



Choice, Decision Making & Self-Direction

Data and discussion in this brief are focused on the following quality assurance outcomes:

People make their own decisions

Describes how people have choices and are supported in making important decisions in their everyday lives.

People direct their own services

Reports on measures related to people who are supported to direct and manage their own services. Self-direction is a relatively new, but growing, service type in Massachusetts and across the nation.

Quality Assurance Briefs are topic-specific reports on data collected by the Department of Developmental Services (DDS) and other sources to measure the quality of services and supports provided to individuals in Massachusetts who receive DDS supports. These Briefs replaced the annual DDS Quality Assurance Report in 2009. This is the fourth Brief issued to date.

The QA Outcomes are monitored using specific indicators of quality that are measured in multiple ways. DDS reviews patterns and trends reported through this and other sources as part of its continuous quality improvement efforts. See Appendix B for notes on how data are collected and presented and reminders of how to interpret the data.

Special Notes on the Data

In past briefs, data was compared with prior years to show trends. Recent changes in both the DDS Licensure and Certification (Lic & Cert) processes and in the National Core Indicator (NCI) questions prevent direct comparison of data beyond one reporting cycle. DDS Lic & Cert data are shown for Fiscal Year 2012 (FY12) and compared with Fiscal Year 2011 (FY11). NCI data are shown for FY12 and compared to Fiscal Year 2009 (FY09).

Data in this brief are primarily drawn from two sources:

Licensure and Certification:

Data are collected through routine licensure and certification processes by which public and private providers of community services are licensed and certified by DDS to provide supports. Data are collected on-site by a team of trained Quality Enhancement Specialists through interviews with staff, families, and service recipients as well as reviews of documentation and observations of residential and/or day/employment services. The goal of this licensure and certification process is to ensure that providers meet an acceptable level of quality, that essential safeguards for service recipients are in place, and that outcomes for specific service types are achieved. The data are collected in a manner that informs whether the provider has met or not met each standard and results are restricted to these two rating categories.

System Change: In July 2010, DDS implemented an enhanced Licensure and Certification system to make the process more transparent, objective and quantifiable.

National Core Indicators (NCI):¹

The National Core Indicators project is a collaboration of participating U.S. states to collect data and report on performance indicators of service delivery systems that support people with intellectual disabilities. Data are collected each year, in each participating state, by trained staff through face-to-face interviews. These data indicate program preferences and overall satisfaction with services as assessed through interviews with a sample of people who live in Massachusetts and who receive paid supports from the MA DDS. Unlike licensure results, data from these interviews are often rated in more than two categories which can help show more gradation in results.

Modified Questions: NCI implemented modified questions in the 2008-2009 reporting cycle.

Individual states choose each year whether or not to participate in the data collection through face-to-face surveys. Massachusetts participated in the 2008-2009 and 2011-2012 reporting cycles. National averages shown in this brief are based on samples of individuals from all participating NCI states in the 2011-2012 reporting cycle.

Adjusted Data

Much of the NCI data shown in this brief are risk adjusted in order to control for differences in the individual characteristics of people who completed the NCI Survey across states. It is necessary to risk adjust the data to account for the fact that states have different eligibility definitions for services and may have samples with different characteristics. The indicators are risk-adjusted using the following seven individual characteristics: age, level of intellectual disability, primary means of expression (spoken or not), level of mobility, health status, mental illness/psychiatric diagnosis, and

¹Data retrieved from the National Core Indicators Website: <http://www.nationalcoreindicators.org/charts/>

whether any behavioral supports are needed to prevent self-injury, disruptive, or destructive behavior.

Risk adjustment was performed using logistic regression that produced a predicted value of what one would expect to observe given the individual's characteristics. The state's average observed rate (i.e., the state average prior to risk-adjustment) was adjusted by the average predicted rate to produce the risk-adjusted rate. Risk-adjusted rates remove differences based on characteristics such as age, level of intellectual disability, and health status. Risk adjusted data are labeled as such throughout this brief.

