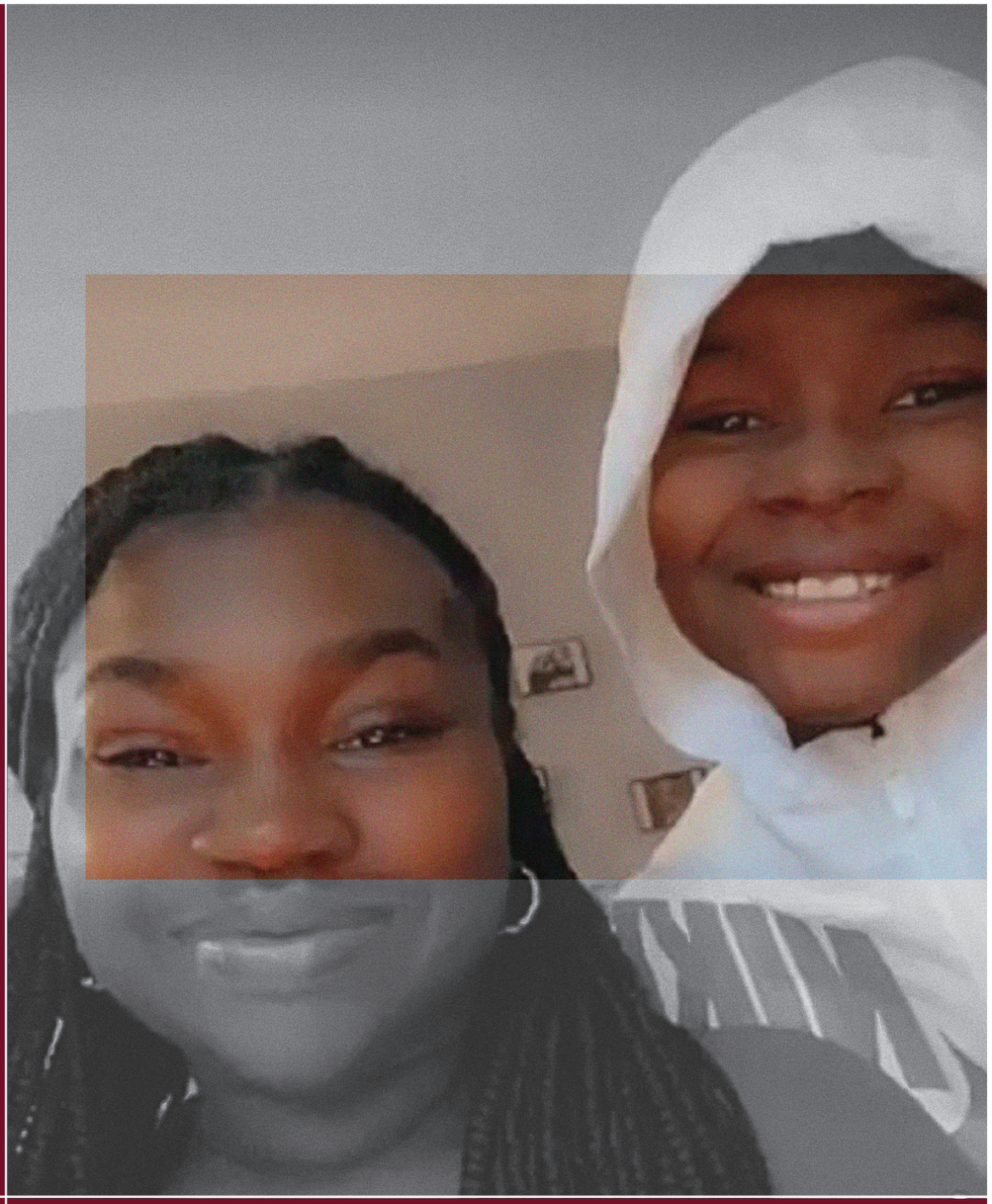

October 2021

NEW JERSEY PARENTS' CAUCUS

The Children's Mental Health Crisis in New Jersey's Marginalized Communities

NEW JERSEY PARENTS' CAUCUS
20TH ANNIVERSARY
FAMILY DRIVEN & YOUTH GUIDED

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This report presents a description and evaluation of the Professional Parent Advocacy Training Program developed and offered by the New Jersey Parents' Caucus. The purpose of the program is to increase access to all available and appropriate services for New Jersey children who have emotional, behavioral, mental health and substance use disorders by educating and training their caregivers. The training could not be successful without the motivated and dedicated parents, caregivers and family members who have committed themselves to learning more about their children's conditions and the system of available services. We would like to extend our sincere gratitude to several constituents and supporters of the program.

First of all, we are most thankful to all of the parents, caregivers and family members residing in New Jersey's marginalized communities who refuse to give up and continue to struggle to access appropriate care and treatment so their children can reach their full potential.

We are indebted to Trinitas Regional Medical Center for their continuous support and commitment to parents, caregivers and family members raising children who struggle with emotional, behavioral, mental health and substance use challenges.

We are also grateful to the National Juvenile Justice Network (NJJN) and the Youth Justice Leadership Institute for their guidance, expertise, technical support and their commitment to children with mental health challenges who are involved in the youth justice system.

Finally, we are grateful to the New Jersey Parents' Caucus volunteers, researchers, staff, board trustees and members who devote their time and knowledge to make the Professional Parent Advocacy Training Program successful.

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Executive Summary

The Professional Parent Advocacy Training Program is a component of the Parents Empowerment Academy offered by the New Jersey Parents' Caucus. The training program is consistent with the organization's long history of advocacy and support provided by, and for, parents of children with behavioral and mental health challenges. PPA training seeks to empower parents and caregivers so they can assume full partnership with professionals in the care of their children in the context of New Jersey's Children's System of Care.

