and 65 ISPs. I do not have time to provide adequate service coordination to anyone, but especially those who are self directing.
- Initial paperwork
- Just need more time
- Managing families expectations of the program; being creative
- Monitoring that services are properly implemented without fraud.
- On-boarding staff (credentialing), determining what invoices should be approved/denied
- Paperwork to start services (EOR/ new employee/Invoices); helping people find workers which is nearly impossible; having to re-explain how the PPL portal works to clients/families; ISPs which aren't on HCSIS and we need to complete the entire thing (assessments/goals/progress notes) because clients, families and workers don't know how and aren't trained
- Understanding my role and how it fits with others on the team



“Other” Responses:

- Several of these would be good, but it will only allow me to choose one.
- Streamlined and organized information processes, knowledgeable and accessible PPL customer service, more time to commit to PDP caseload

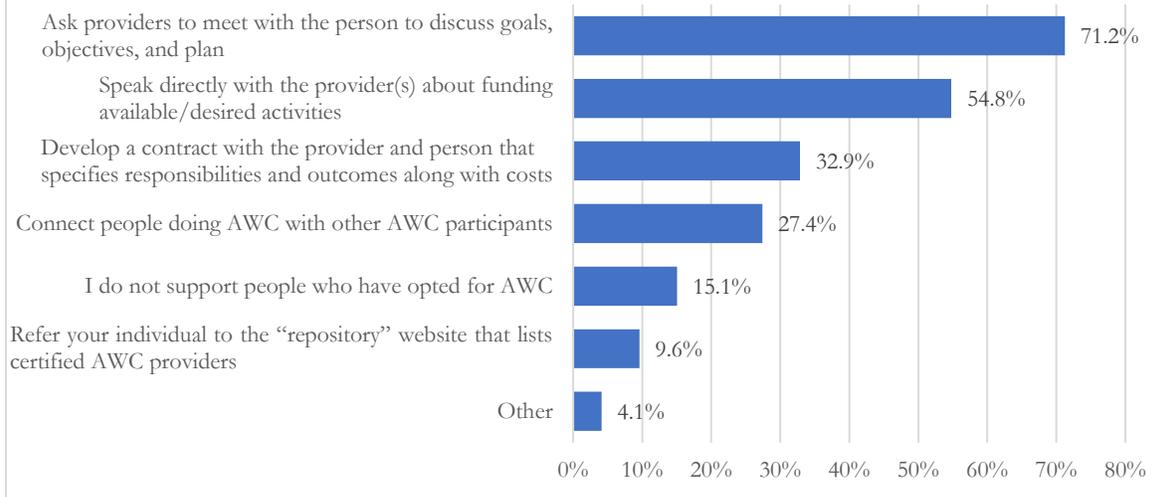
Q37: If you are not currently supporting people who are self-directing, what would you need to support PDP or AWC participants? (N=45)

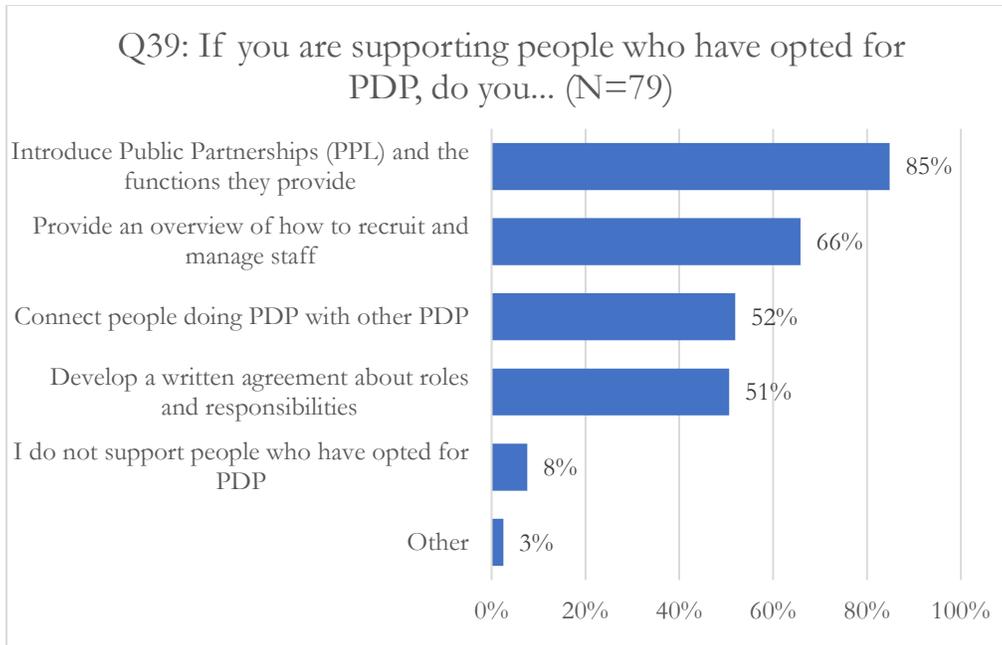


“Other” Responses:

