



Family Support and Family Involvement:
Building Skills, Knowledge and Participation

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Parent/Professional Advocacy League
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A Report on Surveys Conducted by the Parent/Professional Advocacy League

January 2012

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Thanks & Acknowledgements

This family-driven study, *Family Support and Family Involvement: Building Skills, Knowledge and Participation* provides a perspective on the training needs of parent support providers¹ in Massachusetts, as well as families whose children have emotional and mental health needs. Massachusetts leads the country with the largest number of parent support providers in the country and their work experience ranges from newly-hired to veterans of more than 10 years.

We are grateful to the following people for helping us develop the survey questions. Without them, we not have been able to frame our questions and get our responses: Chantell Albert, Dalene Basden, Melissa Kneeland, Jan Lamberg, Mary Lambert, Barbara Macias, Mary Mercier, Beth Pond, Meri Viano, Sherol Watson, and Mark Zanger

Many thanks go to the family partners, family support specialists and others providing family support as well as the parents who took our survey and participated in the focus groups. Without you, there would be no report.

Parent/Professional Advocacy League (PPAL) is the leading public voice for families whose children have emotional, behavioral and mental health needs in Massachusetts. PPAL is the statewide chapter of the Federation of Families for Children' Mental Health and is dedicated to promoting change that will improve the children's mental health system statewide.

This project was funded by a Statewide Family Network grant from Substance Abuse and Mental Health Services Administration (SAMHSA)

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¹ For more information about Parent Support Providers, visit www.ffcmh.org/national-initiative-for-parent-support-providers/certification-2

Executive Summary

In August and September 2011, Parent/Professional Advocacy League (PPAL) invited people working in parent support provider (PSP) roles (e.g., family partners, family support providers) as well as parents, to participate in one of two surveys. One survey was focused on parent support providers and the other on families whose children have emotional, behavioral and mental health needs.

Massachusetts leads the country in the number of parent support providers and has a significant number who have been on the job for two years or less as well as a large group who has worked five years or more. The first survey was distributed to 150 parent support providers and 90 completed the survey. They represent a range of experience, training and work across the state. Many respondents affirmed that family peer-to-peer support is the foundation of the work of a parent support provider. While training can be essential to successful outcomes, personal experience lays the foundation for the connection and understanding that make this work effective.

The second survey arose out of the changing role of parents. Massachusetts has shifted many of its services and treatments to the home and community and parents are managing at home while being asked to serve on committees, attend focus groups or share their stories. This survey asked parents what supports they needed to keep their children at home and in community. It also queried parents to identify the skills and knowledge necessary to participate in leadership activities. More than 230 families filled out surveys and 27 attended focus groups.

Parent Support Providers

Respondents to the survey of parent support providers identified themselves as parents of a child or youth with mental health needs (98%). Half of those who responded work for a community service agency, 26% work in mobile crisis intervention, 14% work in Department of Mental Health funded family support roles and one percent work in Department of Children and Families funded Family Resource Centers. 41% have been in their positions for 1-1/2 to 2 years; another 21% have been in their jobs for more than 5 year. The length of time a PSP has been in her position has a strong impact on how she sees her needs and strengths.

The majority of parent support providers say that lived experience is the most important training or experience they bring to their jobs. More than twice as many respondents valued lived experience over a combination of lived experience and work experience. It is the foundation of their work and the base upon which they build other skills. As PSPs gain more work experience, they value the growth of their skills and knowledge and rely upon it more and

more. For the most experienced PSPs, specific knowledge and skills, especially in accessing special education services, gains greater importance. Newer PSPs did not identify special education training as a priority.

As parent support providers become more experienced, they find training on how to do their job less important and value content knowledge more. Respondents pointed out that the families they work with have complicated and serious needs such as parental mental illness, trauma and domestic violence. While newer PSPs found training on how to participate in wraparound or work on mobile crisis teams the most valuable trainings, more experienced PSPs wanted specific skills and knowledge. Many requested training on mental health diagnoses and effective treatments.

Parent support providers characterized their job as highly rewarding. Several said that the connection they had through shared lived experience with families gave them satisfaction. Others stressed that the job is unique and requires patience, flexibility, compassion and self-reflection. Nearly all pointed out that there was no career path for professional development and advancement. Many said the salary is inadequate and the importance of what they do is not respected.

Parents and Family Members

Respondents to the parent survey identified themselves as parents of children and youth with mental health needs. They live in 187 of the 354 towns and cities in Massachusetts and represent a range of cultures. Almost 55% were insured by MassHealth, 21% were privately insured and 29% had a combination of public and private insurance.

Parents were clear that their children and families need more than home or community based services and treatments. They were eager to gain more knowledge, find resources in their communities and take the next step toward participating on committees and in public forums.

Parents said they need 3 things to manage at home: behavioral strategies that go beyond sticker charts, special education advocacy and help finding community resources. Many parents (67%) believe that managing difficult behaviors is possible, but they need sophisticated strategies. Second, parents also find that if the school plan doesn't work, it has a negative impact. They identified a need to advocate for special education services (61%) with expertise in mental health issues. Last, parents (56%) said that finding community resources for their child and themselves is very important to them.

Parents want to participate in committees and other community leadership roles, but worry about being unprepared. Many believe others might be reluctant or unaccommodating and want to build their skills and knowledge. The most requested trainings

topics were an overview of children's systems, understanding legislative strategies and communication and public speaking skills.

Introduction

Massachusetts leads the country in the sheer numbers of parent support providers² (the national name for family partners, family support specialists, parent coordinators and family advocates) who deliver support and direct services to families whose children have behavioral health needs. Their work provides information, support and skill-building for the parents they support. They ensure family voice is heard. Additionally, they help reduce feelings of isolation and promote confidence and hope and provide a link between the family's experience and children's systems.

Though both the Departments of Mental Health (DMH) and Children and Families (DCF) have funded community based parent support providers for more than 15 years, their numbers have remained constant with limited expansion. That began to rapidly change less than three years ago. Beginning in 2009, the Children's Behavioral Health Initiative (CBHI), resulting from the *Rosie D. v. Romney* federal lawsuit, rolled out an array of new services, delivered in the home and community through a wraparound approach. CBHI wraparound teams include both an Intensive Care Coordinator and a Family Partner. Another CBHI service, Mobile Crisis Initiative, also includes Family Partners as team members. These new parent support provider roles are funded through Medicaid and are available throughout the state.

A joint procurement of the residential system, funded by DMH and DCF, also includes Family Partners in its proposed design. This additional cadre of family support positions will expand the existing workforce to more than 400 parent support providers by 2013.

