Real Lives Evaluation: Year 2 Report

VALERIE BRADLEY
HUMAN SERVICES RESEARCH INSTITUTE
REAL LIVES ADVISORY COMMITTEE
DECEMBER 5, 2018

Evaluation Goals

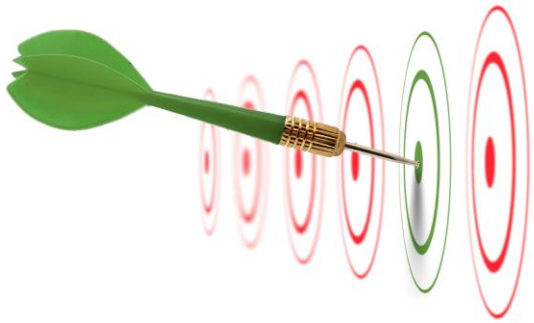
Year 1: Current focus

Evaluate the effectiveness of training and outreach efforts currently being used in Massachusetts.

Year 2:

Evaluate the quality and effectiveness of systems in place to support self-direction.

Year 3: Evaluate satisfaction of services for individuals currently directing their services and supports.



DDS Accomplishments

- DDS outreach included:
  - Informational sessions in each region almost monthly.
  - Sessions in multi-cultural Family Support Centers
  - Regular sessions through Family Support Centers
  - Public speaking training for self-advocates through the creation o Speaker's Bureau
  - Inclusion of families and individuals in self-direction forums to tel their stories
  - Presentations in Russian, Spanish, Haitian
- DDS is building mentoring relationships among service coordinators/service brokers, providing person-centered training, holdi an annual support broker conference
- DDS is improving materials for participants and service coordinators, ha issued guidance, and has a to ensure consistent guidance in the future.
- DDS has taken steps to improve outreach using social media and is producing two videos per region and a fraud/ abuse video.
- SD Managers and Autism Leads are introducing self-direction at transition fairs and forums.

Evaluation Tools: Year Two

Interviews with AWC providers

Interviews with state DDS staff

Focus groups

On line survey with service coordinators/service brokers

Mail surveys of PDP and AWC participants

Review of best practices in self direction in other states

Review of DDS data

Research Questions

What are the characteristics of those who are self-directing?

Are there regional differences in the number of individuals who are self-directing?

What services and supports are people most likely to include in their individual budgets and how do the costs compare with traditional services?

What do service coordinators and support brokers see as the challenges to supporting people who are self-directing and what do they see as ways that the process can be improved?

What do participants, DDS staff, and families see as the challenge and benefits of self-direction and the ways in which the process can be improved?

What do stakeholders (participants, DDS staff, and families) see as the ways in which the process of self-direction can be enhanced?

How do budgets get developed for PDP and AWC participants?

Where does the funding come from for self-direction and is it adequate?

What types of infrastructure do other states have to support their self-direction programs and what can be translated into the Massachusetts context?

Highlights from Survey of Participants in Person Directed Program (n=195 out of 568 sent)

- 96% of respondents are 18-65
- Almost half (48%) live at home with their family
- Majority (92%) ill continue to self-direct and 88% would recommend it to others
- 95% had a good experience with their support broker/service coordinator; 76% of respondents indicated that they get all the help they need from their support broker/service coordinator.
- 56% of respondents said they have not had any problems self-directing and 40% said that they have had problems, but someone has helped resolve them.
- Of those who had problems, 40% noted that the process is complicated and 17% said they still have questions about the process.
- 23% said it takes a long time to make a change in their services and 12% said it is hard being the boss
- Almost all (92%) of respondents stated that the people they hire do what they want them to do. However, a third (37%) said that it is hard to find and keep good staff

Impact on Individuals Enrolled in PDP

Around two thirds of respondents said that they are learning new things (61%),

71% are making more choices, more than half feel better about themselves

55% said they are more independent.

Many said they have more friends, their health is better, and they have jobs.

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

Highlights from Survey of Participants in Agency with Choice (n=126 out of 440 sent)

- Most respondents are ages of 18-65; about 71% of respondents live at home with family
- 93% said they would continue to self-direct and 88% of respondents said they would recommend self-direction to others.
- More than half (61%) said they received all the information they needed about self -direction and about 30% said they needed more or still had questions;
- More than half said they had encountered problems but 43% said their problems were addressed; almost three quarters (74%) said they know who to ask if they have questions
- Two thirds said they feel like they are making choices all the time – very few (2%) said not much of the time.
- A third said the process is complicated, more than half said it is hard to find good staff, and a fourth said it takes a long time to make changes to their services; only 5% said they were having problems with their agency
- Most of the participants know who to contact in the agency they are working with (95%) and 93% reported it was easy to contact the agency.