The PPA training program has graduated hundreds of parents and caregivers since inception, for the benefit of many more children. After training, participants feel more confident about their ability to secure appropriate and effective care for their children. They become more active in joint decision making. Parents and caregivers believe that the resulting services better meet their children's needs and are better aligned with their strengths and needs. The data suggest that NJPC has successfully contributed to an important shift in caring for the state's most vulnerable population, children in need of behavioral and mental health services. By enabling children to receive relevant and effective care in a timely way, PPA training is a positive factor in reducing youth involvement in the out-of-home care and the juvenile justice system. More children are able to receive preventative services like tailored educational plans, counseling, and medication early, to avoid tragic outcomes later in life.

Introduction

The primary purpose of this document is to report on the results of a training program, Professional Parent Advocacy (PPA), provided by the New Jersey Parents' Caucus (NJPC). PPA training is designed to reduce the gap between the need for children's mental health services and the provision of effective individualized services that are community based and culturally sensitive. NJPC has a long history of supporting and advocating for children and families in New Jersey, working within the context of, but also influencing, the formal state-run systems. The PPA training program is aligned with the current goals of New Jersey's Children's System of Care (CSOC) which oversees mental and behavioral health and substance use services for children. As a result of the training, parents and caregivers are able to access appropriate services and better ensure that the services are individualized and as effective as possible for their children.

New Jersey Parents' Caucus (NJPC)

The New Jersey Parents' Caucus has over 30 years of history and acquired expertise in supporting system-involved youth and their families. They provide a range of direct services, as well as playing a role in influencing policy and advising other organizations and jurisdictions. The value of the Professional Parent Advocacy training is more easily understood in the context of knowing the other contributions and services of NJPC, as described in the following sections.

History and Credentials

The New Jersey Parents' Caucus (NJPC) is a family-driven and youth-guided nonprofit organization that was founded in 1990 by a group of parents raising children with special needs whose goal was to create systematic changes to the public systems that served their children. Its mission is to ensure that families raising children with emotional, behavioral, mental health and substance use challenges have the opportunity to play a strong and active role in the development and delivery of services. As such, NJPC is committed to ensuring that parents and caregivers are supported, informed, educated and empowered in their quest to identify and access the most appropriate services for their children and families in a timely way.