While this new workforce has received training to increase skills and knowledge, anecdotal evidence from veteran parent support providers indicates that new skills and information are often required. In order to better understand what trainings parent support providers find valuable or still desire, the Parent/Professional Advocacy League (PPAL) conducted two surveys in August and September 2011. One survey was focused on parent support providers and the other on families whose children have emotional, behavioral and mental health needs.

The first survey was distributed to parent support providers. Family partners who were hired to work on wraparound teams or mobile crisis teams have received training to understand their specific roles. Additionally, PPAL conducts a monthly training for family partners and family support specialists and topics are based feedback from participants. Understanding that parent support providers use the knowledge and skills they have to help families, PPAL asked questions to determine what they had found useful to date and what training was still needed.

The second survey was focused on the changing role of parents. Massachusetts has shifted many of its services and treatments to the home and community. This shift has also changed the role of parents, who are often managing behaviors while attempting to understand what

² Parent Support Provider is defined by the national Federation of Families for Children's Mental Health as a peer parent who provides support, coaching and direct services such as building skills around decision-making, advocacy and locating needed resources.

they mean. Parents are being recruited to serve on local systems of care committees, participate in focus groups and are asked to articulate their intuitive understanding of what works and what does not. This survey asked families what supports they found necessary to keep their children at home and in community. It also queried parents about the skills and knowledge they found useful or wished for in order to participate in leadership activities.

Methods

Surveys

In August and September 2011, PPAL invited people working in parent support provider roles (i.e., family partners, family support providers) as well as families, to participate in one of two surveys. The goal of each survey was to learn more about the training needs of each group. To ensure that the surveys were designed to reflect the experiences and knowledge of parent support providers in Massachusetts, PPAL recruited eight leaders to serve on an advisory group. This group was instrumental in developing the questions and the format for both surveys.

The first survey contained twelve questions and was disseminated to family partners and family support specialists across the state. Of the total of 150 people who were sent this survey, 90 people completed the survey, for a response rate of 60%. The second survey contained six questions and was distributed to parents whose children have emotional, behavioral and mental health needs. Each survey was posted online on SurveyMonkey, which provides online survey software.

For the survey of parents and family members, the survey was electronically distributed to agencies providing mental health services to children and youth and paper copies of the survey were also distributed through PPAL's network and upon request. A link to the survey was also provided in PPAL's monthly newsletter and on its facebook page.

Over a period of two months, 135 surveys were completed electronically, and 97 surveys were received through the mail, for a total of 232 surveys. It is impossible to calculate the exact response rate because both the number of family members who were given the survey through agencies and support groups is unknown, and the number of families who have children with mental health needs is also unknown. However, the surveys received came from 187 out of 354 towns in Massachusetts, so while the sample size is small, it is fairly representative.

Data from both surveys were entered into a data base using the Statistical Program for Social Sciences data collection and analysis platform. The information from the three focus groups was transcribed verbatim, and answers to questions were also coded for emergent themes and categories.

★★★★★★★★★★

The most useful training in my job was being a parent of a child with mental health issues. No other training made me as capable as that.

★★★★★★★★★★

Focus Groups

In addition to the survey of parents and family members, three focus groups were conducted in communities that have higher representation of families from diverse cultures (Roxbury, Holyoke and Lynn). The purpose of the groups was to learn more about what families from diverse backgrounds need to succeed in navigating the children's system. All family members signed consent forms to participate, which assured them of the confidentiality and anonymity of their responses. All participants also completed the family member survey.

Results - Parent Support Provider Survey

Characteristics, Job Tenure and Job Titles

Of the 90 parent support providers who completed this survey, 72 (98%) identified themselves as a parent or caregiver of a child or youth who has mental health needs. Many of these

family members had children who are now adults or were foster parents in the past. Half of those who responded work for a community service agency, 26% work in mobile crisis intervention, 14% work in Department of Mental Health funded family support roles, and one percent work in Department of Children and Families funded Family Resource Centers. The rest answered that they work for privately funded programs, family support center for Department of Developmental Services and non-profit agencies.

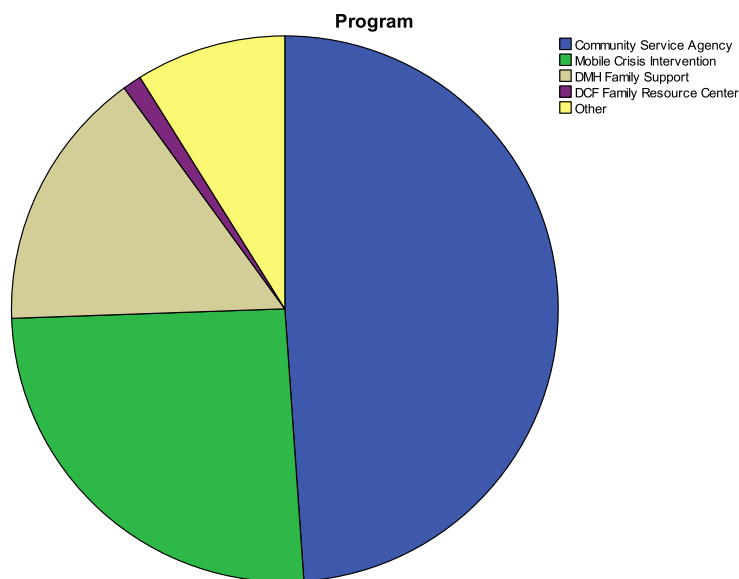
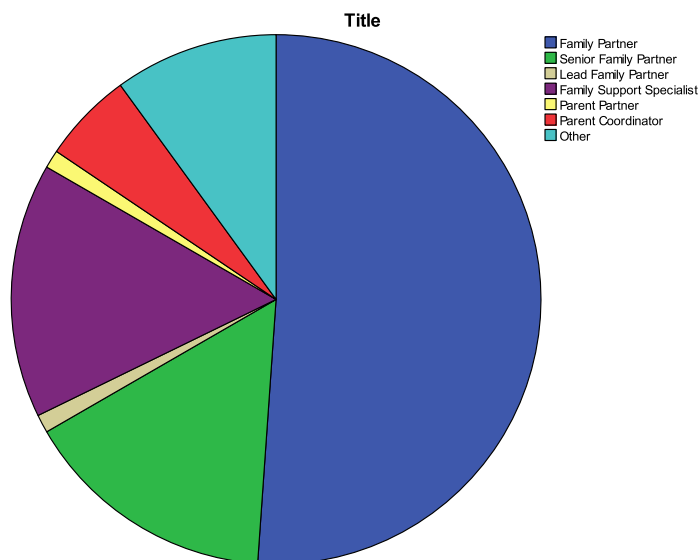


Figure 1: What type of program do you work for?

providers have worked in their respective jobs was between less six months to over five years; however, most have been working between one and one half and two years (41%) or at least five years (21%). The range of titles for their positions was also wide, although most common title was family partner. Other job titles included Family Support Specialist, Parent Partner and Parent Coordinator. is predictable considering there are thirty-two community service agencies employing family partners through the Children's Behavioral Health Initiative.