Differences in results of Licensure and Certification reviews as compared to NCI

Please use caution when viewing these results. Direct comparisons between the Licensure and Certification data and the NCI data may not be possible due to differences in the populations reviewed, the services reviewed and the manner in which questions are posed. The following distinctions should be considered when reviewing the data:

- The licensure and certification reviews consist of homes with 24 hour staff support, homes with less than 24 hours of staff support, individualized home supports, placement services and day programs. The NCI surveys include these populations, as well as individuals living independently or in their parents' home.
- The NCI survey asks respondents about their satisfaction with specific outcomes (e.g. does the person make choices in their daily schedule), whereas the licensure and certification review asks whether people are supported by staff to achieve personal outcomes (e.g. does an individual receive staff support to make choices in their daily schedule).

Results from these two very different processes should be reviewed with caution. Both are presented here in order to give the reader greater context for understanding the Department's quality measures.

Table 1: Licensure & Certification Choice & Decision Making Indicators FY 2012 (See Figure 1)

Indicator	Measure	Results	Compared to Past Yrs
Staff provide supports for people to develop skills to enable them to maximize independence and participation in typical home activities and routines.	Percentage of staff who are knowledgeable about people's support needs and who are providing necessary supports to maximize independence and participation.	99% of staff reviewed were knowledgeable about support needs and were providing appropriate support to maximize independence and participation in typical home activities.	Consistently positive with FY11 (100%)
Staff support people to make choices regarding daily household routines and schedules.	Percentage of staff who are knowledgeable about people's choices and who support these choices ² .	99% of staff reviewed were knowledgeable about people's choices and supported people to make choices in their daily routines.	Consistently positive with FY11 (100%)
Staff support people to explore their interests for cultural, social, recreational and spiritual activities.	Percentage of staff who support individuals to explore their interests in cultural, social, recreational, and spiritual activities	93% of staff reviewed could determine interests of the individual and then support exploration and participation of the individual in these activities on a consistent and sustained basis.	Consistently positive; slight change from FY11 (96%)
Staff assist people to purchase personal belongings.	Percentage of staff who support people to purchase items they want ³ .	99% of staff reviewed assisted people to purchase personal belongings that were preferred by the person.	Consistently positive with FY11 (100%)
Staff support people to personalize and decorate their rooms according to their preferences.	Percentage of staff knowledgeable about people's preferences and who provide support in personalizing bedrooms and home ⁴ .	99% of staff reviewed assisted people to personalize their bedrooms and home.	Consistently positive with FY11 (100%)
Providers assist people to make knowledgeable decisions	Percentage of providers whose staff assist people to make knowledgeable decisions ⁵ .	100% of staff reviewed understood people's capability to make decisions and provided support to make decisions.	Consistently positive with FY11 (100%)

² Includes choices in everyday home activities like what to wear, what to eat, when to get up or go to bed.

³ Support to purchase personal items is an important and valued aspect of choice.

⁴ This includes incorporating individual preferences into decorating common areas.

⁵ Using a variety of techniques, such as brainstorming, discussing, and guiding the person to analyze their choices, staff understand a person's capability for making decisions and then provide needed support to enhance that ability.

Table II: NCI Choice & Decision Making Indicators FY 2012

Indicator	Measure	Results	Compared to Past Yrs
The proportion of people who make choices about their everyday lives, including: housing, roommates, daily routines, jobs, support staff or providers, social activities, and what to spend money on.	Percentage of people who chose daily schedules.	89% of people chose their daily schedule independently or had some input [†] (Figure 2).	Schedule choice similar to FY09 (88%)
	Percentage of people who chose how to spend their free time ⁶ .	91% of people choose how to spend their free time, either independently or had input [‡] (Figure 4).	Consistent with FY09 (91%)
	Percentage of people who choose what to buy with their own spending money.	86% of people surveyed exercised some degree of choice in spending their own money [‡] (Figure 5).	Slight decrease from FY09 (89%)
	Percentage of people who choose own staff ⁷ .	67% of people surveyed reported having choice in home staff [†] , 68% reported choice in job site staff [†] , 58% reported choice in day program staff [‡] and 34% reported choice in Service Coordinator (SC) [↓] (Figure 6).	Increase from FY09 in home and job staff (63% & 51%); Day and SC constant (57%; 33%)
	Percentage of people who choose own roommates.	43% of people surveyed reported they chose or had some input in choosing their roommates [†] (Figure 7).	Choice in roommate remained consistent with FY09 (42%)
The proportion of people who have been provided options about where to live, work, and go during the day.	Percentage of people who choose own home.	56% of people reported they chose or had some input in choosing where they live [†] (Figure 8).	Notable increase in home choice from FY09 (42%)
	Percentage of people who chose day activity.	56% of people chose their day activities independently or had some input in the choice [‡] (Figure 3).	Slight increase in day activity choice from FY09 (54%)

[†] Result is higher than the NCI national average, adjusted for risk.