In its early days, the NJPC led a coalition of children's advocacy groups to change existing policy and expand services to families and children struggling with special needs. The coalition formulated the "Ten Principles of Care" which would eventually govern a new state-wide system. The principles were presented to family organizations, child-serving agencies, county-wide government boards, and other active legislators to gather support.

In 1999, through diligence and hard work, NJPC achieved its long-range goal to convince state officials that the system serving children with mental health challenges was in dire need of change. On January 24, 2000, Governor Whitman adopted the "Ten Principles of Care" as a foundation for the new Children's System of Care Initiative (CSOCI).

At last, this meant comprehensive reform for children's mental health services with a core value of partnering with families at all levels, from local to state, and at all phases of activity including planning, oversight and quality assurance.

In the year 2000, NJPC incorporated with its current mission. For the next 2 and 1/2 years, NJPC was contracted by the NJ Department of Human Services to serve as the first statewide parent advocacy agency for the CSOCI. NJPC was charged with building Family Support Organizations (FSO) in all counties, to insure that the family voice was heard and that families played a necessary and integral role in the development and implementation of their children's individual service plans.

In addition to NJPC's accomplishments with the State Department of Human Services, the organization was selected as one of forty-two funded Statewide Family Networks through The Substance Abuse Mental Health Services Administration (SAMHSA) of the US Department of Health & Human Services and charged with working with youth, family members and professionals to improve outcomes for children with emotional and behavioral disturbances and their families. In 2005, NJPC was contracted by the SAMHSA Technical Assistance (TA) Center to provide technical assistance to other Statewide Family Networks throughout the country to build capacity and ensure sustainability. NJPC also works with new family-driven grass roots organizations throughout New Jersey to help them build capacity. NJPC has served in a consulting capacity to the National Technical Assistance Center for Children's Mental Health at Georgetown University's Center for Child and Human Development and National Cultural Competency Center providing Transformation Facilitation Technical Assistance and Support to state children's mental health directors throughout the country.

In 2008, NJPC was selected by the US Department of Justice/Office of Juvenile Justice & Delinquency Prevention (OJJDP) as one of twelve organizations throughout the country and the only organization in the state to provide family strengthening prevention services to families raising children and youth at risk of entering the juvenile justice and child welfare systems. NJPC's Families Uplifted Prevention Initiative was charged with providing family strengthening strategies and programs that focus on improving family economic success, family support systems, and building thriving and nurturing communities in which healthy families can pursue long-term goals. Continuing to support parents raising justice-involved youth with emotional and behavioral challenges, NJPC developed the New Jersey Youth Justice Initiative (NJYJI). NJYJI is a family-driven justice program which seeks to improve outcomes for justice-involved youth, end the practice of waiving youth to the adult system, ensure family and youth involvement on all levels of decision-making, end solitary confinement for youth, and ultimately decrease recidivism rates through a myriad of supportive programs.

In the fall of 2014, NJPC published the data brief - Psychotropic Medication Use among New Jersey Children & Youth - in which more than 56% of children and youth reported the use of one psychotropic medication in the previous year. In 2014, NJPC received a state spotlight and was highlighted by the National Juvenile Justice Evaluation Center (NJJEC), identifying their data analysis and evaluation studies representing more than 20,000 parent training hours and 6,000 children, which showed improvements in the 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 demonstrated reductions of family involvement in the child welfare system.

In addition, NJPC was highlighted in 2014 and 2015 by The National Center for Mental Health and Juvenile Justice (NCMHJJ) for the publication of two reports: *Navigating the Juvenile Justice System in New Jersey: A Family Guide and The Incarceration of Children and Youth in New Jersey's Adult Prison System*. The latter report highlights the high prevalence of mental health disabilities among children who are incarcerated in the adult system.

