

# THE EFFECTS OF NJPC'S PROFESSIONAL PARENT ADVOCACY TRAINING ON CHILDREN'S MENTAL HEALTH IN NEW JERSEY



NEW JERSEY PARENTS' CAUCUS BRIEF

FEBRUARY 2019

NJPC PROFESSIONAL PARENT ADVOCACY TRAINING



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*The New Jersey Parents' Caucus Inc. (NJPC) is a coalition of parents, caregivers, and youth whose mission is to ensure that every family who has children with emotional and behavioral needs is given an opportunity to play a strong and active role in the conceptualization, development, and delivery of effective and timely services in the mental health, juvenile justice, and child welfare systems.*

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**Authors:** Linda McConneyhead, Kathy Wright and Armando Garcia,

**Research Assistants:** Zohar Massey, Pamela Benjamin, Tuhina Bhat

**Report Designer:** Nicholas Johnson

## 1 | About Us

The New Jersey Parents' Caucus (NJPC) is a volunteer non-profit organization primarily governed and staffed by system-involved youth, parents and caregivers of children with emotional and behavioral challenges, and family members. The organization was established in 1990 when a group of concerned parents raising children with special needs came together to create changes to the public systems that served their children.

In January 2000, NJPC incorporated with the mission to ensure that every family who has children with special emotional and behavioral needs is given an opportunity to play a strong and active role in the conceptualization, development and delivery of and timely services for their children. For more than 18 years, NJPC has worked diligently with parents, caregivers, family members, other family organizations, government agencies, active legislators, and interested professionals throughout New Jersey to ensure that the state addressed the special needs of families raising children with emotional, behavioral and mental health challenges.

As part of their commitment to children, parents and families, NJPC provides a myriad of supportive family and youth-driven services in the mental health and juvenile justice systems which include:

- Advocacy & Informal Support
- Community Outreach & Parent Initiatives
- Support Groups
- Publications/Data Briefs
- Parents Empowerment Academy Training & Education
- NJ Youth Justice Initiative
- Direct Services
- Technical Assistance



## 2 | Executive Summary

New Jersey is in the midst of a silent mental health crisis concerning some of its youngest residents. These residents are living in some of the most underserved areas of the state. Requisite services are not available in all the areas and this is exacerbating the treatment of mental health issues for these children and youth. While the state of New Jersey has taken steps to rectify the lack of accessible mental health services for children, parents continue to struggle with access and there are still little to no public educational programs in our communities for parents who must navigate these systems.

The Parents Empowerment Academy is the flagship program of the New Jersey Parents Caucus (NJPC). The Academy offers a myriad of free workshops, trainings, and certifications to parents and caregivers on a variety of topics related to improving the quality of life for families raising children with emotional and behavioral challenges. The New Jersey Parents' Caucus believes that to help underprivileged children with mental health challenges, many parents and caregivers must first learn how to advocate for their children and families.

In addition to the challenges of raising a child with special needs, parents and caregivers must navigate a complex web of child-serving agencies to access appropriate information and services for their children, in order to ensure that they remain safe at home, successful in school, and in their local communities. The Professional Parent Advocacy Program (PPA), under the umbrella of NJPC's Parents Empowerment Academy, gives parents and caregivers the information and understanding needed to negotiate with government agencies and other system partners, through the development of leadership skills and professional advocacy abilities.

The PPA training comprises 15 modules including:

- Professional Parent Advocacy
- Professionalism and Communication Skills
- Empowering vs. Enabling
- Conflict Resolution Skills & the Power of Persuasion
- Understanding Childhood Mental Health Challenges and the DSM 5
- How Knowledge of the Brain Influences Adult/Child Interaction
- Navigating the Special Education System and the IEP Process
- Developing a Transitional Plan
- Zero Tolerance & IDEA – Individuals with Disabilities Education Act
- NCLB – No Child Left Behind
- Understanding the Juvenile Justice System in New Jersey
- Infusing Family Involvement in DCP&P - NJ's Child Welfare System
- Cultural Competency and Multiculturalism in the Child-Serving Community
- Collaborating with NJ Child-serving Organizations
- Train the Trainer

Ultimately, the PPA provides the opportunity for parents to:

- Strengthen their knowledge of the systems that serve their children and families
- Learn their rights and responsibilities within those systems
- Increase and secure better access to appropriate care and treatment for their children
- Understand childhood mental health disorders, as well as the appropriate medication and treatment options
- Ensure culturally competent and blame-free environments in child-serving agencies
- Evolve into essential and equal partners in the design, development, and implementation of services for their children
- Participate on local boards and commissions to influence public policy, and become catalysts for systems change
- Empower other parents by providing training in their local communities

Those children who do not receive appropriate mental health care often fail in school and are at risk of escalating into the juvenile justice and/or child welfare system. Parents often struggle to navigate child-serving systems and there are several barriers they face. Some parents may not be aware their child needs treatment. Often, the need for mental health care manifests itself in challenging behavior. Parents are challenged with managing this behavior in their homes, which may lead to involvement with child-welfare or the juvenile justice system because the parent or caregiver isn't sure what to do to meet their child's needs.

Many parents who do recognize their child's need for mental health care, may also struggle to access appropriate care as well because of system barriers. Many parents are unaware of the services available to their families and their rights and responsibilities within those systems. For some families, culture impedes their opportunity to access care. In addition, stigma prevents many families from seeking help. Far too often, families are blamed for the child's illness. Finally, poverty and a lack of economic resources for families continue to affect their ability to access care. Parents must find and absorb costs of transportation, childcare and loss of work in order to obtain services.