- I currently have a self-direction on my caseload.
- I do support self-direction; a reduced caseload is essential
- Not applicable given my current position
- Training for families, ensuring they have the knowledge/skills/abilities to successfully run a program and keep up with ISP documentation and human resource responsibilities on top of managing day supports/service delivery/staffing

Q38: If you support people who have opted for AWC, do you... (N=73)





## Open-Response Questions

**Q11: If not interested [in learning more about self-direction], why? Please explain.**

- Already extremely involved in all aspect of these programs.
- Already learned this through training
- At this time, I have sufficient information regarding self direction to meet my needs in my current position.
- Currently do not have anyone that is self directing. Of course when I do yes.
- Doesn't apply
- Doesn't pertain to my current role at this time.
- Have been involved to some degree for a long time and if I have questions the Regional Manager is responsive.
- Have full knowledge how the support services operate
- I already know it very well
- I am becoming more educated on self direction because I attend monthly meetings and trainings when offered.
- I am confident in my basic working knowledge of the option and this time do not have anyone on my caseload who wants to access self direction.
- I am retiring next month.
- I attended a training already.
- I carry a very high caseload of Hispanic families and feel that this would be difficult for most to manage.
- I continually ask questions to better understand the programs and feel I am able to explain the supports to guardians and family. If there is a true interest in the program, I set up a meeting with the SC in our office that oversees that type of programming. I rely on their expertise for support.
- I do not have anyone on my caseload in the Self Direction Program.

- I do not mind learning more about self direction to help families educate families. just the information necessary.
- I do offer it as an option to individuals and families who have funding and might be interested in it. There is a Service Coordinator in my office who has a caseload of people who self-direct.
- I feel I am well versed though not an expert and am not in a position of needing to 'sell' the idea to families. my role includes the enrollments, POCs, etc and I feel I know more than enough to tend to these tasks. I also know who I can go to with specific questions for problem solving.
- I feel I have adequate resources at my work site from whom I can find additional information if needed.
- I feel I have enough information to speak to this service.
- I have been involved with self direction cases for some time and can reach out when specific information is needed.
- I have enough information to assist clients who want to explore self-direction
- I have enough knowledge about this
- I have enough to do and worry about and my case load is high. I don't have the time and it's not fair!!!!
- I have no interest and I am going to retire in the next 2 years.
- I have sufficient knowledge.
- I have worked with this service and with my current caseload, it is way too time consuming for a SC to try to manage, work with the families and keep track of spending. My experience is that the families are entitled, exhausting, cant manage it well on their own and seek the SC to assist with finding direct care staff, activities and social rec to manage their child's time. The paperwork and calling PPD is painful.
- I know enough. It needs to be explained better to families so they are not afraid to use it.
- I like the idea/philosophy behind the service. I love the idea of people having flexibility in their lives and have non-traditional choices. I would not like to have to manage the financial aspect of this service.
- I understand my job. I am self-directed. Don't feel I need more instruction
- I would rather get the info I need from my co-workers rather than attending additional trainings. We have several trainings per year as well as bi- monthly meetings. This is fairly time consuming already.
- If have a bilingual caseload and having more than two PDP cases will be way too much.
- I'm not good with numbers.
- Is not something that catches my interest.
- It's a lot of upfront work, and maintenance the first year. Second year can also be challenging if things did not go well the first year and changes need to be made. Caseloads are high, staff are already behind in their work, so not too many staff are interested in adding that kind of intense work to an already over burden caseload.
- It's not part of my job. I'm administrative Assistant
- It's not relevant to my role.
- I've had some experience with PDP /AWC consumers, at another area office. My family's found these options difficult to work within and/or there was no interest in these two options
- My interest would be directly related to serving an individual who uses it and I have no such person on my caseload currently.
- My job is already very busy with a caseload of over 60 people.
- My job mostly entails RISK monitor and Action Plans or Administrative Reviews for dppc complaints.
- n/a
- Never heard of it before
- Not interested in the money management piece and oversight of services
- Not something that I would want to be managing as a SC
- Other persons in office hold that function.
- Prior involvement; not interested
- These options are a lot of work over the normal responsibilities. These options are difficult to manage.