From its beginning as an organization founded by parents to ensure that their children would receive adequate and appropriate services, NJPC has established itself as a leader. To date, overall, NJPC has trained over 3,200 parents of more than 5,000 youth, certifying over 1,970 caretakers as trainers, with more than 20,000 training hours. State and federal organizations have recognized NJPC for its expertise in effectively engaging families so that children's issues can be addressed early and comprehensively in an attempt to prevent avoidable negative outcomes such as outplacement, and/or involvement in the child welfare or juvenile justice system.

Services for Children and their Families

As part of NJPC's commitment to children and families, NJPC provides a myriad of services and supports related to the mental health and juvenile justice systems which include:

- Advocacy and Informal Support
- Community Outreach
- Parent Initiatives
- Parents Empowerment Academy Training and Education
- New Jersey Youth Justice Initiative
- New Jersey Youth Caucus
- Support Groups
- Publications
- Data Analysis
- Direct Services-Strengthening Families

The subject of this report, the Professional Parent Advocacy Training Program, is offered as a component of The Parents' Empowerment Academy© which improves outcomes for children and families by increasing access to comprehensive, coordinated, timely and individualized care that is child-centered, family-focused, and strength-based. When children with serious emotional disturbances receive individualized, strength-based care provided in partnership with their family the following outcomes are achieved:

- Families and children remain together
- Children are successful in school
- Children remain in their local communities
- Families and children thrive
- Children abide by the law

NJPC's Parents' Empowerment Academy©, is a natural outgrowth of the organization's origins. The Academy is a comprehensive, parent-driven, training and education program, with curriculum and program offerings that:

- enable parents and caregivers of children with emotional and behavioral challenges to appropriately and collaboratively negotiate with government agencies and other system partners
- provide the opportunity for parents to strengthen their knowledge of the systems that serve their families and their rights and responsibilities within those systems
- offer parents, caregivers and professionals a thorough understanding of children's mental health disorders, NJ's community-based services, and medications associated with childhood disorders
- assist professionals in understanding the reality of raising a child with an emotional disorder and prepares them to seek out and partner with families in order to develop and implement treatment plans that will achieve optimal outcomes
- enable parents and caregivers to ensure mental health services are culturally competent
- offer opportunities for parents to become certified to train and
- provide volunteer and paid opportunities for parents to provide training in their local communities.

The Parents' Empowerment Academy© offers training in the areas of *Professional Parent Advocacy, Understanding Childhood Challenges, Building Systems of Care: An Overview for Families, Engaging Youth as Partners, Bridging the Gap for Professionals Dedicated to Children's Services, Empowering Families & Communities Through Public Policy Work and Empowering the Parent Trainer*. The programs empower parents, caregivers and youth to serve as "agents of transformation" and promote reforms in the service delivery system to support effective mental health service delivery which is consumer and family-driven. The Parents' Empowerment Academy© aids families in overcoming the isolation, shame, blame, guilt and stigma associated with childhood mental illness. Families who attend training: (1) learn how to appropriately and collaboratively negotiate with service providers, policy makers, government agencies and other system partners, (2) strengthen their knowledge of the systems that serve their families and (3) better understand their rights and responsibilities within those systems. In addition, families learn about the spectrum of children's mental health disorders, providing greater awareness of what may be causing their children's behavior. As a consequence of this training, family members are more knowledgeable, empowered,

assertive and participatory in the planning of care for their children, resulting in more comprehensive, coordinated, individualized and strength-based care. Parents and caregivers who embrace the education and training are able to accomplish things that extend beyond their own families. Some graduates of the programs partner with service providers and schools, provide voluntary informal support to other families, educate legislators on issues related to children's mental health, serve on local mental health advisory councils and boards, and provide local community-based advocacy trainings themselves.

As one of the offerings of The Parents' Empowerment Academy, The Professional Parent Advocacy (PPA) Training Program is specifically designed to align with the state framework for children's mental health care. The next section describes the development of, and the current state of, New Jersey's system to provide services to children with behavioral and mental health issues. This is followed by a description of how PPA training seeks to bolster the effect of NJ's Children's System of Care and increase the chances that all children in New Jersey will receive the care they need.