As a byproduct of teaching parents to partner with professionals and providers, **NJPC believes and has demonstrated that the PPA can increase accessibility of government programs by increasing local program literacy among parents and caregivers who attend the training. The evaluation data shows improvements in utilization of mental health, special education, and developmental disability services, and declines in the involvement of children and youth in the juvenile justice system. The analysis also demonstrates reductions of family involvement in the child welfare system.**



An additional positive benefit of PPA training is the capacity to foster community engagement to help fight parental and community-based stigmas that are all too often attached to mental illness.

By educating parents on how to access appropriate services and supports in New Jersey's child serving systems, NJPC believes that they can help reform those same systems to be less stigmatizing, more inclusive and transparent about the treatments and services which they provide.

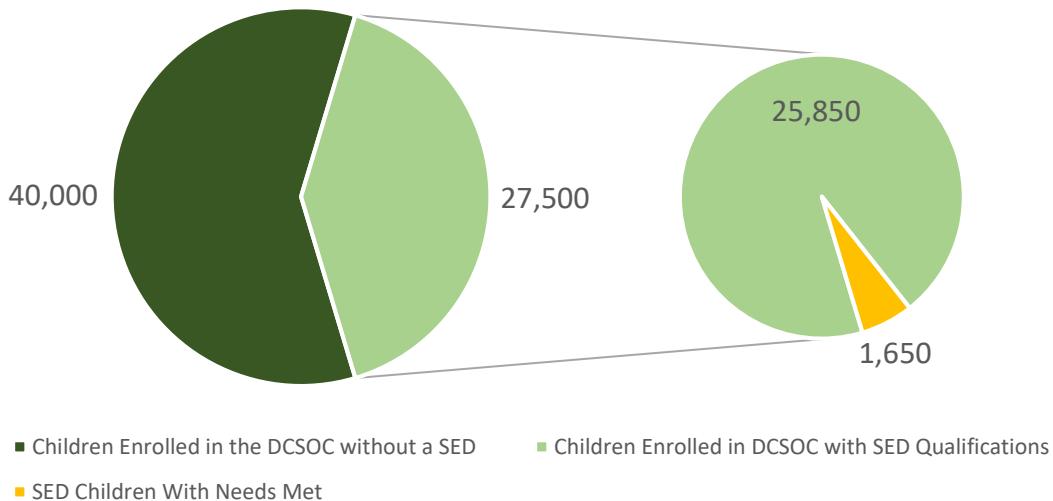
In addition, once parents complete the last module, Train the Trainer, and graduate, they have the knowledge and skills to teach other parents, exponentially spreading the knowledge they have received. It is through these trainings that the PPA serves as the beginning of a **new, family-focused way to inform parents** about the health systems available to their children. To date, NJPC has offered educational training through The Parents' Empowerment Academy to over 3,222 parents of more than 5,000 children and youth, certifying over 1,973 parents as trainers, and representing over 20,000 training hours.



## 3 | New Jersey Children's Mental Health Crisis

From 2018 US Census estimates, there are 1,959,875 children aged zero to seventeen in New Jersey and as many as 313,265<sup>1</sup> have some diagnosable mental health need. Of these children, as many as 198,444 have a need severe enough to interfere with their functioning. According to the *New Jersey Division of Mental Health and Addiction Services Block Grant Report 2015*<sup>2</sup>, during 2012, the number of active enrollees in the NJ Children's System of Care (CSOC) was approximately 40,000. Of this number, about 27,500 met the criteria for Serious Emotional Disturbance (SED). Currently, New Jersey's current system of care is meeting the needs of approximately 1,650 of the children with SED (*Figure 1*). These statistics, and therefore NJ's ability to help its youngest citizens, is woefully low.

Figure 1: NJ CSOC Ability to Meet Children's SED Needs

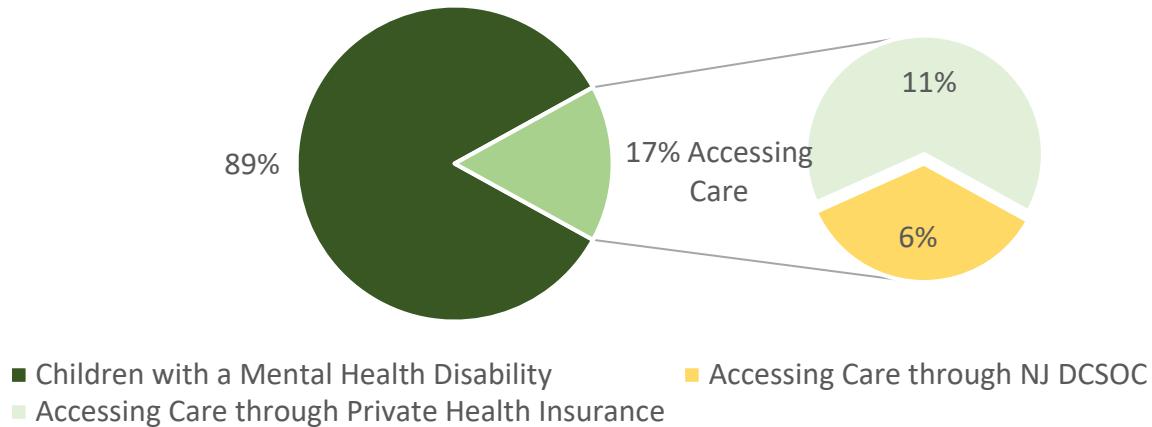


Additionally, in an ongoing survey by NJPC highlighted in *Figure 2* below, 145 New Jersey parents enrolled in the Parent's Empowerment Academy were asked if they had a child with a mental health disability, and, if so, were they accessing care and from where. According to the responses, even though 89% of the parents were raising a child with a mental health disability, only 17% were accessing mental healthcare and treatment. Of the 17%, only 6% were accessing services through NJ CSOC and eleven percent were accessing services through a private mental health provider. As shown by *Figure 2*, many families do not access available mental health care for their children, and when they do, they rarely use the systems put in place by the state of New Jersey.