The range of time that parent support



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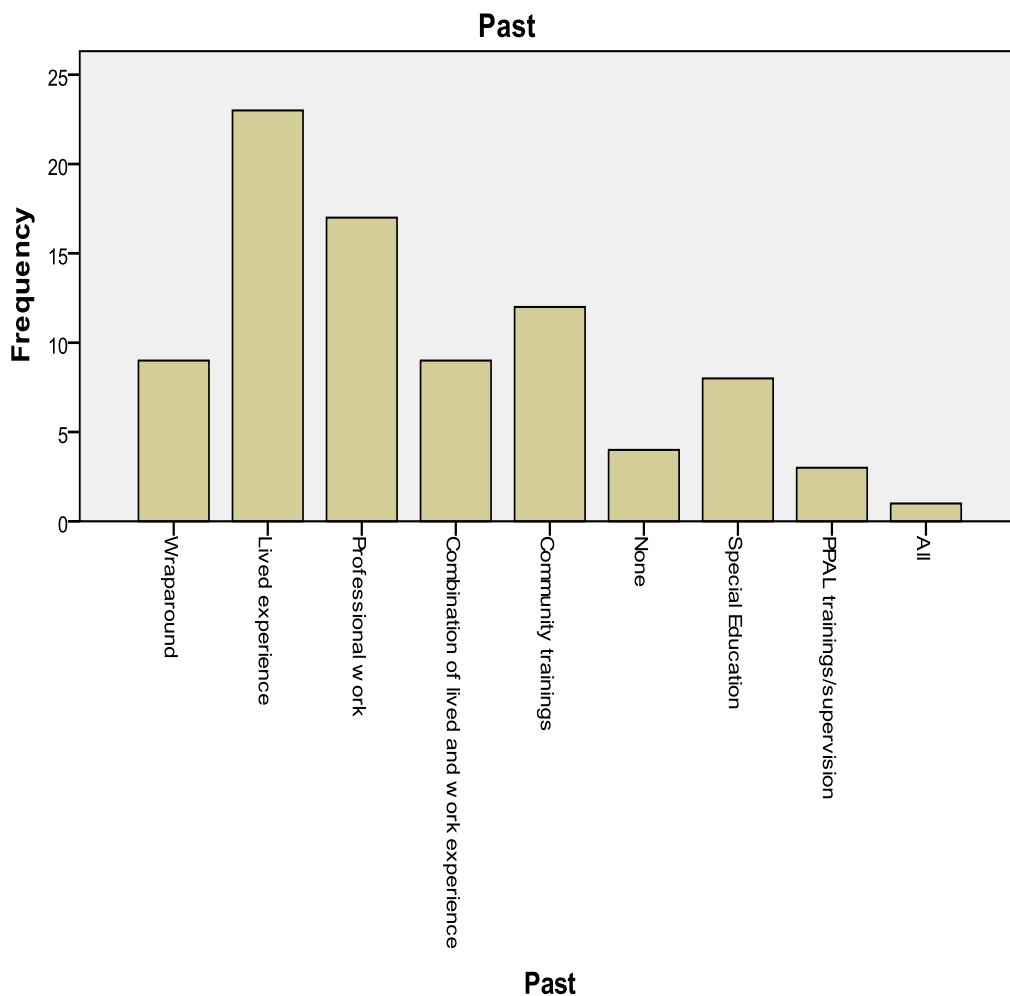
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Life Experience and Past Trainings

Family peer-to-peer support is the foundation of the work of a parent support provider. While training can be essential to successful outcomes, personal experience lays the foundation for the connection and understanding that make this work effective. In order to find and share common elements of parent partner program models, the national Federation of Families convened a Parent Partner Assessment Workgroup (PPAW), a coalition of families and evaluators. In May 2008, PPAW defined a “family peer” as someone who 1) is currently raising or has raised a child or youth with emotional, behavioral or mental health challenges, 2) has current knowledge of the children’s mental health system and 3) has experience with and

conscious-ness of the struggle, recognizes the standpoint of the parent.³

In this survey, when asked what previous trainings, workshops or experiences they found useful **before** they became a parent support provider, the majority rated lived experience as the most important. As can be seen by the chart on this page, the top five answers were lived experience, previous professional work, community trainings, wraparound trainings, and a combination of lived and work experience.