Children's System of Care

New Jersey, like many other states, changed from a provider-driven model (in which the healthcare professional is the primary decision maker) to a family-driven, child-centered, and community-based model. A major impetus for the change was Congress' passage of the State Comprehensive Mental Health Services Plan Act in 1986. The act:

> "required all states to develop and implement plans to create community-based service systems for persons with serious mental illness, including adults and children, and mandated participation of family members and consumers in the development of state plans. This legislation reinforced the premise that most states would need to redirect funds from hospital and institutional care to build community-based systems of care." *(Pires, 2002, p. 3)*

A notable move toward family-driven care was by the Substance Abuse and Mental Health Services Administration *(SAMHSA)*. SAMHSA's initiative, the Comprehensive Community Mental Health Services for Children and their Families Program, began in 1993 and emphasizes a youth-guided and family-driven approach to service delivery *(Stroul & Blau, 2008)*. The model for a children's system of care was informed by the Stroul-Friedman framework *(Stroul & Friedman, 1986)* originally designed to support children with severe emotional disorders.

The core values established by Stroul and Friedman in their seminal paper *(Stroul & Friedman, 1986)* were:

- The system of care should be child centered and family focused, with the needs of the child and family dictating the types and mix of services provided.
- The system of care should be community based, with the locus of services as well as management and decision-making responsibility resting at the community level.
- The system of care should be culturally competent, with agencies, programs, and services that are responsive to the cultural, racial, and ethnic differences of the populations they serve.

The "Children's Initiative" Concept Paper was published by the NJ Department of Human Services in 2000, laying out the vision and goals for a new community-based system in the state that prioritized the engagement of children and their families. The Children's System of Care *(CSOC)* was first implemented in three counties in 2001, with all New Jersey counties included by 2006. The family-driven model positions the families, not healthcare professionals, as the centerpiece in children's healthcare. The ultimate goals of a comprehensive system of care include keeping children in their homes and communities, improving educational performance and overall social functioning, decreasing children's involvement in child welfare and juvenile justice systems, and reducing the need for and longevity of psychiatric hospital and residential treatment.

To achieve the vision of the CSOC, core values and principles were established to communicate priorities and guide decision making *(New Jersey Division of Mental Health and Addiction Services, 2016, pp. 70-71)*.

Core Values:

- Family driven
- Youth guided
- Individualized and community based
- Culturally and linguistically competent
- Evidence based

Principles:

- All children who need services should receive the same accessibility to services.
- Availability and access to a broad, flexible array of community-based services and support for children, and their families and caregivers, to address their emotional, social, educational and physical needs, should be ensured.
- Services should be individualized in accordance with the unique needs of each child and family.
- Services should be guided by a strength-based, wraparound service planning process and a service plan that is developed in true partnership with the child and family.
- Services should be delivered in the least restrictive settings that are clinically appropriate.
- Treatment outcomes for children and families should be quantifiable.

Through an organized network of services and supports, the New Jersey Children's System of Care is committed to providing emotional or behavioral health, intellectual or developmental disability, and substance use treatment services *(PerformCare, 2016)* that are:

- Clinically appropriate and accessible, without regard to income, private health insurance, or eligibility for NJ Family Care (Medicaid) or other health benefits programs.
- Individualized, reflecting a continuum of services and/or supports, both formal and informal, based on the unique strengths of each youth and his or her family.
- Provided in the least restrictive, most natural setting appropriate to meet the needs of the youth and their family.
- Family-driven, with families engaged as active participants at all levels of planning, organization, and service delivery.
- Community-based, coordinated and integrated at the community level, with the focus of services, as well as management and decision-making responsibility, resting at the community level.
- Culturally competent, with agencies, programs, services, and supports that are responsive to the cultural, racial, linguistic, and ethnic differences of the populations they serve.
- Protective of the rights of youth and their families.

