

# The Rockport Report<sup>1</sup>

## A Vision for Supporting Families

produced by

Massachusetts Families Organizing for Change

November 2019

**massfamilies.org**

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*Many thanks to the following individuals who contributed their time and energy to generating this content: Kathleen Amaral (Southeast Regional Coordinator), Elizabeth Bostic, Pat Cameron, Karen Claudio, Sara Cohen, Linda Cox, Sue Crosby (West Regional Coordinator), Sory DeOliveira, Louise Dominique, Allisa Duffany, Ebony Flint, Sagrario Guerrero, Sara Harper, Roxanne Harvey, Sandra Heller (Co-Chair, Board of Directors), Lisa Jennings, O. Sophia Johansson (Co-Chair, Board of Directors and Northeast Regional Coordinator), Sandy Lebon (Treasurer, Board of Directors), Lauri Medeiros (Metro Boston Regional Coordinator), Lisa Modenos, Fadilah Muhammad, Bethany Nelson, Haran Phaneuf (Director of Development), Raquel Quezada, Cara Schneider, Bonnie Thompson, Sopheap Tran, Craig Warner, Peter Weiss; and the Board of Directors of Massachusetts Families Organizing for Change.*

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<sup>1</sup> The title of this report pays homage to, *The Wingspread Report*, named for the venue where a vision for supporting families across the lifespan convened.

## INTRODUCTION

On June 5th and 6th, 2019, twenty-eight members of Massachusetts Families Organizing for Change (MFOFC), including Regional Coordinators and graduates of both Advocacy Bootcamp and the Family Leadership Series, convened to develop a vision for Family Support in Massachusetts. Participating family members represented: all five regions of MFOFC; loved ones with disabilities ages 4 through 39; myriad family structures (e.g., single mothers and fathers; step-parents; same sex couples); and culturally, linguistically, and racially diverse families (including Latino, African-American, and immigrant families).

The purpose of this gathering was to revisit the inaugural 1990 Family

Leadership Series in southeastern Massachusetts, at which families were asked, “If family support were truly supportive, what would that look like for your family?”

The decision to convene in early June 2019 was two-fold: 1) to generate recommendations regarding Family Support programming and delivery in light of the upcoming Department of Developmental Services (DDS) *Requests for Responses (RFRs)* for Family Support contracts, and 2) to engage in meaningful dialogue with families given in response to Massachusetts’ recent acceptance into the Supporting Families of Individuals with Intellectual & Developmental Disabilities National Community of Practice (Supporting Families CoP).

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## PROCESS

Over the course of two days, participants engaged in a variety of facilitated activities, including lecture, large group discussion, small group discussion, work with one or two partners, and writing exercises.

All participants were presented with the following goal: ***“To generate recommendations for how our state’s ‘DD agency’ can better support families and our loved ones so that we can enjoy full participation and membership within and of our respective geographic and cultural***

***communities.”*** Subsequently, there was a comprehensive discussion about what Family Support programming currently is, what RFRs are, an explanation of Communities of Practice, and a description of the Supporting Families CoP. Participants were provided with copies of the DDS Family Support Directory, which outlines each currently existing Family Support program. In addition, participants were also presented with the following definition of Community of Practice:

*A group of people who share a concern or a passion for something they do,*

and learn how to do it better as they interact regularly.

Three key elements:

- **The domain:** members are brought together by a learning need they share (whether this shared learning need is explicit or not and whether learning is the motivation for their coming together or a by-product).
- **The community:** their collective learning becomes a bond among them over time (experienced in various ways and thus not a source of homogeneity).
- **The practice:** their interactions produce resources that affect their practice (whether they engage in actual practice together or separately).<sup>2</sup>

Participants received the following purpose statement behind the Supporting Families CoP, as presented on their website (supportstofamilies.org): “To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.” This CoP is grounded in the LifeCourse Framework, which has the Core Belief that, “All people have the right to live, love, work, and pursue their life aspirations in their community.”