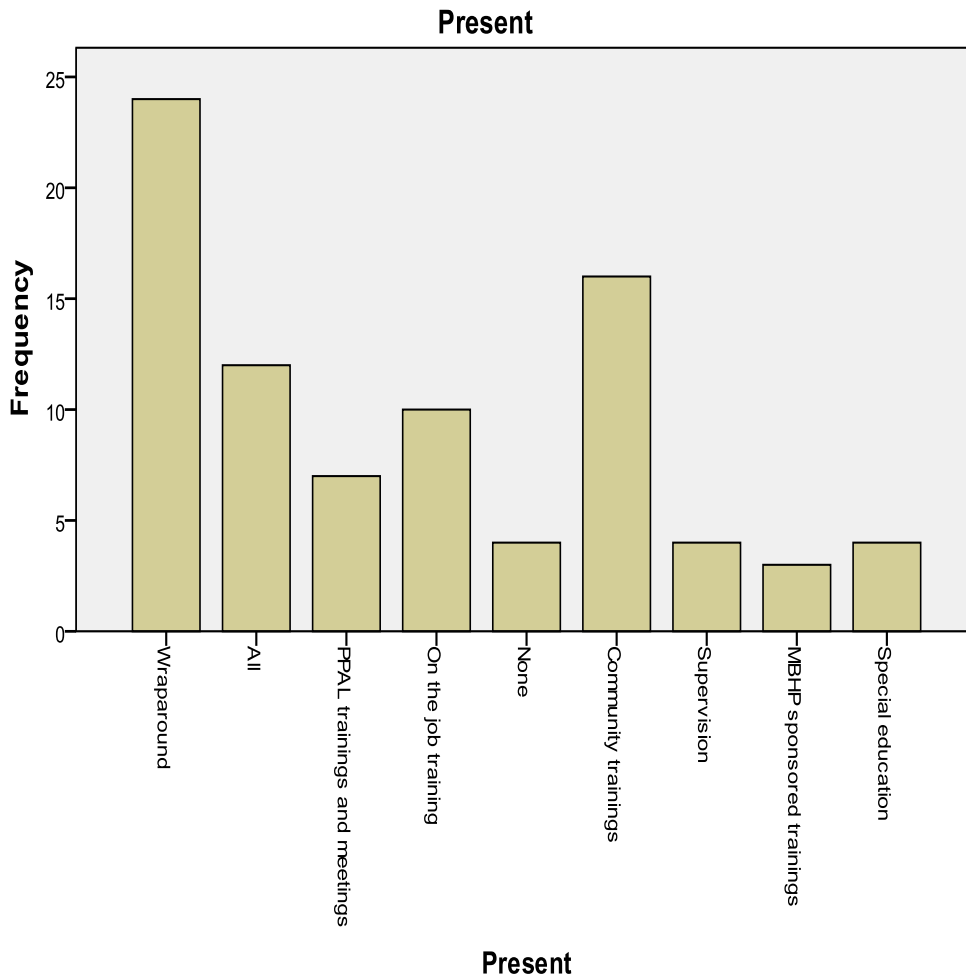


It is interesting to note that more than twice as many respondents valued lived experience alone over a combination of lived experience and work experience. One noted, “Nothing could have prepared me more than “lived experience”...living what I speak about is the only way one can feel the pain and anxiety of another parent.”

³ “Family Peer-to-Peer Support Programs in Children’s Mental Health: A Critical Issues Guide.” September 2009. Federation of Families for Children’s Mental Health, Rockville, MD.

Trainings to Date

A successful parent support provider program will be able to offer comprehensive, high-quality training that is specific to this unique role. Family members hired to provide peer-to-peer support need training, supervision, and support to ensure they have the opportunity to access information and to develop skills needed to be successful. Their needs also include clearly defined expectations and responsibilities and supervision that helps them further develop their skills, not manage their personalities or “stories.”



When asked which trainings, workshops and experiences have been most useful **since** beginning their work as a parent support provider, respondents identified wraparound and community trainings as the top two trainings which have prepared them for their role. Once again, this is not surprising considering that the majority of respondents are working in community service agencies which operate wraparound programs. The third most popular choice was ALL trainings, which is also not surprising given that the majority of parent support providers in

Massachusetts have been working less than two years.

Parent support providers were also asked, “What do you know now that you wish you knew when you first started?” and the responses varied widely. Many reported that they discovered that the families they worked with had a very high level of need. This could include mental illness in the parent, domestic violence or complicated family dynamics. A few reported that they had to learn patience; the parents they worked with were not ready to access support for themselves that did not mean they were not doing a good job.

The most common response was that the parent support provider had learned, and was often still learning, how to find and access resources. One noted how frustrating it can be if those resources are not readily available when needed. Many also reported that they had had to learn about state agencies, how they operated and where to refer families. This included learning more about local schools and special education.

★★★★★★★★★★

When working with parents, they may be very competent in some areas, and need a lot of support in others. In the beginning, I believed that parents were either in the do for, do with, or cheer on stage totally. They are not. They may be in all three stages at the same time. I have become much more aware of this, and support accordingly.

★★★★★★★★★★

if

★★★★★★★★★★

I wish I'd known that my role was to be an advocate for family voice/choice. At first we tended to act like junior clinicians.

★★★★★★★★★★

Last, parent support providers noted that both they themselves were learning more about their own role every day. One said, “It takes a very long time before you learn the complexities of the job. Many also reported that their agencies still did not entirely respect their position. One stated, “Positive results with a family are not necessarily the most important factor in the eyes of administration and the insurance companies, and family partners are very low on the list of priorities.” Still another summed it up this way, “You

learn more and more each day with each family and you need to keep the hope and the patience that things will fall into place.”