<sup>1</sup> The Annie E. Casey Foundation. *Kids Count Data Center*.

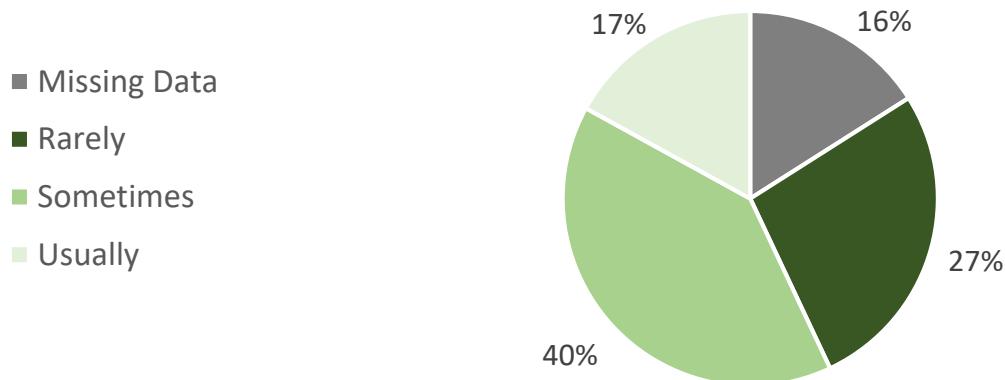
<sup>2</sup> New Jersey Division of Mental Health and Addiction Services. *Mental Health Block Grant Implementation Report 2014-2015*.

Figure 2: If and How Families Access Children's Mental Healthcare



*In self-report surveys taken on week 1 of training, 89% of parents reported having a child with mental health needs. Of this 89%, only 17% were currently accessing care. Of this 17%, 11% were receiving care through private health insurance and only 6% were receiving care through the NJ CSOC (N=145).*

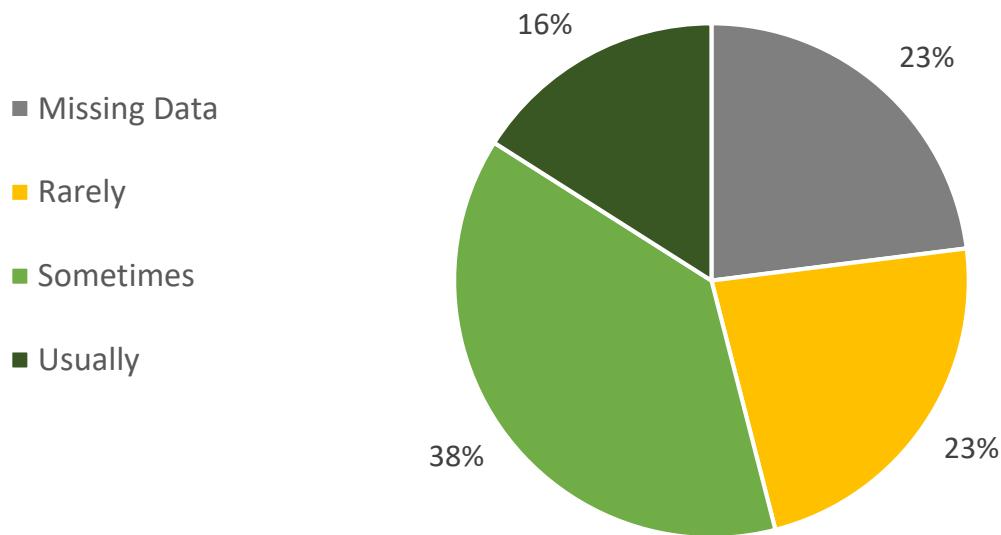
Figure 3: Services Tailored to Child's Needs



*In self-report surveys taken on week 1 of training, only 17% of parents reported that they believed that mental health services were tailored to their child's needs when compared with 67% that answered "Sometimes" or "Rarely." (N=353).*

The statistics show that not only is New Jersey unable to meet the needs of young citizens that require mental health care (Figure 1), but many parents are not seeking out treatment for their children (Figure 2). While there are several contributing factors, NJPC believes that system-level institutional factors are a contributing factor of poor access to children's mental health treatment. Additionally, **Figure 3** above shows that **even when families access these services, parents don't believe that the system is accurately tailoring treatment to their child**. In addition, **Figure 4** illustrates that **parents of children with mental health issues also don't believe that the treatment their child receives is inclusive of their child's strengths**. In fact, only sixteen percent said that the services are "usually" tailored to their child's strengths.