Participants were also grounded with this statement from AIDD National Agenda on Family Support Conference in 2011:

*The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of **self-determination, interdependence, productivity, integration, and inclusion** in all facets of community life for their family members. [emphasis added]*

Participants first developed a set of agreements under which to operate. The group generated the following agreements, or assumptions, to guide the discussion and labor over the following two days:

#### FAMILY NEEDS AGREEMENTS:

- Families define what “family” means to them.
- Understand Families need varying levels of support in empowering their loved ones with disabilities in order to be self-determined.
- Recognize that needs may change and must be fluid over time.
- Provide recommendations that are flexible and adaptable to individual family needs (including the needs of the person with disabilities).

#### PEER & COMMUNITY AGREEMENTS:

<sup>2</sup> Wenger-Trayner, 1998

- Recommendations will increase accountability and participation in the community.
- Preserve, promote, protect family networking and peer-to-peer support.
- Leverage parent/caregiver experiences and skills.
- Promote transparency throughout the process, to heal the past, and move forward to build community.
- Recommendations should not be bound by system restrictions; think outside of the system.
- Utilize everyday, plain, conversational language and vocabulary.
- Stay focused and on task to arrive at our end goal.
- Generate a solid first draft.

Following these agreements, small groups developed a vision for family support and presented these to the larger group. Event facilitators identified five themes that were represented in these visions for Family Support services. They were:

#### INCLUSION AGREEMENTS:

- Acknowledge the worth, dignity, and value of everyone.
- Proceed with the assumption of fairness and that fair is not always equal.
- Give recommendations that are inclusive across diagnoses, culture, language, race, ethnicity, eligibility, and lifespan.
- Include families who are in need but not currently eligible for services.
- Be sensitive to the fact that families and their loved ones with disabilities are vulnerable and at-risk.

1. Cultural competence
2. Knowledge, information, and navigation
3. Community membership
4. Meaningful support across the lifespan
5. Family driven

Participants then joined groups based on their interest in a specific theme and generated the following information:

#### PRACTICAL AGREEMENTS:

- Promote growth, not just fill gaps or fix a break.

- Identified gaps and barriers related to the theme.
- Described what hasn't worked and brainstormed solutions.
- Listed which resources are utilized within the service system.

- Listed the linkages to resources outside of the eligibility-based service system.
- Identified how this/these solution(s) increase access to full participation and membership in the community for people with disabilities and their families.

One person from each group was selected to present the outcome of these discussions to the larger group. To prepare for this, they presented the findings of the previous discussion to a new set of group members. This new set of group members considered the following questions as a method for

preparing the presenter to share the findings with the larger group:

- Does anyone have clarifying questions about content?
- What are ways that we can better describe the gaps and challenges?
- How can we strengthen the potential solutions?

Based on the outcome of this second discussion, presenters then shared with the larger group. This content from five presenters is captured in this report.

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## VISION FOR FAMILY SUPPORT

The participants at the Advanced Family Leadership Training developed a vision for family support. Five core themes emerged from small group discussion: cultural competence; knowledge, information, and navigation; community membership; meaningful support across the lifespan; and family driven. Each of these themes are explicated in the following sections.

### **Cultural Competence**

There exist significant language barriers and lack of cultural competence. Professionals working with families are often unfamiliar with the specific disability and/or how a person's culture may relate to

disability. Culturally and linguistically diverse family members struggle to obtain accurate information in a timely manner while service workers and agency staff fail to connect with the families that reach out to them. Social opportunities to engage with both other families experiencing disability and families within the community are lacking. Agency staff and service professionals struggle to overcome challenges associated with supporting families whose heads of household have not previously accessed education and therefore have low literacy rates. These idiosyncrasies exacerbate challenges with navigating systems and services.

The group primarily represented Latino families, pointing out that their Spanish-speaking peers experience a perceived lack of ability to learn English because it is too difficult. Latino communities have immigrated by necessity and choice. The learning of any language is a choice that many parents of children with special needs have the option of making, though many people might talk themselves out of making this decision because they may not have the confidence or resources (time, educational background, motivation, etc.) to believe they can learn another language. This, in turn, is responsible for a lack of understanding and equal participation in crucial communications with anyone providing supports to children, youth, and adults with disabilities including support staff, therapists, school personnel, and more. Families do not have enough opportunities to connect with other families for support and to share knowledge.