⁶ Having a choice or having input to choose what to do with free time is an important indicator of how well people are supported to make decisions.

⁷ Only individuals who have residential, day, or job staff are asked about choice for each staff type. Measures includes whether the individual chose the staff or *were aware that they could request to change* their staff.

[↓] Result is lower than the NCI national average, risk adjusted (Choice in Service Coordinator is unadjusted data).

[‡] Result is similar (within 3 percentage points) of the NCI national average, adjusted for risk.

[‡] Result is similar (within 3 percentage points) of the NCI national average, adjusted for risk.

Table III: Summary of Self-Direction Indicators and Measures for DDS, FY 2012

Indicator	Results	Compared to past yrs
Number of people with at least one self-directed support option.	MA DDS reports that 453 individuals self-direct at least one support option (Figure 9).	Slight increase from FY11 (434 individuals)
The number of self-directing individuals who utilize each support option.	72% of individuals who self-direct are using financial services, 34% self-direct individualized home supports, and 17% self-direct individualized day supports (Figure 10).	n/a. FY12 is first year of data collection

Table IV: Summary of NCI Self-Direction Indicators and Measures, FY 2012

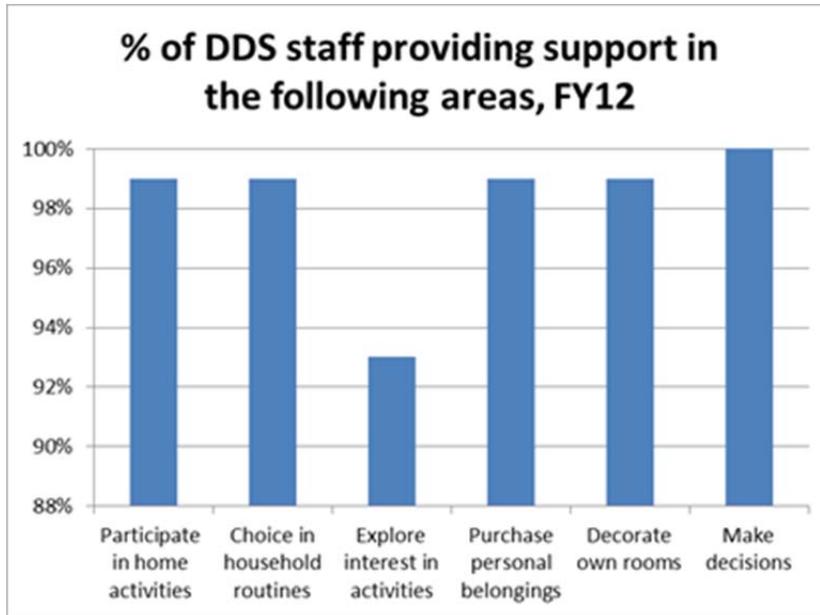
Indicator	Results	Compared to past yrs
Percentage of people who report they receive assistance with budget/services ⁸ .	67% of individuals who self-direct services indicated they have enough help with budgets [±] , 100% had someone talk with them about their budgets [↑] , 100% felt information in the budget was easy to understand [↑] , and 86% felt they could make changes to their budgets if they wanted [↑] .	Increases from FY09 (get enough help 66%; talk with someone about their budget 74%; easy to understand 48%; and can make changes 60%)
Percentage of people self-directing whose support workers come when they are supposed to.	100% of individuals who self-direct services reported that their support workers come when they are supposed to [↑] .	No change
Percentage of people self-direction who get the help they need to work out problems with their support workers.	100% of individuals who self-direct services reported that they receive this help when needed [↑] .	No change

⁸ These data are based on an extremely small sample size due to the small number of individuals who self-direct services. Data should be interpreted with caution.