The components of New Jersey's CSOC include a state-wide Contracted System Administrator (CSA), Family Support Organizations (FSOs), and community-based Care Management Organizations (CMOs). The CSA, PerformCare, provides a single point of access for families and caregivers to explore available services and support for children in New Jersey with behavioral health, intellectual and developmental disabilities and/or substance use issues. FSOs are nonprofit, county-based organizations that are run by families whose children have behavioral health challenges. The role of the FSOs is to provide peer support, education and advocacy for families. CMOs are nonprofit, county-based organizations that coordinate the delivery of services for children with serious behavioral health needs that could otherwise result in their removal from the home. The goal of the CMO is to develop, under the direction and authority of a child and family team, an integrated care plan that combines interdisciplinary clinical services with family and community resources and aims to safely keep the child in their home and community.

The role of the family in providing care and support to children is central to New Jersey's CSOC. Parents and other caregivers have the most knowledge of the child's history and current behavior. Since young children cannot give accurate health and social histories, parental involvement in treatment is essential. Beyond the needs of the individual child, parents and caregivers can serve as catalysts and advocates to hold the system accountable for operating in the best interests of the child and in accordance with its values and principles. Likewise, if a child is to be given the best chance to benefit from a treatment plan, that plan must align with the realities of the family situation and have the support and engagement of the family.

Spencer, Blau, and Mallery (2010) examined the evolution of family-driven care in the United States. The authors note that in the previous twenty-five years, the mental health field shifted from viewing parents as the cause of their children's issues to active participants, not only in treatment, but also in policy development and system reform efforts. Spencer et al. (2010) cite several studies that demonstrated the positive effects of family involvement, including better school and mental health outcomes for the children, and greater commitment and adherence to treatment. The authors note the success of two parent support efforts, one in Kentucky and one in New York, where peer support is a key component as it is in the PPA training program.

> As family members make the transition from clients to partners and leaders in system change, they require an understanding of the child-serving system and its legal mandates. Training and leadership development help family partners acquire the skills necessary for system change and establish a foundation for sustained involvement and success. *(Spencer et al., 2010, p. 179)*

NJPC has greatly contributed to this healthcare reform. NJPC, along with other organizations, has been working toward reforming healthcare models to become more family-driven. This structure allows families to play a more integral role throughout the course of medical care and establishes an equal partnership with clinicians. A key requirement for the success of a family-centered system, however, is ensuring that parents and caregivers are informed partners in the planning, execution, and efficacy of the services provided.

NJPC – Bridging the Gap

The need for the services provided through the New Jersey Children's System of Care is great. With infrastructure in place in all counties, and a goal of addressing individualized needs with active family engagement in a way that is community based and culturally and linguistically appropriate, the foundation has been laid. Unfortunately, barriers remain with regard to assuring that all children who would benefit from the services are receiving them in a timely way. The NJPC plays a key role in addressing the gap by educating and training parents and caregivers so they can be more proactive in accessing and effectively utilizing relevant services.

Nationally, and locally in the counties of New Jersey, a coordinated and wholistic approach to addressing the mental health and negative behavioral activities of children has resulted in desired outcomes. In New Jersey, fewer children are entering the juvenile justice system and out-of-home care since the CSOC was implemented. The system maintains the central role of the family in the decisions, policies, and treatment for individualized care. Results of

NJPC surveys suggest, however, that not all parents and caregivers are accessing the CSOC as intended. The PPA training was developed with the explicit objective of empowering families to take advantage of the resources offered by NJ CSOC to obtain the most appropriate care for their children in a timely way so as to avoid more negative consequences in the long term. The CSOC can only be successful if the parents and caregivers are able to fulfill their expected roles as advocates and decision makers for their children's welfare. Combining the parents' knowledge of their child with the cross-sectional expertise of professionals is expected to result in more precise and more effective mental health care for New Jersey's children.