Potential solutions were grounded in increasing funding to accommodate challenges experienced by Latino families, with the understanding that these challenges are affecting other linguistically, culturally, and racially diverse groups that experience poverty, racism, and discrimination. Solutions include increasing funding to combat particular challenges with transportation and respite so that family members can participate in events and connect with other families; increasing communication and outreach to families through a variety of channels; offering regular professional development

opportunities to increase cultural competence and encourage passion among service providers for working with and empowering culturally and linguistically diverse families. Additionally, it is crucial to make a specific investment in providing families from other cultures access to highly trained staff in order to receive quality family support services, regardless of residency status, country of origin, or race.

There are also opportunities to invest in the professional development and education of people within culturally, linguistically, and racially diverse communities so that families can be served by people who they perceive as their peers. This would inevitably lead to providing families with trainings and leadership development opportunities in the language they are most comfortable receiving information, instead of simply providing live-language interpretation and translated materials.

It should be recognized that access to resources, including transportation, funding for respite, leadership development, training in how to navigate services and supports are critical to participation and membership in the community. This requires specific investment in culturally, linguistically, and racially diverse families who experience greater barriers to achieving optimal outcomes for their loved ones.

Service providers and state agency personnel should also pay special attention to the challenges that are arising as a result of increased

scrutiny of immigration status and the recent Public Charge Rule (despite its rollback). In order for families to feel comfortable accessing services and supports, they need to trust that personnel at state agencies and contracted providers won't call immigration authorities. Families need to be assured that their information is private and that they are protected. It should be noted that state agency personnel and staff at contracted providers are not perceived as unsympathetic. To effectively reach families, service consumers need to see themselves reflected in the people doing outreach to them.

### **Knowledge, Information, and Navigation**

Acquiring information, amassing knowledge, and developing navigation savvy remain persistent and pervasive challenges across all families. One significant gap and barrier is that families do not become known to state agencies and providers through one port of entry: instead, there are numerous application processes. There are certainly solutions *within* specific systems (i.e. Family TIES Resource Directory, peer to peer programming funded by the DPH and the Mass Down Syndrome Congress), but there is not one place where families can gain a comprehensive understanding of everything that's out there. Furthermore, much of the information available is tied to specific schools or systems a family is currently considered eligible for.

One proposed solution to this is to develop a hub within community centers and utilize family liaisons to outreach to and support families in connecting to a wide array of supports. Organizations outside of the disability specific system can be utilized to do this. For example, schools' PTOs and SEPACs can work together; there can be a website maintained by a specific regional coordinator to follow up on inquiries so that guidance can be provided through real-time, reciprocal interaction.

Another gap identified is effective communication between medical, school, and other providers. In this arena, too, there are solutions inside of systems like family engagement coalitions, school coalitions, the Parent Advisory Councils, and Family Support Centers. Outside of disability-specific systems, much can be done. For example, hospitals and insurance companies can be incentivized to successfully share information through comprehensive care and case management. There can also be a statewide, cross-system campaign to promote readiness within geographic and cultural communities to accept and embrace children, youth, and adults with disabilities and their families. This campaign can improve awareness of disabilities by de-stigmatizing disability, as well as share information about supports that exist for families and people with disabilities.

There are currently insufficient human resources to provide information to families and their loved ones with expediency and accuracy.

Thought should be given to financially supporting and maintaining peer to peer support and resources. More effort should be invested in communication within and between communities, rather than systems and state agencies dictating how information is shared and spread.

Communities are not ready to meaningfully support families within them to understand, access, and implement the supports and resources that should be available to all. One solution is to fund specialized supports with the expectation that they are provided within the community, by organizations already serving all of the community.

Another challenge is the lack of transparency in funding regulations and how to file complaints with providers and state agencies. Appeal processes and complaint processes are not widely publicized, nor do they exist in all areas where decisions are made. For example, if families disagree with an Area Office's decision not to reimburse an expense clearly listed as an "allowable" in the Family Support Manual, there is no clear path to appeal this decision.

There are currently no coordinated efforts to implement change across all communities, both within disability-specific systems and outside of them. Advocacy groups should be encouraged and supported to continue engaging community-based organizations so that knowledge and information about resources, as well as how to acquire them and navigate between services and supports, is

information that is easily accessible wherever families are.