[±] Result is similar (within 3 percentage points) of the NCI national average, adjusted for risk.

[↑] Result is higher than the NCI national average, adjusted for risk.

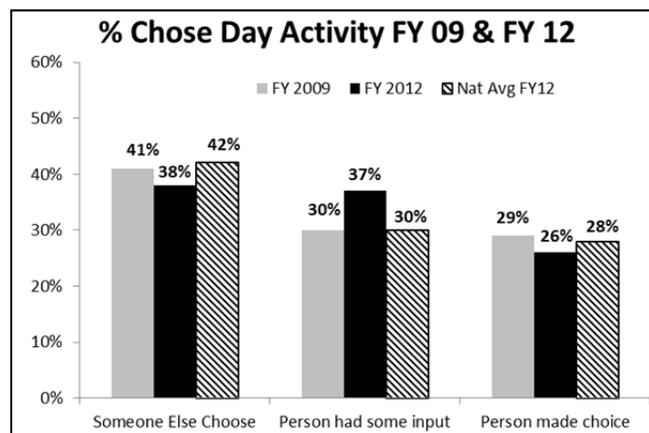
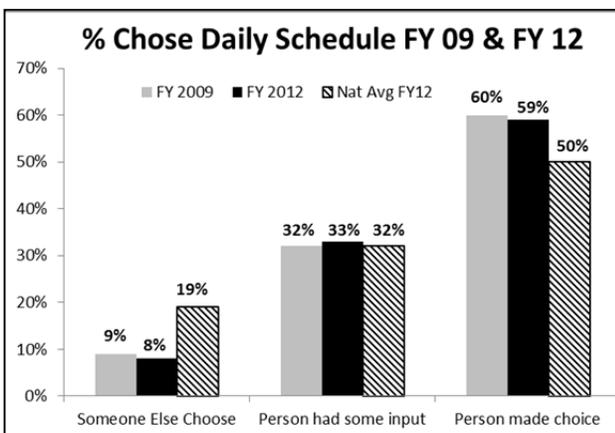
Figure I: Proportion of DDS Provider Staff who Support People in Developing Skills and in Having Choice



Source: DDS Licensure and Certification Data.

Licensure and certification data indicate that the majority of staff surveyed are providing supports in the six areas shown in Figure I. Comparisons to FY09 data show that these data are consistent with previous years. Provider staff continue to provide positive support to people in maximizing independence and participation in home activities such as laundry tasks, meal preparation, and shopping as well as choice in household routines, activities, and in decorating personal space. Additionally, as indicated in Table I, DDS Licensure and certification data shows that 99% of staff reviewed were knowledgeable about people’s choices and supported people to make choices in their daily routines. Similarly, 98.8% of staff reviewed were knowledgeable about, and were providing, appropriate supports to maximize independence and participation of people in typical home activities.

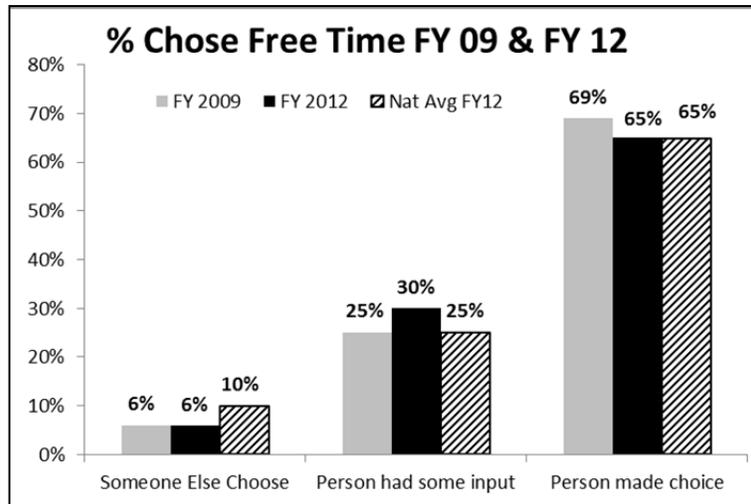
Figures 2 & 3: Choice in Daily Schedule and Activity



Source: NCI. Unadjusted data.