According to the US Census population estimates for 2109, there were 1,634,153 children aged three to seventeen in New Jersey, and as many as 320,060 of them had some diagnosable mental health need. Similarly, the Center for Disease Control (CDC) estimates that one in six children, age 2 – 8 years old, living in the United States has a diagnosed mental, behavioral, or developmental disorder. The instance increases to 1 in 5 children for those living below the poverty line. According to a meta-study about children's mental health (Williams, Scott, and Aarons 2017), approximately 10% of children in the country meet the criteria for serious emotional disturbance (SED), indicating the presence of a psychiatric disorder that seriously interferes with functioning at home, in school and/or in the community.

The concerns for mental health illnesses among New Jersey youth continues to rise. Many children who do not receive the appropriate care often fail in school and are at greater risk of becoming involved in the juvenile justice (New Jersey Division of Mental Health and Addiction Services, 2016) or child welfare systems. Nationally, 65-70% of children and young adults formally involved with the juvenile justice system have at least one diagnosable mental health need (Shufelt & Cocozza, 2006). In a recent survey conducted by NJPC of 120 youth waived to the adult prison system, 52% were involved in special education, 34% were involved in child welfare, and 69% were involved in the mental health system prior to their incarceration. Additionally, 68% had been previously diagnosed with at least one mental health disability prior to incarceration and 37.5% had two or more diagnoses (NJPC, 2018).

In a previous survey by NJPC, 145 New Jersey parents enrolled in the Professional Parent Advocacy Training 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 caregivers 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 Division of Children's System of Care (DCSOC) and eleven percent were accessing services through a private mental health provider or physician.* 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.

In the state's Community Mental Health Block Grant application for 2014-15, the section on the Division of Children's System of Care (DCSOC) referenced a need for greater awareness of their services. Providing the resources, in and of themselves, will not result in reducing the need for heightened services, such as hospitalization and out-of home treatment. In order to be more proactive and preventative, the system relies on parents, caregivers, school professionals and pediatricians knowing what services are available and making appropriate referrals as early as possible. "Families and other stakeholders often are not aware of services that already exist. DCSOC needs to find ways to better communicate statewide about the services that exist." *(NJ Division of Mental Health and Addiction Services, 2014, p. 143)*

There are likely several contributing factors for the gap in utilization versus need, including system-level institutional factors. Data collected by the NJPC shows that even when families access these services, many parents don't believe that the system is adequately tailoring treatment to their child. In addition, 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 a prior survey by NJPC, only sixteen percent said that the services are usually tailored to their child's strengths. The survey responses can be attributed 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 adequately include family members when making treatment decisions. Regardless of the cause, out of the parents surveyed by the NJPC in the past, only 26% say that they are "usually" confident in their participation in their child's treatment. Both the state's 2014-15 Block Grant Report and NJPC questionnaires and surveys seem to suggest that parents are unable to connect to, communicate with, or understand the very systems that are purposefully designed to help their children.

Some families don't feel comfortable participating in their child's treatment, likely due to feelings of being ignored by professionals, insecurities, and/or fear of stigma. In these cases, the family's interests are not adequately represented and a cornerstone of the CSOC philosophy is not able to be realized. Despite the obvious positives of parental interaction with the current systems in place, the unfortunate reality is that the majority of parents that enter the CSOC 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. It is here, in the realm of parental empowerment through peer education, that NJPC recognizes the need for improvement and brings its expertise and resources to bear.

[1]The Annie E. Casey Foundation. Kids Count Data Center, accessed June 14, 2021 through the website of Advocates for Children in New Jersey (acnj),direct access at https://datacenter.kidscount.org/data/tables/100-child-population-by-single-age?loc=32&loct=2 - detailed/2/32/false/1729,37,871,870,573,869,36,868,867,133/42,43,44,45,46,47,48,49,50,51,52,53,54,55,56,57,58,59,60,61/418

[2]The Annie E. Casey Foundation. Kids Count Data Center, accessed June 14, 2021 through the website of Advocates for Children in New Jersey (acnj), https://acnj.org/kids-count/ - NJKCreports, direct access at https://datacenter.kidscount.org/data/tables/10668-children-who-have-one-or-more-emotional-behavioral-or-developmental-conditions?loc=32&loct=2 - detailed/2/32/false/1696,1648/any/20457,20456