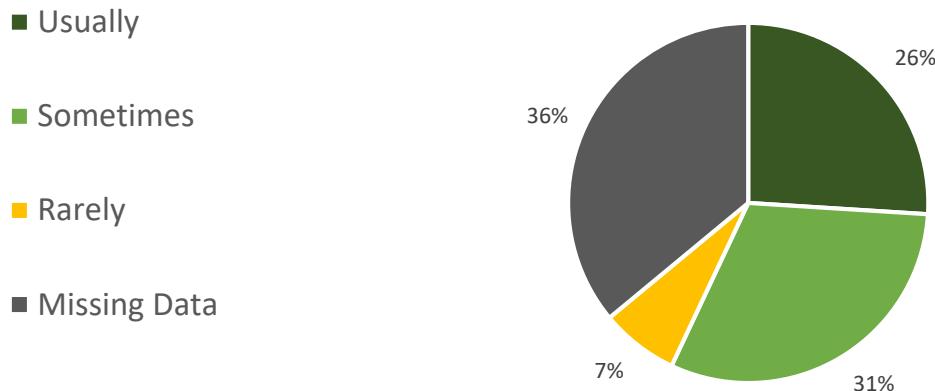
**Figure 4: Are Services Tailored to Your Child's Strengths?**



*In self-report surveys taken on week 1 of training, only 16% of parents reported that they believed that mental health services were "usually" tailored to their child's strengths when compared with 61% that answered "Sometimes" or "Rarely." (N=353).*

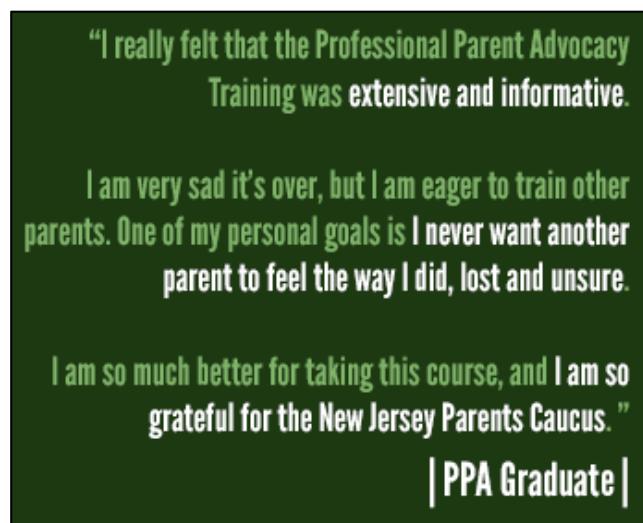
The survey responses shown in *Figure 3* and *Figure 4* can be contributed to several factors, including an inability of the parents to understand their child's diagnosis or treatment, the system's lack of emphasis on informing the parents, and the system failing to include family members when making treatment decisions. Regardless of the cause, *Figure 5* shows that, out of the parents surveyed by the NJPC, only 26% say that they are "usually" confident in their participation in their child's treatment when compared to the 38% that answered "sometimes" or "rarely."

**Figure 5: Parent's Confidence in Treatment Participation**



*In self-report surveys taken on week 1 of training, only 26% of parents reported that they were confident that mental health services were tailored to their child's needs when compared with 38% that answered "Sometimes" or "Rarely." (N=353).*

Both the state's 2015 Block Grant Report and NJPC questionnaires and surveys (Figures 2-4) seem to suggest that parents are unable to connect to, communicate with, or understand a series of systems designed to help their children; and, NJPC is committed to increasing access to care and treatment.



## 4 | A Family-Driven Healthcare Model & Implementation

New Jersey, like many other states, has already taken the necessary steps by changing from a provider-driven model (in which the healthcare professional is the primary decision maker) to a family-driven model. The family-driven model positions the families, not healthcare professionals, as the centerpiece in children's healthcare:

**Families have primary decision-making role in the care of their own children as well as the policies and procedures governing care for all children in their community, state, tribe, territory, and nation.** This includes choosing supports, services, and providers; setting goals; designing and implementing programs; monitoring outcomes; participating in funding decisions; determining the effectiveness of all efforts to promote the mental health and wellbeing of children and youth.<sup>3</sup>

New Jersey's DCF Children's System of Care (CSOC), which oversees youth mental healthcare, thankfully takes its cues from the family-driven model. In short, the family-driven model which the NJ CSOC endorses attempts to accomplish three goals:

- **Families and mental health professionals must embrace the family's role in treatment.** This means that the inclusion of family members throughout the treatment process is a necessity. When both entities accept their responsibility as part of the process, treatment can be administered not just at a healthcare center or a doctor's office, but through several environments, including in the home and at school. This way, treatment stays consistent over time regardless of environment.
- **The system must be focused on deconstructing existing societal stigmas surrounding mental health.** Provider-driven systems can enable a "blame and shame culture"<sup>4</sup> that has the propensity to stifle family interaction with healthcare providers. The inclusion of the family in treatment diminishes this stigma because regardless of the cause of the disorder, the family is working as a unit to cure it. The elimination of the "blame and shame" culture starts within the family unit and eventually moves outwards into the community unit, eliminating stigmatization which leads into the third broad goal of the family-driven model.

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<sup>3</sup> Osher TW, Osher D, Blau G. Families matter: Family influences on childhood behavior and development evidence-based prevention and treatment approaches. New York: Routledge; 2008. pp. 39–61.

<sup>4</sup> This culture takes the form of social avoidance and discrimination towards the targeted family, as well as towards the diagnosed individual. This can leave the individual with feelings of shame and guilt regarding their condition, greatly impeding treatment. In other words, the public's view of troubled families can often leave the family isolated and shamed for their perceived role in the mental health diagnosis. (Corrigan, P. W., Miller, F. E., & Watson, A. C. 2006).