- Too busy with current responsibilities.
- TOO MUCH WORK ON TOP OF MY EVER INCREASING WORKLOAD.
- Very time consuming, caseload approaching 70.
- We already have a PC 2 in our office who has picked up on the role with the SC's.

**Q34: Do you have suggestions regarding how to resolve complicated/troublesome aspects for self-direction for you as a support broker/service coordinator?**

- I think this is something that just needs more repetition. the more you do it , the more simple it seems to be.
- Clear business processes, a self-direction manual, weighted caseloads
- Have a Self Directed SC
- Have someone specifically trained to assist in recruiting staff.
- I have folks in office to review with and our regional manager is fantastic in answering questions and illuminating program
- Each Area Office needs to better understand the PDP process so that SC are more confident in offering this service to individuals. A lot of SC don't understand or choose not to understand thus their presentation to families lack the knowledge and enthusiasm to promote the program.
- 1) Put ISPs on HCSIS and let support brokers fill out everything there
- 2) give us the ability to use self-direction money to hire workers through agencies when clients can't find workers, or have an agency hired for a short period of time to help someone find a worker
- 3) create instructional videos on YouTube so clients/families can refer back to them if they forget or still have questions after meetings (ex: where to find y our budget, how to manage it, what an EOR/EIN is, how to do timesheets online etc.)
- 4) have an updated manual for support brokers and clients that explain rules/guidelines in simple clear terms
- Does licensing review self-direction cases? I think each case should be monitored by some representative of the licensing body regularly to ensure proper implantation of funds.
- Using videos to review and discuss each phase of self-direction with DDS staff and others using self-direction that can be accessed on DDS website. Therefore, families can watch several times to better understand the process.
- None
- Lower caseload. better resources for individuals and families to hire staff. Having other non support broker DDS staff have more knowledge of self-directed services so that they can better begin informing people considering self-directed supports.
- A paid website to recruit and display ad's to hire individuals
- Create a worker database with resumes so individuals can search through them.
- Training/orientation for families/participants, consistency throughout the matrix for all services.
- More specific trainings geared toward problem areas or challenges with the budget.
- Peer support meetings
- There needs to be a designated support broker who is also a service coordinator in each office, with no more than 25 individuals on their caseload, and they need to meet in person with each individual once a month. This is how the Children's Autism Medicaid Waiver is run and it works great.
- The Department have certainly invested a lot of time and resources to help us better understand the process

- Task list for hiring people or starting people on PPL.
- Be available; research answers; simplify questions and answers
- Have PPL staff be a resource.
- No.
- Decrease caseload so that I have more time to work with families and provide intense case management and training.
- Develop comprehensive training manuals that are standardized across the state; provide additional individual friendly documents across the internet about self direction; develop training videos for individuals/ families instead of delaying this idea; make all PDP systems more user friendly for all users ( Hsc/ families) ;
- Continue to build on the training manual
- Develop a comprehensive binder for individuals and families that HSC/broker can use to educate and guide them through the process, and that they can refer to when they have questions. Create a checklist for HSC/brokers to monitor where individuals/families are in the process and what information they have covered together. Formal training for new brokers to teach them the process and an established mentor they can go to with questions. A method to easily share ideas, tips, tricks, and successful methods as well as questions across the state.
- I encourage making staff wages as competitive as possible so that staff want to work in self direction and stay employed in self direction (despite no sick, vacation or personal time and/or health insurance offered).
- More guidance regarding code allowables and disallowables. more interactive training re: a Self direction start-up. better brochure materials to present to families. more info on how to help families recruit staff. better response times from customer service
- This program needs more positions and funding. It is difficult to help families begin the process. There are many positions at the area office, regional, and central that are all involved, but there are few experts. Additionally, it is not possible for 99% of individuals to run this program, it requires family help. The vision ends up being the family's, which sometimes aligns with the individual vision, but not always.
- Helping individuals find reliable staff is an on-going issue. I do keep a list of staff people interested in working with others so that if staff leave, we have a potential resource to help the individual locate new staff. Having something like this state-wide may be helpful - but I understand it is difficult to manage as we would only want to refer exceptional staff.
- More direct Assistance by Supervisor and AAD would be helpful
- Dedicated Support Brokers are absolutely necessary. Systemically disadvantaged people (lower income, people of color, and people without strong natural support networks) need more hands-on support to be successful and as it stands people can't realistically explore self-direction unless they have their own resources to manage the program.

Fiscal management system is cumbersome and poorly run. Information is not kept to date and families and employees do not receive any real support in addressing issues unless pursued by the support broker.

- Less people on caseload
- A full-day training