The percentage of people reporting choice in daily schedules remained nearly identical across categories of choice in FY12 as in FY09. The percentage of people making choices independently remains higher than the national average in FY12. More people reported having input in choosing their day activity in FY12 than in FY09, and these numbers are higher than the national average. Slight decreases were observed in the percentage of people who reported choosing their day activity independently in FY12 as compared to FY09. A slight decrease was also observed in the percentage of people reporting that someone else choose their day activity in FY12 than in FY09.

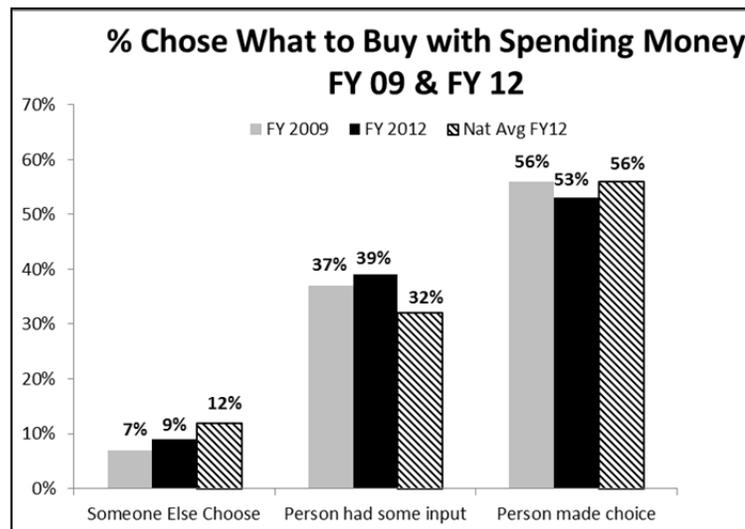
Figure 4: Choice in How to Spend Free Time



Source: NCI. Unadjusted data.

More people reported having input on how to spend free time in FY12 than in FY09, but slightly fewer people reported making this choice independently. The percentage of people reporting that someone else made the choice remained consistently low between FY09 and FY12, and was lower than national averages. As indicated in Table I, DDS Licensure and Certification data show that 93% of staff reviewed in FY12 were able to determine interests of the individual and then support exploration and participation of the individual in these activities on a consistent and sustained basis.

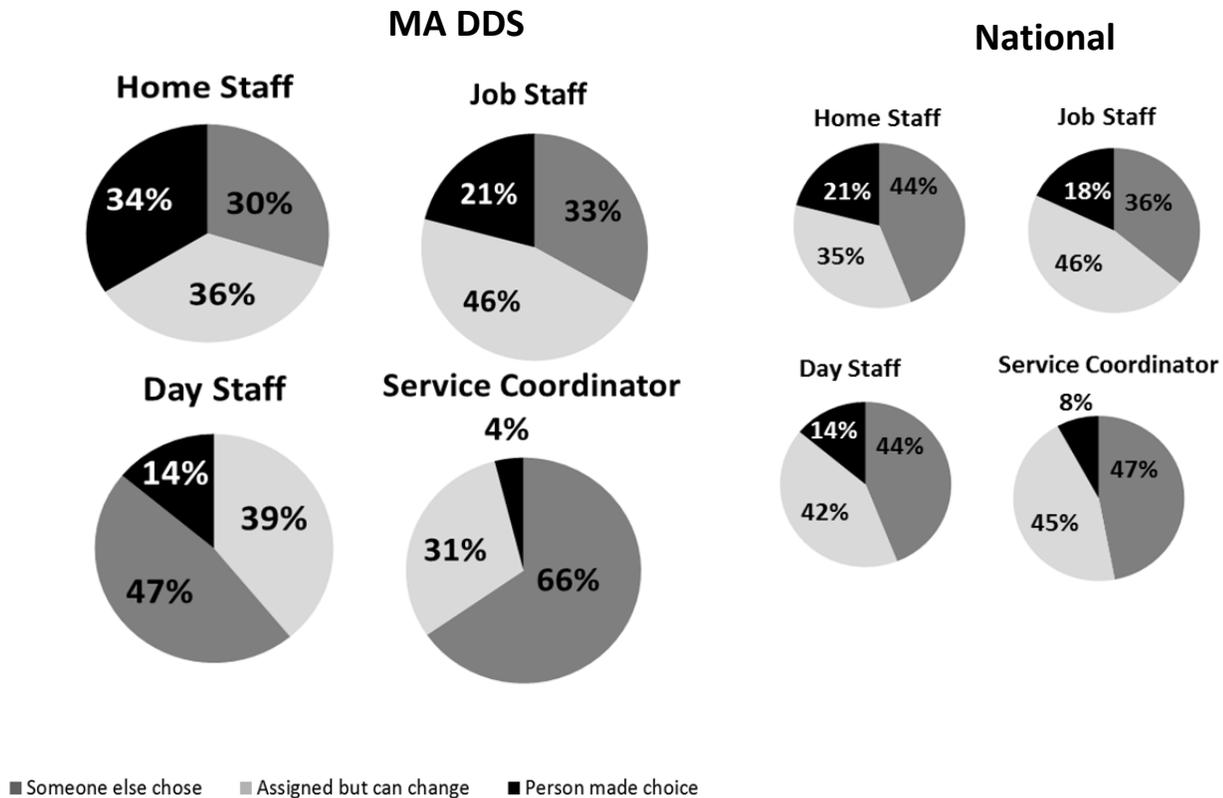
Figure 5: Choice in What to Buy with own Spending Money