- When social communities are involved in treatment of individuals, harmful *courtesy stigmas*<sup>5</sup> can be resolved and eliminated, which allows the entire community to participate in the recovery of the child. Shared decision making is a vital component of the family-driven model. Various opinions must be considered when making critical adjustments to a child's life, and this means that parents, children, and community representatives (e.g. counselors and caseworkers) must be given a voice when creating plans for a child receiving care

The inclusion of the family in this process is not for show. Family members are in the best position to promote rehabilitative change, and the strong relationships they maintain with their child are integral to treatment. Knowledge about a child's history and early childhood is often unobtainable without family inclusion. Young children cannot give accurate health and social histories about their own early childhood, making parental involvement in treatment invaluable. Parents provide the information necessary for professionals to treat their child while simultaneously supporting their rehabilitative efforts. In many ways, this is a catalyst for systems change.



Occasionally, however, families don't feel comfortable participating in their child's treatment, likely due to feelings of being ignored by professionals, informational insecurities, and/or fear of stigma. In these cases, the family has their interests set aside and the system struggles to uphold its cornerstones. It is here, in the realm of parental education and advocacy, that NJPC recognizes room for strong improvement.

**Despite the obvious positives of parental interaction with these systems, the unfortunate reality is that the majority of parents that enter the DCSOC are improperly informed about the services, rights, programs, and choices available to them. Having limited knowledge about the functionality or goal of specific programs presents an unnecessary challenge to the family being assisted, and without comprehensive knowledge about the system and its components, high-quality care is unattainable.**

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<sup>5</sup> Defined as "the prejudice and discrimination that is extended to people not because of some mark (e.g., mental illness, disorder) that they manifest but rather because they are somehow linked to a person with the stigmatized mark (Corrigan, P. W., Miller, F. E., & Watson, A. C. 2006).

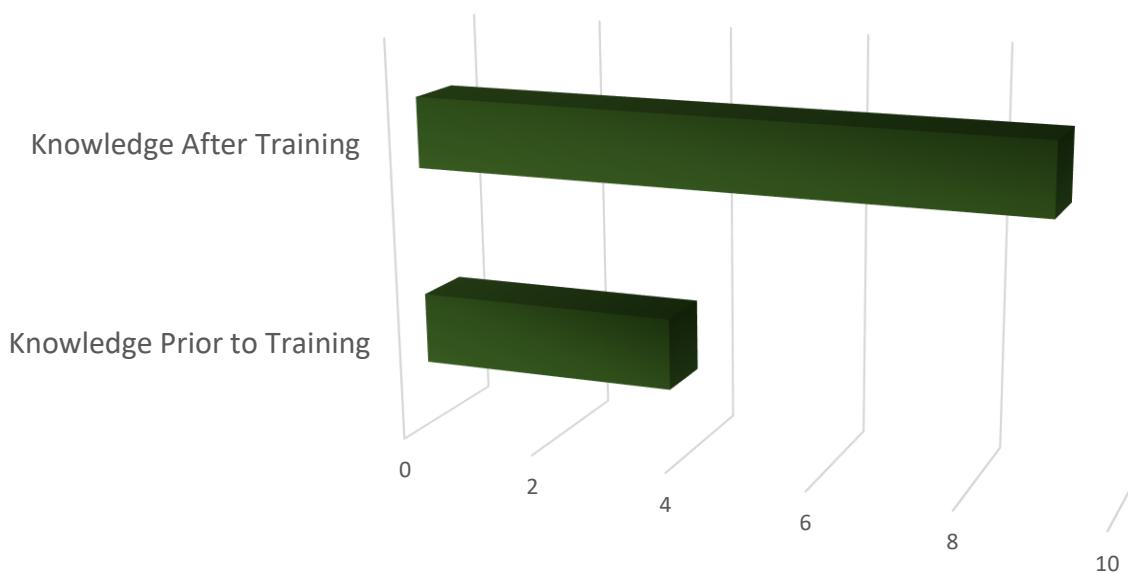
## 5 | New Jersey's Need for NJPCs Professional Parent Advocacy Training & Education Program for Parents & Caregivers

Many of the current gaps in the children's mental health system are centered around parent involvement and collaboration. **Transition from a provider-driven to family-driven model doesn't change treatment for children so much as it changes the role of parents and caretakers in that treatment.** Issues arise when parents are improperly equipped for this new role. Uninformed parents cannot be expected to make informed decisions, yet they are still expected to share responsibility in decision making. **If parental involvement and collaboration is a requirement, so too should comprehensive parent educational programs.**

**"Over the parent training course, the instructors educated and inspired our group of approximately twenty-five parents to be able to more effectively support, educate, and nurture our precious children."**

Programs like the Professional Parent Advocacy Training (PPA) can inform parents of their rights and responsibilities and teach proper techniques for parenting children with emotional and behavioral challenges. Many times, parents may be unaware of their knowledge gaps, which may lead them to make poor decisions with the best of intentions. The PPA and similar programs are

Figure 6: Self-Reported Knowledge Before and After PPA



*In self-report surveys taken on week 6 of training and 6 months post-graduation, parents reported their knowledge about the PPA training material as an average of 3.91 out of 10. This increased to 8.94 out of 10 after the 6-month period (N=285).*

uniquely qualified to step in and fill this gap, and NJPC research shows that the PPA accomplishes this goal. *Figure 6* shows that parental knowledge of NJ CSOC and other NJ systems increased enormously post-PPA from where they were prior to the parent's engagement in the course.