### **Community Membership**

Barriers to community membership exist in recreational activities and spaces, as well as transportation. There are insufficient resources to support organizations in welcoming children, youth, and adults with disabilities to their activities. Families experience significant segregation because inclusion practices are poorly executed and there is infrequent adherence to ADA compliance. One blanket response to these challenges would be to increase community awareness of these challenges through numerous means and to market solutions, including training for organizations and volunteer groups, and opportunities to offer activities in direct and close partnership with Family Support Centers.

Affordable and effective transportation is lacking in urban, suburban, and rural areas, with various factors preventing access to activities. Challenges include sensory overload, frequency, noncompliance with ADA, cost, and a focus on seniors as opposed to focusing on serving people across the lifespan. Regional Transportation Authorities are not currently linked across the state, thus exacerbating fragmentation of public transit systems.

Families also experience hostile, negative, and unsupportive behavior from people organizing events and attending activities. Many families



attribute this to stigma associated with disabilities and behavioral challenges. While individual support for children with disabilities is often required, the support is not provided effectively or in a way that builds connections between people. In other words, support is not *individualized* to increase connections and build relationships between people with and without disabilities. These poorly executed activities reinforce segregation of people with disabilities from their non-disabled peers because there are rarely any positive outcomes. As a result, families that include children, youth, and adults with disabilities often seek events with families like their own instead of continuing to engage in community-wide activities.

Solutions include reliable transportation to different activities of a family's choosing; increasing community readiness to welcome all people into their activities; and funding specialized supports for organizations currently offering recreational and leisure activities to members of their regional and/or municipal communities.

These activities can lead to long term, reciprocal relationships between children, youth, and adults with disabilities and non-disabled peers. Community-based organizations require additional resources to increase outreach to and improve engagement of children, youth, and adults with disabilities. It should be noted that these activities and efforts will be instrumental for changing the

culture and combating stigma around disability.

### **Meaningful Support Across the Lifespan**

The gaps and barriers to meaningful support across the lifespan are comprehensive: there is restrictive inflexibility in the system, a lack of timeliness, a lack of quality providers throughout the lifespan, lack of whole person systems, and a lack of infrastructure to support effective and excellent supports.

All potential solutions can be generated between partnerships within and outside of disability-specific services and supports. They include: appropriate compensation for qualified professionals who receive comprehensive, specific training about transitions and how to expertly navigate them, with particular attention to issues around less restrictive alternatives to guardianship (i.e. Supported Decision Making); proposing and passing legislation to require and appropriately fund qualified specialists to assist and support families and their loved ones across their whole lives; particular attention is given to transportation and developing reciprocal relationships within the community. Additionally, families and their loved ones with disabilities should all have the opportunity to work with someone expertly trained in the LifeCourse Framework to chart their life course and set a trajectory.

In considering meaningful support for families and their loved ones across the lifespan, the state agencies and advocates should consider whether or not there is a need for current family support systems and providers to receive additional training or if there is a need to develop an entirely new approach to services and supports. The fact remains that families need to be able to work with one person who is qualified and has the skills to support them throughout the lifespan.

### **Family Driven**

Family support services should be driven by families, both on an individual level and on a systems-wide level, as well. A tremendous barrier to accessing family support services is that it is not an entitlement and driven by the specific needs of the consumer, but a support that is offered based on the resources that are currently available in the state budget. Additionally, families who are not known to the family support providers or the state agencies are not receiving the supports that they require. While a diverse array of families are currently accessing these much needed resources, there still isn't adequate representation across cultures. This lack of representation is ubiquitous across the state and these families for whom the system has not made contact or provided with meaningful assistance are at a tremendous disadvantage for changing these circumstances. They often lack the knowledge of how to engage with providers and agency representatives,

as well as how to effectively advocate with these systems.

Outreach to families must be intentional, deliberate, and evolving. It is notable that some of the most effective family support specialists are, themselves, parents of people with disabilities. Support staff should prioritize these types of connections between families: the best resources are other families who have had to navigate similar challenges. Family Support Plans could be redesigned to look more like caregiver assessments. These could be shared and completed utilizing low-cost technology.