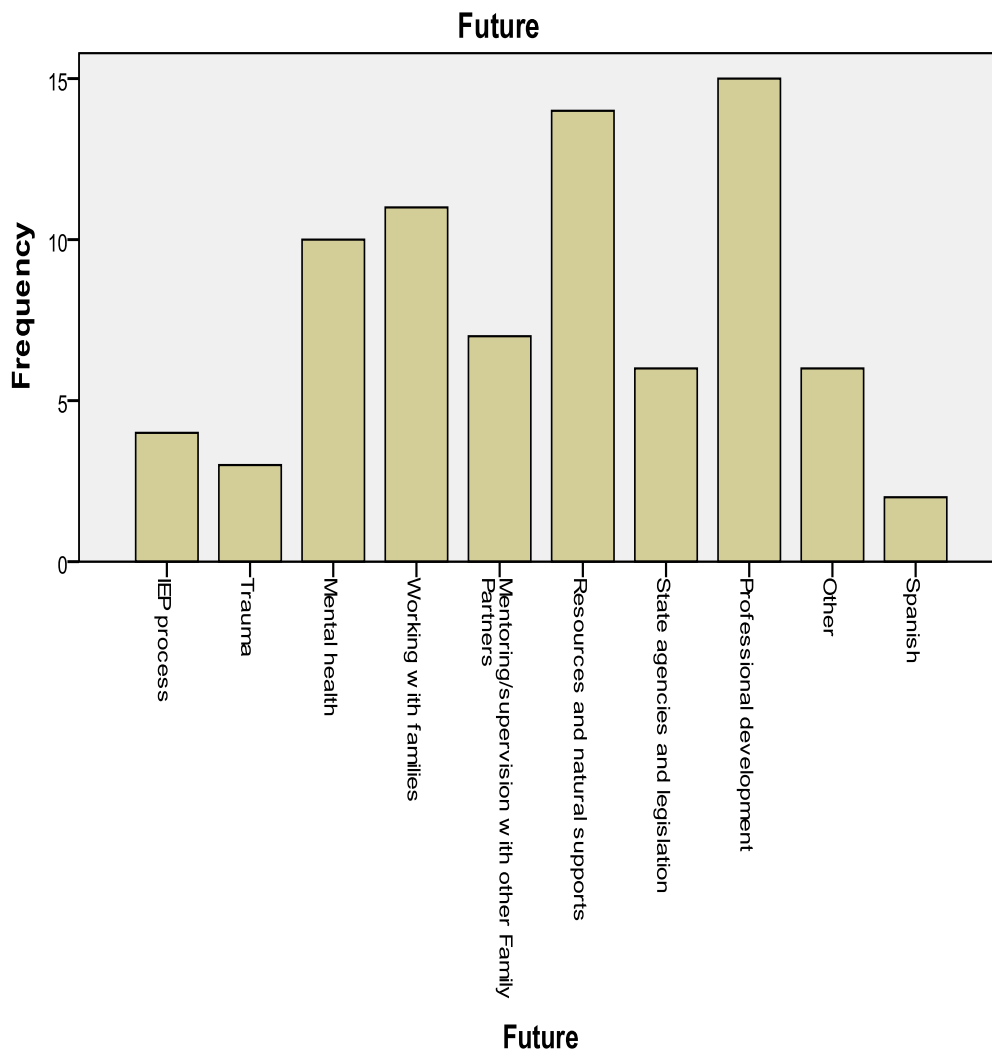
Future Training Needs

The children’s system in Massachusetts can be complicated and children, youth and families often receive services from multiple sources such as schools, clinics, state agencies and through in home therapy programs. Those in parent support roles find themselves continually learning, not only about these systems, but how to do their jobs better and more effectively. When asked, “What would you like to learn more about in the future?” there was a wide range of responses.

As can be seen in the chart below, the top four responses were professional development,

information on resources and natural supports, working with families, and more knowledge about mental health diagnoses and treatments.

Some saw training as a way to do their job better while others expressed a desire for a career path. One saw the need for a way to “further the family partner role so that it will be considered ‘professional, respected and a financial equal.’” Another responded that she wished “That our life experiences can have equal bearing to more structured academic knowledge and should be regarded as such on all levels.”

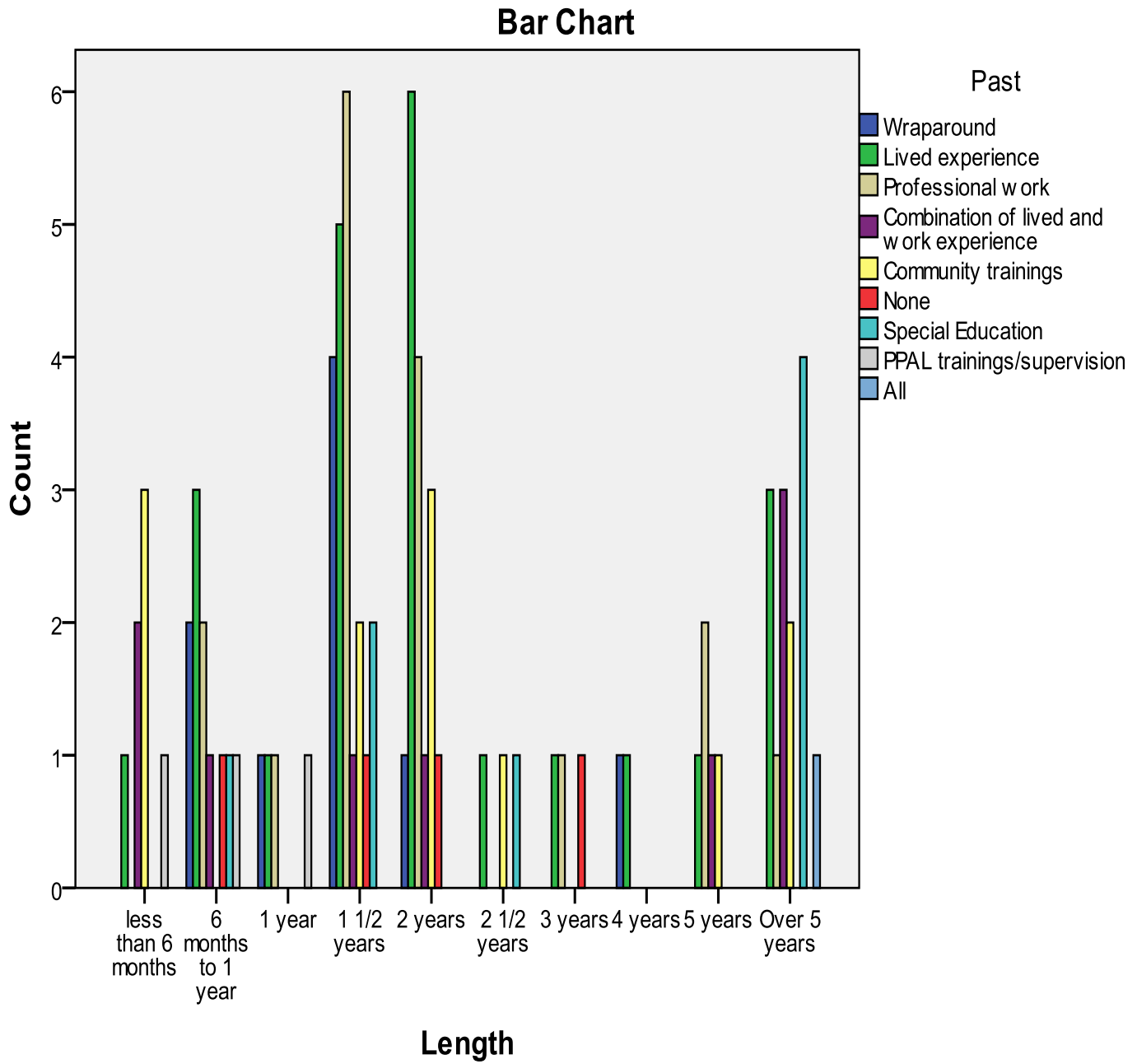


Many saw the need for more knowledge in specific areas such understanding the impact of trauma, learning more about state agencies, special education and understanding specific mental health diagnoses. Still others asked for training on the impact of adoption, substance abuse and domestic violence.

The majority of the respondents reported that their supervisors both understood their role and supported their efforts. However, many believed that the other professionals they worked with undervalued them. One wrote that she wished other professionals “understood how valuable the knowledge we have as ‘parents’ is to the families we work for.” Another added, “I wish they'd remind clinicians to confer with family partners before making decisions- we often have information about family choice and even important clinical information that the clinician doesn't have.”

Impact of Tenure on Training Needs

Previous trainings. In order to determine if there were a difference between what those new to family support roles and more senior parent support providers found useful, PPAL conducted an analysis of types of trainings by length of time employed. The chart below illustrates what previous trainings/experiences parent support providers found useful.



Those who have been working over five years identified special education as their most valuable training followed by lived experience and a combination of lived and work experience as the most helpful.

Parent support providers who had been working two years or less also identified lived experience as the most important asset followed by their on the job experience. those who had worked in this role for two years, the order was switched, with work experience becoming the most valued. For these newer family partners, wraparound and community trainings were the third most common trainings identified.