In addition, programs such as the PPA can also serve as providing impromptu community services by gathering multiple parents with similar situations on a weekly basis. It is not uncommon for parents to keep in touch with members of their training groups after completion, serving to create a community of individuals with similar experiences that can and often do continue to support each other. The social stigmas are also affected for the better by parent training programs like the PPA. Members of the training program are in similar positions and leave better informed about their children's disorders, their role in treatment, and the systems of care that are available to them. By default, this makes them more aware of their peer's situations and less likely to perpetuate the social stigmas that are harmful to their own reality.

**"It was like a seed was planted by the families in the room and their warm spirit allowed it to grow inside of me. I knew it was always there but was hiding due to fear. All I know is that it changed me for the better."**



As part of the PPA evaluation, NJPC administers pre- and post-test questionnaires to parents and caregivers to measure the impact of the training and support provided by the PPA. The data show improvements in utilization of mental health, special education, and developmental disability services, and declines in the involvement of children in the juvenile justice system. NJPC's evaluations also has demonstrated reductions of children's involvement in the child welfare system. In general, the NJPC collects the performance data on an ongoing basis and uses a repeated measures design to collect the outcome data. Data that was collected at Time 1 (i.e., the pre-test) is compared to data collected at Time 2 (end of training) and Time 3 (1 year follow-up) to assess changes in the following primary indicators of access to mental healthcare, parent/parent caregiver professional partnership, service quality, parent empowerment,

and child well-being by demographic variables (i.e. mental health diagnosis, access to care, school involvement, juvenile justice involvement, other system involvement, ethnicity, age, family make-up, type of insurance, etc. NJPC also administers a knowledge exchange questionnaire at the end of each event to assess the degree to which participants came away better prepared to partner with professionals and providers. Parent advocacy trainings are an essential and holistic approach for bridging the gap between NJ's service provision and parents' service utilization to meet the needs of our most vulnerable populations of youth

## 6 | Discussion and Impact of NJPCs Professional Parent Advocacy Training & Education Program for Parents & Caregivers



Parent training programs that implement a volunteer train-the-trainer system have very broad potential reach. The cost of each training program approximately \$5,000 and free for the parents or caregivers, leaving very few barriers. This means that with a small amount of funding, an organization like NJPC can conduct a relatively large number of trainings, and therefore greatly increasing the spread of information. In addition, distributing training materials is a minor inconvenience at worst, putting the PPA training program in a fantastic position to expand. Considering more funding for programs like this are the state's best interest,

given that a more informed public can more efficiently utilize their social programs. Moreover, the improvement of children with emotional and behavioral challenges is already in the state's agenda.

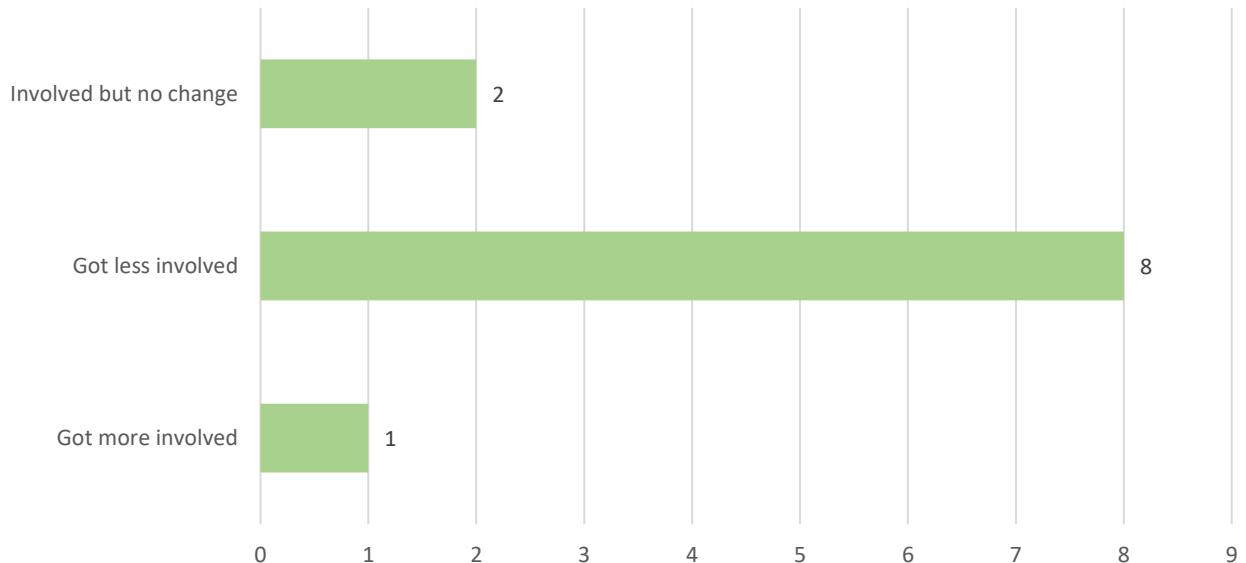
In addition to expanding the program's potential reach, parent advocates often serve on community boards, speaking as informed citizens on the same topics they learned about in the PPA training. Graduating parents have greatly improved knowledge of both the NJ CSOC, but also its application first-hand, as seen in *Figure 6* in the previous section. The PPA training better qualifies them to serve on community boards given their understanding of community issues, mental health, and public services. This allows PPA graduates to act as community mental health advocates in addition to their status as advocates inside the family system. It is important to note that parent training graduates aren't equivalent to mental health professionals, but that's not a bad thing. Parents of system involved children bring the perspective of first-hand involvement and knowledge to guide others through this difficult process when trained in parent advocacy. Many providers and professionals themselves lack this perspective as they often do not live inside the communities in which they serve.