Families have many skills that DDS and other state agencies could utilize more effectively. For example, families are skilled at gathering other families with diverse backgrounds. This could be leveraged as a way to engage families not currently known to the system and to coordinate different types of supports across state agencies, particularly during the transition years (age 14 through 22). This could also improve the overall functioning of family support services and other types of support models; family members could convene and facilitate focus groups so that their peers feel empowered to speak out about what they need. This would be particularly impactful for parents of diverse backgrounds.

Families should be represented on Massachusetts's Supporting Families CoP and various working committees. This perspective is crucial and unique from the insight of parent-professionals, which includes

anyone working as a provider of formal services or in formal agency roles. It is important to make a distinction between parent-professionals and parents who have unique skills around family engagement and leadership development: the latter possess expertise in understanding how to retain their authenticity as parents while also understanding how committees function, as well as how to contribute meaningfully when serving on councils, committees, and advisory groups.

It should be noted that parents don't always have the skills to sit on systems-wide committees so they need access to curricula and support to prepare them for full participation, like the training *Serving on Groups*. People working within the system and advocacy organizations should also receive training on how to effectively partner with families, like the curriculum *Leading by Convening*.

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## **OBSERVATIONS AND RECOMMENDATIONS**

This convening was an effective and inspiring way to engage families. This report represents what can be achieved when a family-run organization convenes family members who have previously had access to comprehensive family leadership development opportunities and been effectively supported to sustain their engagement in these activities. MFOFC should continue to convene families to generate outputs as a way to meaningfully build upon the educational and informational opportunities that are regularly offered. MFOFC should also continue to engage families in generating policy and practice recommendations, particularly in regards to the themes identified during this convening.

There are pockets of excellence across Massachusetts where families are truly experiencing ideal forms of family support. Family Support

providers are well trained and excellent at empowering families to explore person-centered approaches. These staff connect families to learn from each other and keep abreast of innovative strategies and initiatives like Supported Decision Making. More can be done to leverage this expertise and gather specific feedback about what is working effectively and efficiently, as well as where providers and families continue to struggle. This insight can be utilized to increase linkages in the community that are not specific to disability.

A remarkable topic that received peripheral attention is that of housing for both families and their loved ones with disabilities. It is a tremendous challenge to acquire and maintain safe, affordable, and individualized housing arrangements. Anecdotally, the families that seem to experience the greatest challenges are

single-parent households with a history of generational poverty and domestic violence. Renters often report challenges when they are caring for a loved one with behavioral needs that lead to property destruction, aggressive behavior, and noise past “quiet hours.” Families with multiple children, one of whom requires the use of a wheelchair, are extremely limited in their public housing options, as many of these wheelchair accessible units are designed for a single person who lives alone or with a partner. It should be noted that there are two prongs to resolving the housing needs of families and their loved ones with disabilities: first, tackling the affordable housing crisis and the scarcity of suitable living accommodations for people with physical and developmental disabilities; second, making a significant investment in building skills of families to develop individualized housing solutions for their loved ones.

State agencies and contracted providers should increase their engagement of families to solicit regular feedback so they can improve outcomes for children, youth, and adults with disabilities. The Statewide Family Support Council is an excellent example of this. Families should be represented on workgroups internal to DDS; on advisory councils to the Family Support Centers and contracted service providers, as well as in all CoPs that are active across the state, no matter the topic. In order to receive effective support to participate as equals, both families and conveners will need access to

training. The *Serving on Groups* and *Leading by Convening* curricula are two examples of this type of training and content, with strong evidence behind their efficacy. MFOFC is a wonderful candidate to coordinate and deliver this training.

Ultimately, the core themes in supporting families identified by this convening are believed to be ubiquitous across all seven state agencies named in Chapter 171: Department of Developmental Services, Department of Mental Health, Medicaid/MassHealth, Department of Public Health, Mass Commission for the Deaf and Hard of Hearing, Mass Commission for the Blind, and Mass Rehabilitation Commission.

While the purpose of this summit was to generate a solid first draft of a vision for supporting families, MFOFC encourages all of these aforementioned agencies, with particular attention within DDS, to develop strategies to respond to the gaps and barriers identified by this group of family members, as well as to consider the solutions and recommendations proposed in this report. MFOFC is an able and willing partner in all of these endeavors.

