



Human Services
Research Institute

Evaluation of the Massachusetts Real Lives Bill – Year One Report

DDS Real Lives Advisory Committee

December 6, 2017





Overview

- Review of Year One Activities
- Brief summary of findings
- Recommendations
- DDS efforts currently underway that align with recommendations.
- Next steps in Year 2

Year 1 Activities

- Surveys of:
 - ✓ Participants in AWC and PDP
 - ✓ Non-participants
 - ✓ Families and Service Coordinators

(Results provided to Committee at last meeting)
- Key informant interviews with multiple stakeholders
- Observations of training and outreach efforts including a review of websites that describe and provide information about self-direction in MA
- Collection of information on best practices in other states by holding meetings with directors of services.
- Analysis of state data about participants in AWC and PDP to understand regional and demographic characteristics





Brief Review of Year One Findings

Brief Summary of Survey Findings



Of PDP Participants:

- Most live at home, would recommend self-direction to others, had more positive outcomes, and some had problems keeping good staff and needed more support

Of AWC Participants:

- Most said staff were responsive, that they felt better about themselves, would recommend that program, and two thirds said they got enough support

Of Non-Participants:

- Almost half said they hadn't heard about self-direction at their planning meeting, the major reason for not self directing was that they were happy with their services, and some would be interested in self-direction if they had more information. More than half said that they were not interested in managing their own services. For those who had tried SD and stopped, they cited too few resources, and too much paperwork.

Of Families:

- Among those participating in PDP or AWC, choice was based on the desire for flexibility and choice of staff; reasons for not participating included lack of knowledge and satisfaction with current providers

Results of Service Coordinator Surveys

Recommendations:

- Provide more training to service coordinators/service brokers
- Encourage more communication about best practice among service coordinators/service brokers
- Use people who are self-directing and family members as mentors and presenters
- Give participants and families the opportunity to share experience
- Simplify the process including simplification of the service codes

Lessons from Other States

- The program needs to be clear and simple with a modest number of self-direction options;
- Clear and organized policies and procedures make the self-direction option more accessible;
- States that had self-direction specialists who became proficient in helping people decide on self-direction and then operationalize their plans were more successful;
- Support from peer mentors and experienced family members is an important ingredient;
- Special supports are needed for participants who do not have a large involved network of family and friends.



Preliminary Findings from DDS Data Analysis



- People who are self directing are younger than those in traditional services
- Women are somewhat more like to self-direct than men
- People who are self-directing are more likely to have a guardian
- There are substantial differences in the numbers self directing by region (the NE has the highest proportion)



Recommendations

We didn't know self-direction existed until we read about it online in September 2016. It was like a secret. We need training workshops to inform us about what exists.

—Survey respondent, Family Survey

Recommendation 1:
Expand outreach and
encourage peers and
family members to
share their experiences



Service coordinators should be offered the opportunity to be mentored by experienced support brokers. Mentors should be offered an incentive (monetary or otherwise) to provide mentorship.

—Survey respondent, Service Coordinator Survey

Recommendation 2: Build mentoring relationships and structures



Offer computer training to families considering the model to enhance their ability to negotiate the portal. Ensure the PPL staff are troubleshooting and facilitating problem solving rather than [just] identifying [problems] and not working toward resolution.

—Survey respondent, Service Coordinator Survey

Recommendation 3: Improve training materials for participants and service coordinators



Develop a toolbox for everyone to use. It would be easy to understand and provide information guides, resources. . .

-Survey respondent, Service Coordinator
Survey

Recommendation 4: Cultivate self- direction experts in every area of the state





Almost everyone contacted at the area and regional offices addressed the need to rethink the way caseload size is determined.

Recommendation 5: Build Additional Service Coordinator/Service Broker Capacity to Support Self-Direction



I wish there were ways to connect with other people in my area. It would help if everything did not have to go through the support broker.

—Survey respondent, AWC Participant Survey

I've encouraged one of the families to build a Facebook page where families can share their thoughts.

—Service Coordinator interviewee

Recommendation 7: Improve outreach using social media and a web-based presence




Recommendation 8: Introduce self- direction to participants and families prior to transition

Partner with school systems and connect with local SEPAC and Special Education Directors, offer training, and attend collaborative events – all this would help.

—Survey respondent, Service
Coordinator Survey





Recommendation 9: Insure that implementation of self-direction is consistent across regions and areas

Services and options here are different than in most of the state.

—Survey respondent, Participant Survey

I believe there are huge gains in the past few years, but I'm still amazed at the differences in people's awareness from region to region.

—Survey respondent, Service Coordinator Survey

Going Forward

- During the next year of the evaluation, HSRI will examine issues surrounding the infrastructure that DDS has put into place to support self-direction.
- Some infrastructure issues have already arisen during Year One of the evaluation which we will address in Year Two, including:
 - service coordinator/ broker caseload size,
 - the availability of funding for self-direction at the regional and area office level
 - the development of standardized protocols for self-direction
 - reasons for regional differences in the uptake of self-direction
 - and the ways in which budgets are developed.



Questions?