★★★★★★★★★★
Nothing could have prepared me more than "lived experience"...living what I speak about is the only way one can feel the pain and anxiety of another .

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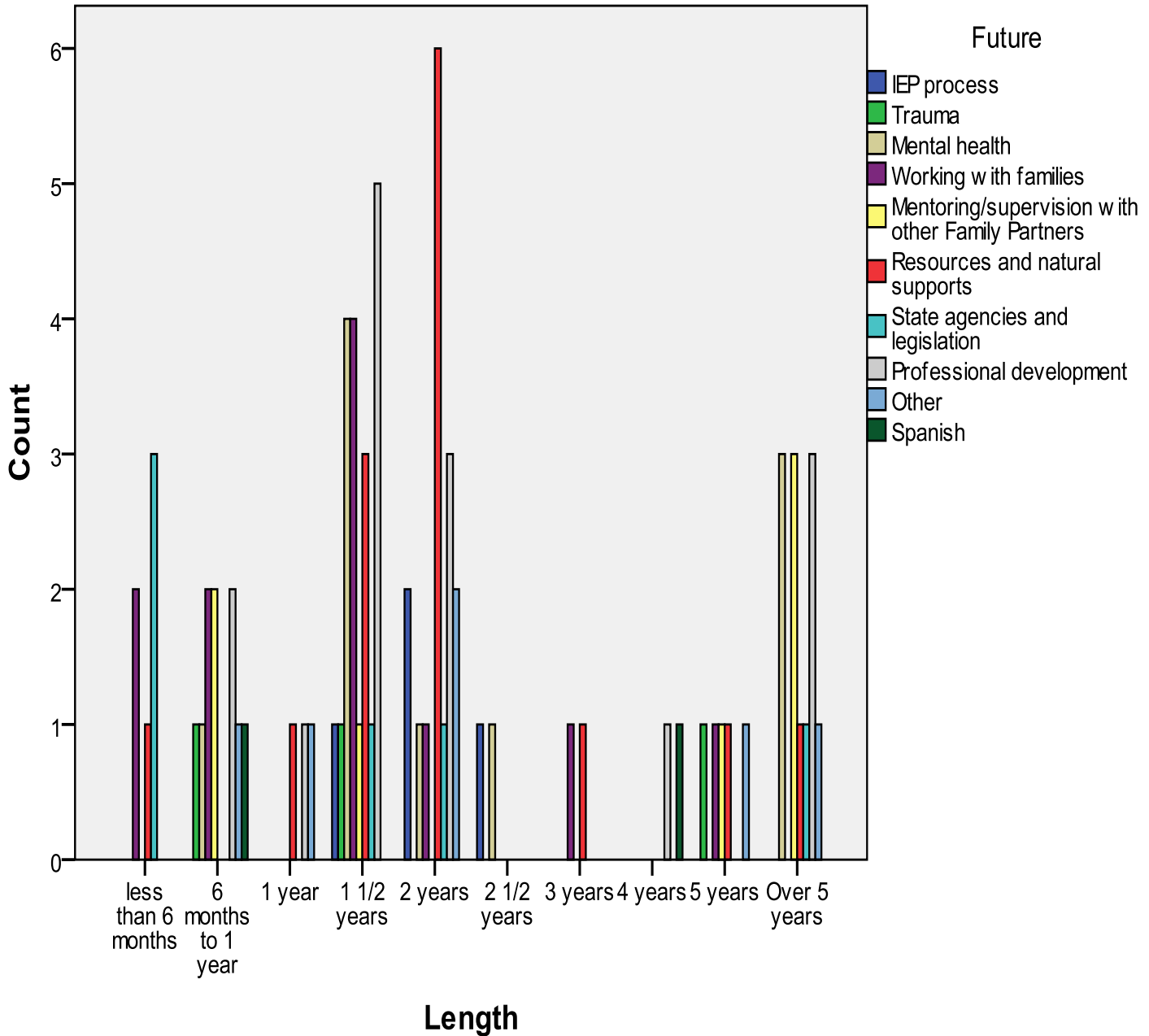
It is important to note that as a parent support provider gains experience they continue to value their lived experience, but their experience on the job is relied on more and more. For more senior parent support providers, the training area identified as most valuable is special education training

Trainings to date. When analyzing current trainings that they found most useful, once again there was a decided difference between those who had worked in family support roles for less than two years and those who were more experienced. A majority of parent support providers who have been working one and one half years or fewer chose trainings in wraparound as the most helpful trainings they had received since they had been hired. For those with two years on the job, the top spot was split between community trainings and on the job trainings. Community trainings are usually focused on a single topic such as the juvenile court or understanding neuropsychological tests. More experienced parent support providers found all trainings helpful (first choice), after which both wraparound and special education trainings were identified as the most valuable. Experienced family support workers stressed the need for a variety of skills and knowledge in order to work with the many different families in their areas. Once again, those who have been working more than five years, identified special education as helpful while newer family partners did not.

★★★★★★★★★★
I love having trainings on special education and how to advocate for social/emotional needs
★★★★★★★★★★

Future Trainings. When asked what future trainings would be helpful, the majority of parent support providers working two years reported that trainings on finding resources and natural supports for families would be the most helpful. For those working one and one half years, professional development, working with families, and understanding mental health diagnoses and treatments were the top three choices for trainings. The top three training requests for experienced parent support providers were trainings on mental health diagnoses and treatments, mentoring and/or supervision with other family partners, and professional development.

Bar Chart



Recommending the Job.

The last question in the survey asked, If you had a friend or relative interested in being a parent support provider, what would you tell them? The most common response to this question was that the work is hard, but rewarding. One family partner wrote, “This is a very

challenging job but it is not just a job, it is an adventure and we can help families because of our experience with our own children.” In fact, 30% of respondents used the word “rewarding” in their comments.

Another common response was that the salary was often inadequate. One person wrote that you would need to have a second job in order to survive financially. Others commented that they thought the inadequate pay reflected the low value their agencies placed on the role of the family partner.