Impact on Individuals Enrolled in AWC

71% said they were making more choices in their life (71%);

47% hire their own staff (47%); 38% can go shopping when they want (38%);

46% are more independent (46%); and

46% said they feel better about themselves

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

Service Coordinator Survey

Survey was emailed from DDS to all 595 Service Coordinators and Service Brokers in the Commonwealth.

Respondents were able to complete the survey online.

HSRI received 117 valid surveys, a 19.7% response rate. (Last year, we received 103).

Service Coordinators were asked their thoughts on areas such as:

- Process, Training/Education, Communication, and the Impact of Self-Direction.
- Caseload sizes and makeup
- How is self-direction introduced
- Who is interested in self-direction

What Did We Learn?

Service Coordinators discussed both benefits and drawbacks/obstacles to self-direction

- Program is flexible and desirable to individuals and families
- More choice available to people
- Empowering individuals
- Works well for people who were unhappy in traditional services
- Services are individualized
- Funding needs to be increased
- Need for more training for DDS staff as well as for individuals and families
- Process is too complicated
- High caseloads for service coordinators don't allow the time necessary to support someone who is self-directing

Who is most likely to be attracted to self-direction?

People who are unhappy with traditional services

People who have capable and involved families

Transition age individuals

People on the Autism Spectrum

Agency With Choice Providers

Agencies and families support the model, however, there are also challenges:

Difficulty in attracting staff especially given that most staff are asked to work part-time

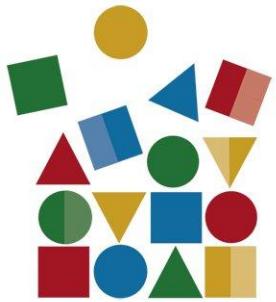
Inconsistent support provided for the model at the Area level including provision of information to participants and families about funding, optional supports, and the process of using the model;

Inconsistent information to providers about what is and what is not allowed under the model;

Lack of adequate funding to providers to enable them to provide the kind of support to individuals that Area Offices seem to expect.