Source: NCI. Unadjusted data.

More than half the people surveyed indicated that they independently chose what to buy with their own spending money. This proportion decreased slightly in FY12 from FY09. People served by the MA DDS were more likely to have some input in choosing how to spend their personal money than the national average in both FY09 and FY12. The portion of people indicating that someone else made the choice remained consistently low between the reporting periods and was lower than national averages. This is supported by DDS Licensure & Certification data shown in Table I indicating that 99% of staff reviewed assisted people to purchase personal belonging that were preferred by the person.

Figure 6: Percentage of People Who Report Choice in Staff, FY12



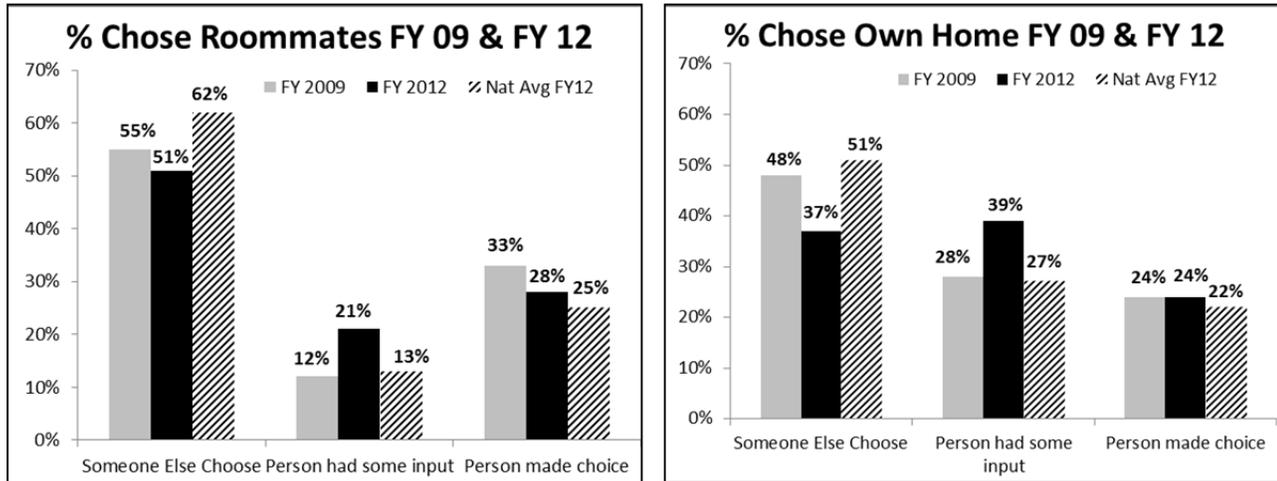
Source: NCI. Unadjusted data.