**"When I first went to the Professional Parent Advocacy Training, in the first three minutes I was convinced that the instructor was speaking from experience and with clarity..."**

**| PPA Graduate |**

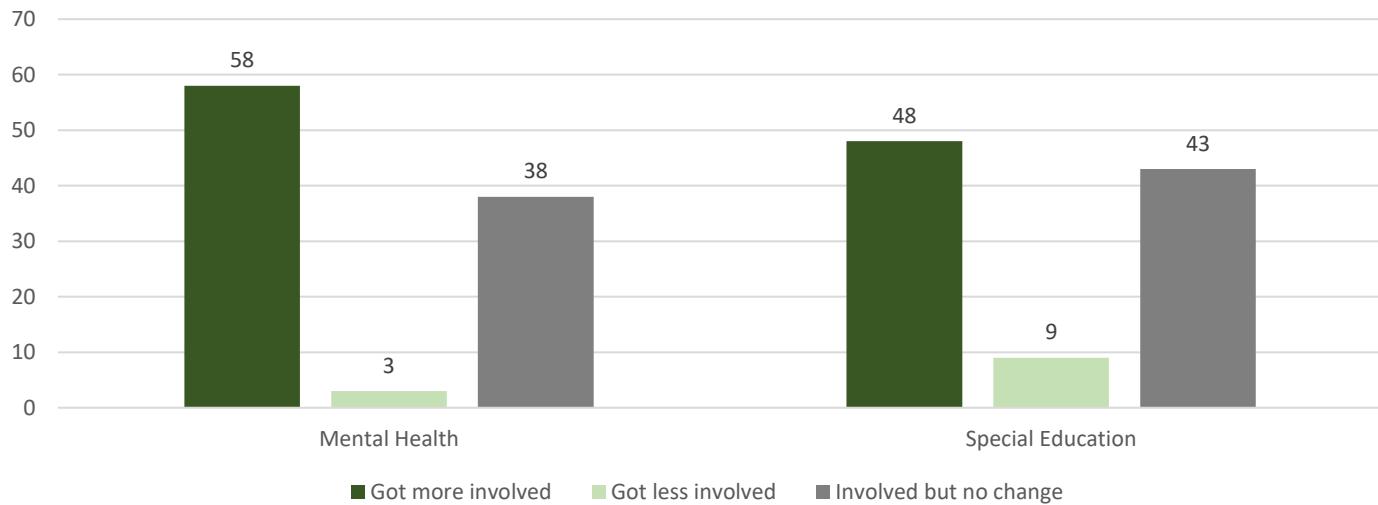
More concretely, the NJPC has discovered a sharp uptick in mental health program usage (Figure 8) and a steep drop in government program participation (i.e. child welfare, the juvenile justice system, etc.) post-PPA involvement (Figure 7). NJPC has found a marked decline in juvenile criminal services involvement, paired with a lower recidivism rate, in the post-PPA surveys. As shown in *Figure 7*, NJPC data shows a 72% decrease in involvement with the juvenile justice system after PPA course completion, suggesting that parents with professional advocacy training are better at keeping their children out of crime. Although evidence-based research should be conducted regarding these results, this observation should be heavily considered for future research in this area. The mechanisms of parent education and advocacy for this observation are sound; familial, social, and educational are the main three environmental circles in which juveniles interact, and they are the three circles emphasized in a family-driven model. Parent training alleviates stress at home and educated parents are more likely to spot the warning signs of delinquent behavior in their children. All these facets should make cost-effective parent training programs like the PPA attractive to New Jersey DCF and legislators.

**Figure 7: Juvenile Justice Involvement**



*In self-report surveys taken post-PPA graduation, 72% of parents reported that their child had less involvement with the Juvenile Justice System. Less involved is better. (N=87)*

**Figure 8: Involvement in Mental Health and Special Education Services**



*In self-report surveys taken post-PPA graduation, 58% of parents reported that their child had more involvement in mental health programs when compared to pre-PPA. Additionally, 48% of parents reported that their child had more involvement in Special Education programs. More involved is better. (N=87)*