Lack of collaboration among providers to build and improve the model

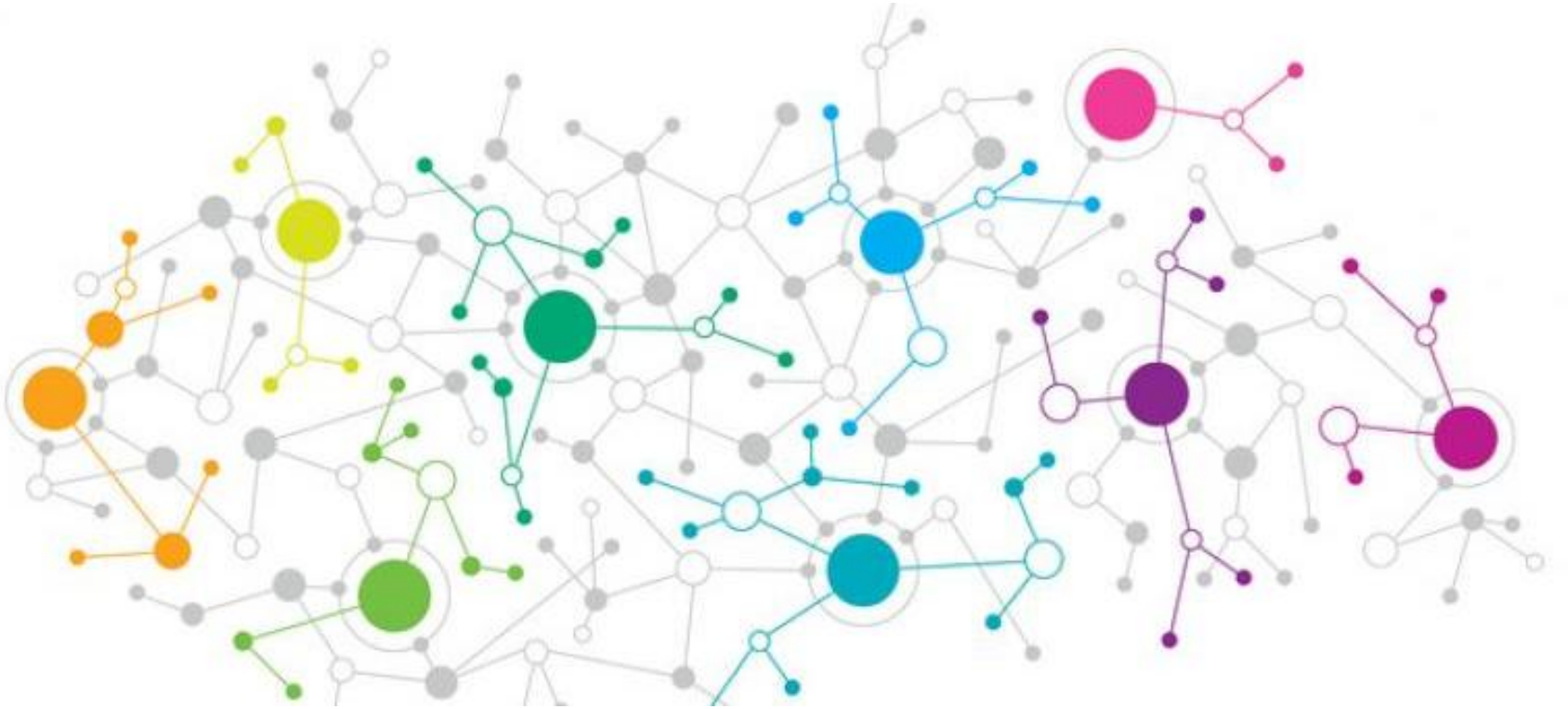
Findings from DDS Data Analysis



- On average, self-directing participants were younger, more likely to be white, prefer English, have a family member guardian, and have higher levels of assessed need
- PDP participants are on average older, less likely to be white, and less likely to have a guardian compared to their AWC counterparts.
- Over the past three fiscal years, the numbers of people who are self-directing has increased; however, the proportion of people who are self-directing has remained stable at around 4%.
- Regional differences in self-direction enrollment were considerable. The growth of PDP has been slower than the growth of AWC except for the Metro East region.
- Individuals self-directed a broad range of service types. With both PDP and AWC combined, the three most commonly self-directed service types were Financial Assistance, Personal supports and Day Services. These three services types combined were also responsible for the majority of the expenditures.
- PDP participants self-directed a wider range of services than their AWC peers and had a higher ratio of self-directed vs. non-self-directed services.

National Best Practices

- All states make support brokers available to participants in self-direction through a variety of means and caseloads ranged from 30 to 35
- States use a standardized assessment—either “home grown” or the SIS—to develop budgets. In New Jersey, the assessment yields budget levels.
- Several states have created consumer advisory boards.
- States noted that self-direction becomes easier as time goes on and as the support broker becomes more knowledgeable.
- Some states take fees for support brokers out of the budget, and some states supply it outside of the budget.
- With respect to training requirements for support staff, one state, Connecticut, requires potential staff to complete online courses via the College of Direct Support.



Findings and Recommendations

CONNECTING THE DOTS

Summary of Findings

- There is a need for additional resources to provide support brokerage if self -direction is to expand significantly in the state.
- There is no dedicated funding for self-direction and support that is available comes out unused or existing funds from preexisting provider contracts and the Turning 22 program.
- Many individuals and families reported a lack of familiarity with their budget amounts both before the development of the plan and over time.
- Everyone who receives services and supports is given a functional assessment; however, there is no standard parameter that links functional levels with individual budget amounts.
- There are significant regional variations in enrollment in the PDP and the Agency With Choice program.
- Though there has been real progress in the development of descriptive and educational material regarding the benefits and mechanics of self-direction, knowledge of self-direction is still not consistent across the state.

Summary of Findings, continued

- The Agency With Choice program is a promising approach to self -direction but has been very slow to expand.
- Self-direction is still a very small part of the overall DDS service system even though there are high levels of satisfaction among those who are enrolled.
- Once the 3-year evaluation is complete, there will still be a need for DDS to track the implementation of self-direction and to determine whether capacity is being built among state staff and providers.
- DDS should consider convening a “users” group of participants and family members to provide advice on self-direction.
- There are continuing issues with PPL, including communication, redundancy, and complexity that should be addressed.

Summary of Recommendations

Explore the possibility of making support brokerage a waiver service to expand the availability of dedicated staff available to support people who are self-directing.

Request additional funding to expand the number of state staff who are support brokers.

Explore the feasibility of requesting that the Legislature create a line item in the DDS budget for self-direction.

Ensure that individuals who are self-directing are appraised of their budget prior to finalization of the plan and know how to access the status of their budgets through the PPL portal.

Examine current methodology regarding the development of individual self-directed budgets to determine whether there are more predictable and consistent ways of linking level of need to an individual budget amount.

Summary of Recommendations, continued

To encourage increased enrollment in self-direction across the state, each region should develop a long-range plan to facilitate the adoption of self-direction with timelines and enrollment targets.

Continue to expand the availability of information on self-direction in a range of formats to educate participants, family members and support coordinators/support brokers.

Take several steps to encourage participation in Agency With Choice both by participants and providers.

Convene a statewide conference on self-direction to showcase both the PDP and AWC program and to highlight the experiences of individuals who are self-directing, providers that support self-direction, and support brokers.

Continue to monitor the enrollment in self-direction through surveys of service coordinators and brokers as well as individual participants and review of regional data to assess whether self-direction targets are being met.

Questions?

VBRADLEY@HSRI.ORG