According to the sample of people surveyed in FY12, people with home staff most often reported a choice in staff at 34%. Choice in other types of staff was lower, with 21% reporting they could choose their own job staff, 14% reporting they could choose their own day staff and 4% reporting they could choose their own service coordinator. Across these four job types, a similar percentage reported (31%-46%) that they were aware they could request to change staff if they wanted, across all staff categories. Compared to national data, the reported choice in staff was similar across staff types.

MA FY09	Home	Job	Day	SC
Person made choice	36%	12%	14%	3%
Assigned but can change	32%	40%	43%	32%
Someone else choose	32%	48%	43%	65%

Choice in staff remained mostly consistent with FY09 results with the exception of choice in job staff. Individuals reporting that they choose job staff notably increased from 12% in FY09 to 21% in FY12. Similarly, the proportion of individuals reporting that their job staff were chosen by someone else notably decreased from 48% in FY09 to 33% in FY12.

Figure 7 & 8: Choice in Roommates and Home



Source: NCI. Unadjusted data.

More people reported having input in choosing a place to live and with choosing roommates in FY12 than in FY09 and these percentages are higher than the national averages. People making an independent choice on their own home remained constant and in-line with national averages; percentages decreased slightly for independent choice in roommates. As indicated in Table I, 100% of staff reviewed during licensure and certification in FY12 understood people’s capability to make decisions and provided the support needed to make knowledgeable decisions.

Figure 9: Percentage of People who Self-Direct, FY12

NCI data indicates that 2% of MA DDS respondents report using at least one self-directed support option. This is lower than the national average of 7%. In FY09, 2% of MA DDS respondents reported self-directing and the national average was 4%.

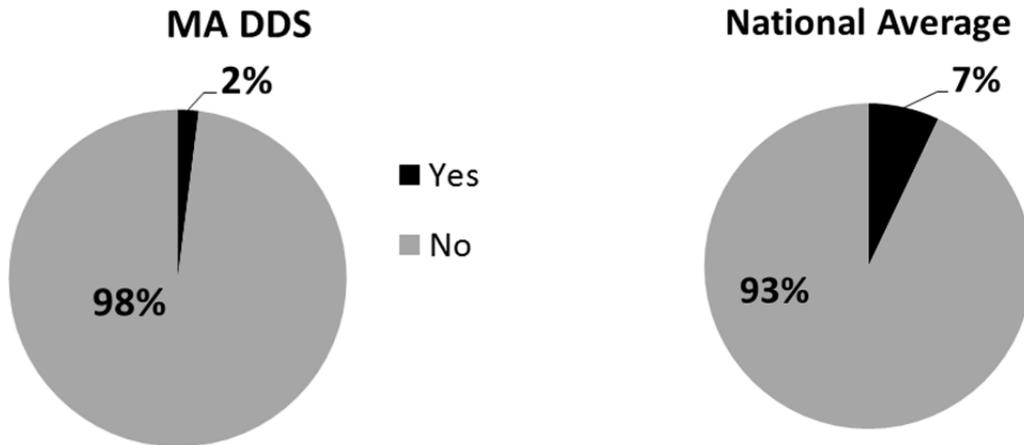
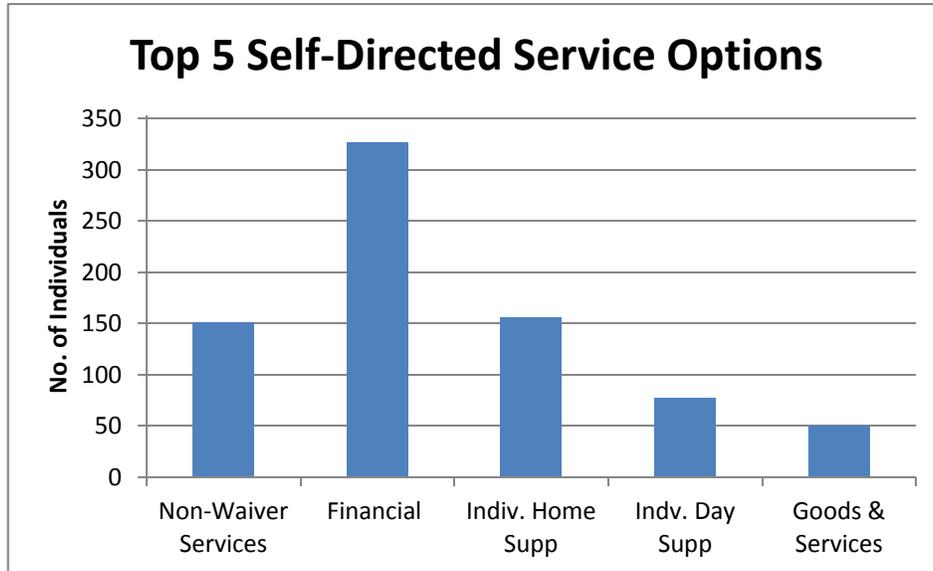