★ ★ ★ ★ ★ ★ ★ ★ ★ ★

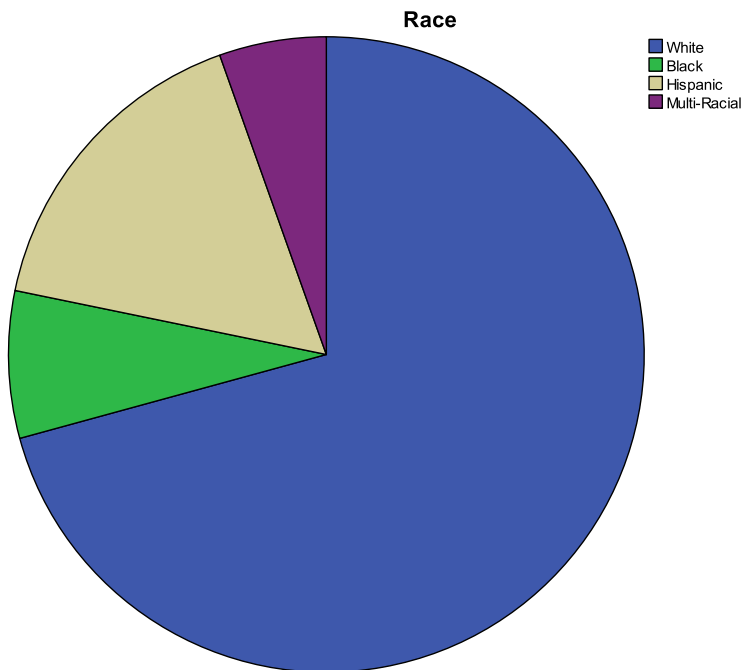
As a matter of fact, since becoming a family partner, I have told many relatives and friends of the joys, rewards, heart wrenching issues, heart breaking stories and dilemmas of what my community is enduring behind closed doors.

★ ★ ★ ★ ★ ★ ★ ★ ★ ★

Many stressed that this role is unique. It demands flexibility, patience, compassion and self-reflection. Often it is emotionally exhausting and many respondents wrote of the need to be aware of its impact and the necessity of taking time to care for yourself. Others were more practical and noted that to be successful, you needed to know the resources in your community and how to find them. Several stressed the need for ongoing training on a variety of topics.

Results - Parent Survey

Massachusetts has shifted service delivery over the last five years to ensure that more children, youth and families receive treatment in their homes and communities. While a great deal of time, resources and attention has been paid to the design and implementation of this shift, far less attention has been given to the information and training needs of families whose children are now residing at home. PPAL's second survey was designed to determine what parents and other family members need to manage successfully at home as well as what knowledge and skills are necessary to become more involved in their local communities. Demographic information about the respondents was collected through structured questions. Other questions were constructed to be multiple select (check all that apply) with options for each category.



Respondents were from all parts of the state and included 187 out of 354 towns in Massachusetts. Ninety-two percent reported that their child had received services in the last year. Because both the online survey and paper copies were written in English, the sample size was limited to English speakers.

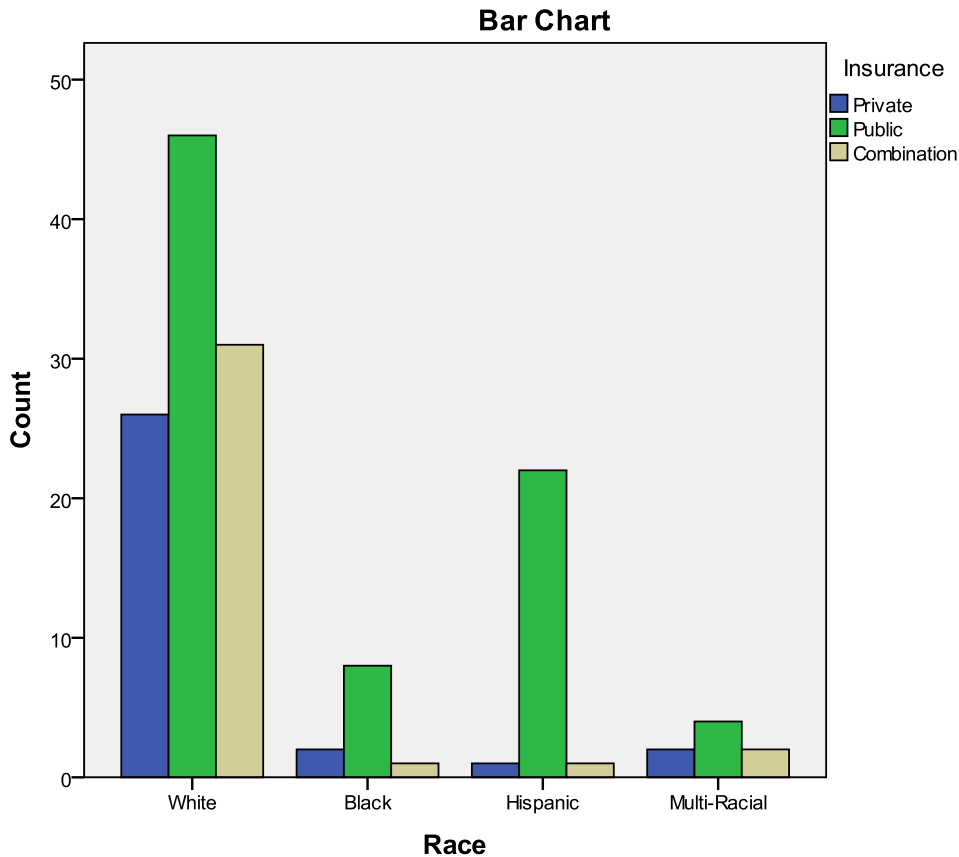
The chart on this page illustrates the race/ethnicity of the respondents. According to U.S. Census data for 2010, Massachusetts' population is 80.4% white, 6.6%

African American, 9.6% Hispanic, and 2.6% multiracial. The racial breakdown of families in this survey was 70% white, 7.5% African American, 16.3% Hispanic, and 5.4% multiracial; only the Hispanic and multiracial families were slightly higher in this survey than the Massachusetts' population.

While the distribution of families who completed the surveys mirrors the percentage of families of families in the state, the distribution of insurance plans for families from this survey does not. In fact, the insurance distribution of families in this survey is almost the opposite of the distribution in the state. According to the Massachusetts Medicaid Policy Institute, most children are on private insurance plans (67%), and only one-third are on MassHealth (33%),⁴

⁴ Seifert, R., & Anthony, S. (2011). The basics of MassHealth. Massachusetts Medicaid Policy Institute: Fact Sheet. February 2011.

while most children from this survey are on public insurance (54.8%). In addition, more children were on a combination of public and private insurance (28.8%) than on private insurance alone (21.2%). The chart below illustrates the racial and ethnic distribution of children by insurance plan.