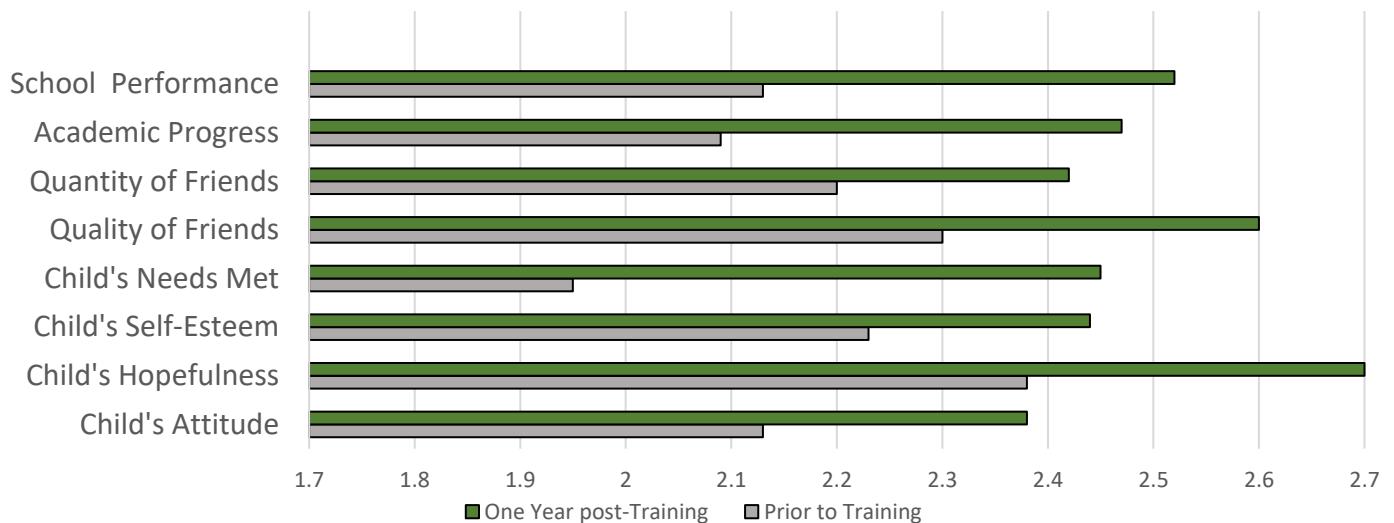
While NJPC saw a decrease in the involvement of children in the Juvenile Justice system, it saw a fifty-eight percent increase in children participating in mental health and a forty-eight percent participation increase in special education programs as shown in *Figure 8*. This clearly speaks to the PPA's ability to foster parental understanding of NJ's mental health care options. By simply learning more about programs like Special Education, parents were seemingly able to identify programs that were pertinent to their child and take advantage of them. This alone will increase participation in these health programs, and in turn assist in lowering the number of children that go without care.

The post-PPA survey also showed an increase across almost all measured points involving how the parents feel about their child's treatment and their own interaction with healthcare professionals. These points include "Services Tailored to Child's Needs," "Services Tailored to Child's Strengths," "Parental Confidence with Professionals," "Child's Needs Met," "Parents Agree With Child's Treatment Plan," "Professionals Understand Parent's Opinions," and "Providers Treat Parents as an Equal Partner" among many others as shown in *Figure 9* below. The NJPC survey also measured parental attitudes towards their child's progress in terms of school performance, quality and quantity of friends, and others.

**Figure 9: Survey of post-PPA Outcomes**

*In self-report surveys taken both pre- and one-year post-PPA graduation, parents reported an increase in almost all measured fields centered on treatment outlook and parent-professional relationships using a Wilcoxon Signed Ranks Test on a scale of 1-3, with 1 being least desired and 3 being most desired. ( $P<0.05$ ,  $N= 45-56$ )*

Here, too, the survey showed significant improvements across the measured fields, as seen in *Figure 10 below*.

**Figure 10: Survey of post-PPA Outcomes (Child-focused)**

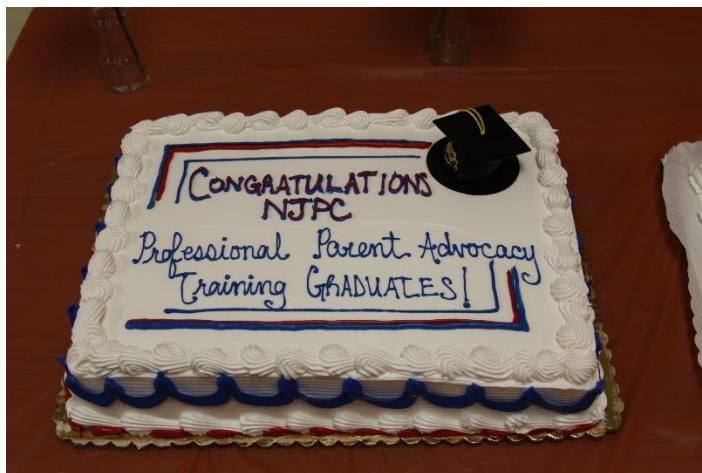
*In self-report surveys taken both pre- and one-year post-PPA graduation, parents reported an increase in almost all measured fields centered on treatment outlook and parent-professional relationships using a Wilcoxon Signed Ranks Test on a scale of 1-3, with 1 being least desired and 3 being most desired. ( $P<0.05$ ,  $N= 45-56$ )*

## 7 | Recommendations

The New Jersey Parents' Caucus recommends a national and state standard for a Parent Advocacy Certification. The standard would include a minimum length of time of 20 instructional hours, a list of required topics in the training materials (information about state-run social programs, mental health diagnosis and what they mean, etc.), and a final certification test. A system like this is in the state's best interest to implement for several reasons:

- It serves as a progress measure for both the certification program and the dissemination of information about state services. Certificate holders would be knowledgeable about the mandatory certification requirements, such as how to properly use the children's welfare system or how to efficiently cooperate with social workers.
- Further research on the topic may uncover correlations between parental education and system efficiency. This is merely speculation, but optimism for the system and comfortability within the parental role are likely precursors for system improvement.
- Most importantly, much of the PPA training is a necessity to be able to make an informed decision about a child's treatment options. Complete, comprehensive information about social programs needs to be more than readily accessible; it needs to be *readily provided* to the population.

Parent advocacy trainings are designed for parents to understand and comprehend, and this should be the standard for informational instruction in the New Jersey Department of Children's System of Care. In fact, the NJ Department of Children & Families should incorporate parent advocacy training as a precursor to involvement in the system. If parental decision making and responsibility is mandatory, then so should proper parental education on the subject matter. Uninformed decision making is incredibly detrimental to both children, parents and the system itself. It simply must be avoided at all costs.



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