Figure 10: Support Options with the Greatest Number of Self-Directing Adults Enrolled



Source: DDS Licensure and Certification data.

This is an unduplicated count of the number of people within each support option who self-directed that support. Some people may be self-directing more than one support option. The total number of people who self-direct is 453.

About 72% of adults who self-direct their services are enrolled in Non-Waiver Financial Services (327 individuals) and receive help with budgeting, paying bills, and planning expenses. About 34% of self-directing adults (156 individuals) self-direct Individualized Home Supports and 17% (77 individuals) self-direct Individualized Day Supports.

Appendix A -Terms

What is Self-Direction?

Self-determination is an opportunity to make enhanced personal choices, to have the authority to control individual budgets and the support to achieve personal goals. Self-direction enables people, at times supported by their guardians and/or families, to design and/or direct supports and services based on their needs, values, and preferences. The individual-directed, person-centered planning process enables the individual to identify and access a personalized mix of paid and non-paid supports to meet unique needs and personally defined goals.

People who self-direct have the flexibility to structure their services to meet their needs in a variety of areas such as transportation, home maintenance, and personal assistance. People can chose to self-direct all aspects of their supports, including hiring and managing direct support workers, or they can chose to self-direct only one service. Self-direction may be provided through a team, financial management services, support for employment of staff, and self-advocacy training.

Budgets

Managing support budgets is an important part of self-direction. Individuals who self-direct manage their own budgets, pay their own support workers, and make decisions about which services can fit within their budget. Many individuals receive assistance from staff to successfully manage their budgets, but ultimate choice and responsibility resides with the individual.

Support Workers

Employing support workers is an important marker of self-direction. As the employer, the person has greater control over the type of service they receive and whether that service truly meets their needs. Employing the support worker includes hiring, directing, and paying the worker. Assistance from staff in managing this process can be an important source of support that enables the person to successfully manage their self-directed services.

Appendix B

Data Reminders

Data in *QA Briefs* are drawn from a variety of quality assurance processes in which DDS is routinely engaged. These quality assurance processes allow for timely review, intervention and follow-up on issues of concern. The information from these activities is integrated to provide a more “holistic” picture of the quality of supports within the DDS system and to help identify areas that may become the focus for quality improvement initiatives and activities. In years past with the guidance of stakeholders, DDS established a set of **OUTCOMES** that represent system expectations and that form the basis for evaluating service quality.



The DDS Quality Outcomes:

- Health: People are supported to have the best possible health.
- Protection from Harm: People are protected from harm.
- Safe Environments: People live and work in safe environments.
- Practice Rights: People understand and practice their human and civil rights.
- Rights Protected: People’s rights are protected.
- Choice and Decision Making: People are supported to make their own decisions.
- Community Integration: People use integrated community resources and participate in everyday community activities, and, people are connected to and are valued members of their community.
- Relationships/Family Connections: People gain/maintain friendships and relationships.
- Achievement of Goals: People are supported to develop and achieve goals.
- Work: People are supported to obtain work.
- Qualified Providers: People receive services from qualified providers.
- **NEW!** Self-Direction: People are supported to self-direct one or more service.

Outcomes, Indicators, and Measures

To help evaluate each of the **OUTCOMES**, DDS has established a series of related **INDICATORS** as a way to know if the outcome is being achieved. Each indicator has a set of **MEASURES**, or specific **DATA** that are used to evaluate progress and trends over time. The relationship between outcomes, indicators and measures is illustrated below:

