YEAR 2 EVALUATION REPORT of the MA REAL LIVES LAW by the Human Services Research Institute

December 2018

Human Services Research Institute (HSRI) was hired by Massachusetts DDS to do an evaluation of how the Real Lives law is helping people to have more control over their services and supports through self-direction.

In 2014, the state of Massachusetts passed the Real Lives law.

The law required DDS to:

- Make sure staff and agencies are trained about what they need to know to help people to self-direct their services,
- Reach out to people who might be interested in using self direction for services and supports and give them the information they need, and
- Make sure the system is set up so that people can truly benefit from self-directing their supports.

The law also said that DDS should hire an independent evaluator to spend time learning about how self-direction is working in MA and report back to the Real Lives Advisory Board on the findings. HSRI was hired as the independent evaluator and is conducting a 3-year study. We have already finished Year 1, which focused on how DDS is informing people about self-direction and reported to the Board on December 6, 2017. Materials are available on the SDAB website: https://www.mass.gov/lists/dds-self-determination-advisory-board-sdab. In Year 2 we looked at the process of self-direction, the services people are using, and the numbers of people who have signed up. What follows is a summary of what we found in Year 2.

HSRI

What did we do this year?

1. We **analyzed the data** that DDS collects about the types of people who are choosing to self-direct services in MA, and the services that people are using.

2. We **sent surveys** to people who were self-directing their services through either Agency with Choice (AWC) or Participant-Directed Programs (PDP).

Program	Number of Surveys sent	# surveys answered	Response rate
Participant Directed Program	568	195	34%
Agency with Choice	440	126	29%

3. We also **sent surveys** to Service Coordinators and Support Brokers to learn about their experience supporting self-direction. DDS emailed a survey to 595 DDS Service Coordinators, with 117 surveys returned (19.7% response rate).

4. We **interviewed providers** of self-directed services and DDS Central Office staff to understand how the services are set up and delivered, as well as the ways that DDS and agencies are working to make the system work well for people.

5. We held **focus groups with families and people who are self-directing** services in each region.

6. We **interviewed people from other states** to learn about other states' self-direction programs, what works for them and what have been challenges.

Summary of what we learned in our Year 2 Evaluation.[1]

Across Massachusetts, MA DDS has been making serious efforts to get the word out about self-direction, and to make sure the program works for people.

For example, DDS has been:

- Holding meetings where people who are self-directing can talk about their experience and answer questions for people who want to know more about how to get more control over their lives.
- Improving training manuals, guides, web-based information, and videos to help describe self-direction and make sure it is available in a consistent way.
- Reaching out at Transition Fairs to young people who are transitioning to adult DDS services to help them learn about options for self-directing services.

We learned from our data analysis that people who are self-directing are, on average:

- Younger
- More likely to be white and English speaking
- Have a guardian, and need more supports[2]

The Self Direction model is growing but still only a small portion of people who get services through DDS self-direct their services.

- The number of people who are self-directing has increased over the past three years[3] but it is still about 4% of the total population of people who receive services.
- The Northeast Region has a larger number of people self-directing, which is probably because that region has been actively promoting self-direction for a longer time.
- In the Metro region, PDP has been the model that continues to grow, while AWC has grown more in the other regions. This may be because Metro received funds several years ago as part of the Robert Wood Johnson foundation self-direction pilot.
- People who are self-directing mostly use the supports for “Personal Supports,” which includes the categories of Individual and Community supports.

[1] This is a summary of the full report that HSRI has provided to DDS.
[2] Need for support is based on the documented ICAP scores. There were many records missing scores, so this is based on only a portion of the group (about half).
[3] We looked at data from 2015, 2016, 2017

In **surveys, interviews, and focus groups** we learned that:

- People participating in the Person Directed Program (PDP) and Agency with Choice (AWC) say they are mostly satisfied with the program, that they have more control over their lives and that they are able to do the things that they choose.

- Self-advocates and families are doing a good job helping their peers understand what self-direction is and how it can give them more power over their services.
- Overall, people who support individuals who are self-directing say they feel the self-directed model improves the lives of the people they are supporting.
- Knowledge about self-direction is still not consistent across the state.
- Support Brokers are experts in helping to support self-direction, but not everyone can have a support broker help them because caseloads for service coordinators and support brokers are still very high.

We also heard from people about self-directed supports budgets:

- In MA, there is no dedicated funding for people who want to self-direct. Area offices need to identify funds for people who want to self-direct from unused or existing funds contracts with provider agencies and from funds in the Turning 22 program.
- People and families did not all know what their budget amounts are, both before the development of their plan and once they are self-directing.
- Everyone who receives services and supports is given a functional assessment but there is not a standard way that DDS connects support needs and individual budget amounts.
- People who are in the PDP program described continued concerns about with PPL, including communication, redundancy, and complexity that should be addressed.

Recommendations

Based on what we learned this year from surveys, interviews, focus groups, and lessons from other states, the main recommendations in the Year Two report include the following:

Consider shifts in how self-direction is supported and funded:

1. Explore the possibility of making support brokerage a waiver-funded service for individuals to expand the availability of dedicated staff available to support people who are self-directing. Other states that are using this model have been able to make sure people are getting the support they need to self-direct.

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

3. Explore a request to the Legislature to create a line item in the DDS budget for self-direction so that area and regional offices have some core funding dedicated for supporting people through self-direction.

4. Make sure that people who are self-directing know what their budget is before finalization of the plan and know how to access the status of their budgets through the PPL portal.

5. Examine the current way that area offices establish individual self-directed budgets and determine whether there are more predictable and consistent ways of linking a person's level of need to an individual budget amount. This is a strategy many other states use to make sure resources are allocated in a fair and reasonable way.

Continue to promote self-direction to people across MA:

6. 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.

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

8. Take steps to encourage participation in Agency with Choice both by participants and providers.
   Suggested steps include:
   - ✓ Make sure information about Agency With Choice is available in a clear and consistent way to families and people who receive supports from DDS, including written materials about what is and is not included as a service option, and web-based materials.
   - ✓ Encourage individuals and families who are using AWC to be mentors to others who are considering getting involved, and those who are just getting started.
   - ✓ Develop ways for AWC staff to get benefits such as paid time off and health insurance. This might happen in different ways, including making benefits more affordable, through a pay increase, or increasing hours worked by supporting multiple people.
   - ✓ Pay staff from provider agencies who are experienced in AWC to work with other agencies as mentors.
   - ✓ Refer people who are interested in Agency With Choice to service coordinators who are knowledgeable and can help people get started and work with an agency that will provide Agency With Choice.

9. Have 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.

10. 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.

There are further details and full descriptions of the results of our surveys, focus groups, interviews and data analysis in the full Year 2 report.