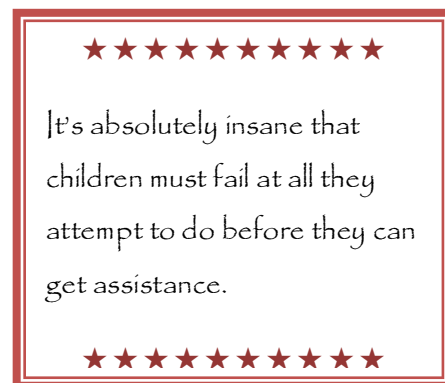
Strategies and Skills to Manage at Home

For many years, PPAL has heard from numerous families that while they might feel competent parenting their “typical” child, they need special skills and resources to parent their child with mental health needs. In this survey, parents were asked what strategies or skills they needed to manage at home. Parents were able to choose from multiple selections and could check as many answers as they wished.

The top three strategies or supports that family members reported they needed in their home were:

- behavior management that goes beyond sticker charts
- how to advocate for special education services and
- finding resources.

The largest number of respondents (67%) answered that they wanted tools for behavior management skills that go beyond simple strategies such as sticker charts. Parents repeatedly report that simple rewards and sticker charts are unsuccessful for children and youth with significant mental health challenges but still believe that managing difficult or unsafe behavior is possible with more advanced techniques or skills. One parent stated that “Not a single tool has been given to my husband and me to control my son’s behavior.”



Parents also identified a need to advocate for special education services for their son or daughter with emotional, behavioral or mental health special needs. Parents regularly say that an adequate special education plan that is implemented consistently is the key to whether their child is successful both at school and in the community. 61% of respondents stated that learning to advocate for special education plans for their child with mental health needs was important to them. This was a consistent theme in all three focus groups as well. It was also identified as an important training need by parent support specialists that had worked for five years or longer.

Percent Response	Type of Resource or Training
67%	Behavior management beyond sticker charts
61%	Special education - learning how to advocate for my child’s mental health needs
56%	Finding resources
55%	Advocacy skills – how to speak up for my child
45%	Networking – finding experts and “go to” people
44%	Mental health treatments – which ones are effective
43%	Mental health diagnoses – what do they mean
38%	Medications – what to ask the doctor

Parents also identified the need to find and access resources (56%). One wrote, “Building natural resources is always a need.” Another stated, “The services not used are the ones not known about.” Bringing treatment and services to the community is important, but it is a small part of the solution for many families. Finding groups, activities, centers and other places

where their children can go and they can connect with other parents is equally important. Many parents (45%) also identified networking – finding the “go to” people in their community as an important factor.

Last, parents said that they wanted to understand mental health treatments (44%), diagnoses (43%) and medications (38%). Many find themselves making important choices with incomplete knowledge. While many parents appreciate an active role in determining their child’s treatment plan, nearly half expressed the need for clearer and more helpful information.

Becoming More Involved

As Massachusetts builds a system of care for children, youth and families, parents must be partners not only in their child’s care, but in design, governance, evaluation and policy. This is an exciting prospect for many parents, while others react more cautiously. When asked what is needed to become more involved in these roles, families were given eight choices and asked to check as many as applied to them

As seen in the table below, the top three choices were

- overview of policies and systems that affect children and families
- information on the legislative process and
- communication skills.

Parents are an untapped source of community leadership. Parents bring a sense of reality to ideas and tasks, can help improve the quality of services and supports, ensure that programs and practices meet the needs of families in their community but worry about assuming a new role they feel unprepared for. When asked to check off the types of trainings that they would find helpful, the majority wanted to gain more information about the children’s system in Massachusetts, including the legislative process.

Percent	Training Topic
40%	Overview of policies and child systems
34%	Information on laws and legislative strategies
34%	Communication skills
27%	Public speaking skills
26%	Reframing personal concerns to solutions
25%	Developing personal leadership style and skills
24%	How community/town government works
23%	Collaboration and coalition building skills
23%	Negotiation and creative thinking

Parents also benefit from being on committees or participating in other leadership roles where they hear others' perspectives, enhance their own skills and learn from the expertise of others. However, they are also aware that they often face the reluctance of others to see them as equals, deal with professional reluctance to overburden families and a general fear of the things parents might ask for. Many respondents also identified skill building, especially communication skills, public speaking skills or reframing their personal experiences and concerns in a way that sounds more focused on finding solutions.

An analysis was done to see if there were any correlations between the culture of families and the trainings they rated as most important to them. The only difference found was that Hispanic families chose communication skills more than any other group. This is may be more representative of the language barriers that exist for those who speak Spanish rather than the need for communication skills such as "active listening" and "reflecting".

★★★★★★★★★★

Respite is a very needed service when dealing with children with serious mental health issues.

★★★★★★★★★★

Finally, the comments made by families underlined the need for direct services and highlighted the barriers they face to attending any training or workshop. There were frequent comments about the need for transportation in order to attend trainings. These comments were echoed by the members of the focus groups. The most frequent comment was about the need for respite care. Respite care has been shown to reduce family stress while increasing coping skills and minimize out of home placements. In a previous PPAL study, *Overcoming Barriers in our Community*, 75% of families surveyed said that respite care was moderately or extremely important to them. Many families whose child or youth has significant emotional, behavioral or mental health needs reports extreme family stress.

Focus groups

The Roxbury focus group had seven participants; four identified themselves as African-American and three were Hispanic. The themes from this group were assistance with advocating in schools for special education services, lack of understanding for their children and their families from service providers, and difficulty with language barriers and transportation. The biggest issue for this group was getting school personnel to understand and positively respond to their children, and the top three training needs identified were for educational advocacy, behavior management, and leadership development.

★★★★★★★★★★

If I were able to learn stress management skills, I would be better able to participate in these forums

★★★★★★★★★★

The Holyoke focus group had three participants, all of whom were Hispanic. Similar to the Roxbury focus group, the main theme was difficulty with schools, particularly in how school personnel did/did not understand their children. Two of the participants commented on how difficult it is for them when the schools call them in the middle of the day to come and pick up their children. All three of them work during the day, which is why this group meets during lunchtime. In fact, one

participant had to leave early to get back to her job. The three training needs identified by this group were communication skills, public speaking, and behavior management. The two biggest barriers to attending trainings were time (evenings or weekends) and transportation.

The Lynn focus group had seventeen participants; eight were White/Caucasian, four were African-American, three were Hispanic, and two were American Indian. This group was highly interactive and reached consensus on the following training needs: (1) trainers should be parents themselves, (2) trainings should be held both at night and on weekends, and there should be childcare and food available, (3) trainings should be conducted in different languages. The top two training needs identified by this group were educational advocacy and grant writing to fund activities. For educational advocacy, the recommendation was to have three levels of training – beginner, intermediate, and advanced – to accommodate different skill levels.