[3]https://www.cdc.gov/childrensmentalhealth/data.html#ref

NJPC Professional Parent Advocacy Training

Content and Logistics

The Professional Parent Advocacy (PPA) Program is a subset of NJPC's Parents Empowerment Academy. The mission of the Parents Empowerment Academy is to provide comprehensive training and education to enable parents of children with emotional and behavioral challenges to appropriately negotiate with government agencies and other system partners. The Parents Empowerment Academy also increases the family's knowledge and provides practical tools and strategies which can be implemented in their local communities and organizations. In addition to the PPA curriculum, the Parents Empowerment Academy provides training opportunities for parents and professionals in:

- Engaging Parents & Family Members
- Building Systems of Care
- Empowering Families and Communities through Public Policy Work
- Developing Mentoring Programs for Children with Special Needs
- Case Management: Engaging Family Members as Case Managers and Peer Advocates

The PPA Training Program is designed to equip parents and caregivers with the knowledge and skills that allow them to be effective advocates and decision makers for their children. Presenters and facilitators are other parents who have or who have had children engaged in the CSOC. Participants learn about the challenges their children may face, how to communicate and engage professionally, the systems and benefits that are available, and how to mentor and teach other parents based on what they have learned. Upon completion of the PPA training, trainees are well-equipped to negotiate with government agencies and other system partners to access and make the most of the available services and supports.

The goals of the PPA Training Program are:

- To equip parents and caregivers of a child who has a mental disorder with the knowledge to advocate and negotiate for their children as they utilize government services and systems that are available to them
- To provide information on the services and systems that are available to parents and caregivers as well as their rights and what is required in order to use these resources
- To provide an overview of mental health disorders, the DSM-5, and the medications or treatments that are prescribed for these disorders
- To give a comprehensive overview of the community-based services and agencies in NJ and allow trainees to recognize cultural awareness as well as promote blame-free environments
- To address ways parents and caregivers can ensure they are equal partners in the design, execution, and development of the plans and services that are provided to their children through these agencies
- To encourage parents and caregivers to be involved in advocating for any public policy changes that will result in a better experience for their children who use these services by being a part of local boards and commissions
- To give trainees the knowledge to be able to empower other parents and caregivers in their local communities

The training consists of 15 topic areas spread over five to six Saturdays. The time required to cover the topic areas varies from about 45 minutes for "Introduction to Professional Parent Advocacy" to a full day (6 hours) each for "Understanding Childhood Mental Health Challenges and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)" and "Navigating the Special Education Process and the Individual Education Plan (IEP) Process." The exact pace of topic coverage varies somewhat for each cohort based on the preferences of the instructor and the needs of the participants. Multiple methods are used to educate and train attendees. Facts and knowledge are conveyed through PowerPoint presentations, while skills are developed through various interactive methods. Participants are asked to complete statements about themselves or their understanding of different concepts. Realistic scenarios are provided and participants are asked to choose the best response among the options provided. Pairs of attendees are asked to identify and discuss relevant personal experiences that relate to the topic being presented. Small groups discuss different approaches to resolving conflict in case study situations and then role play to come to a satisfactory resolution. This active and engaging approach has helped to build skills in a way that parents and caregivers can more easily apply in their own situations.

A typical schedule for the PPA training consists of the following sessions, each designed to be conducted from 9:00 to 3:00 p.m. on consecutive Saturdays:

Session 1: Introduction to Professional Parent Advocacy
Empowering the Parent Voice: Motivation & Assertiveness
Conflict Resolution Skills & the Power of Persuasion
Empowering vs. Enabling
Professionalism & Communication Skills

Session 2: Understanding Childhood Mental Health Challenges and the Diagnostic and Statistical Manual of Mental Disorders (DSM-5)

Session 3: Navigating the Special Education System and the Individualized Education Plan (IEP) Process

Session 4: Navigating the Juvenile Justice System in New Jersey
Understanding the Child Welfare System: New Jersey Department of Child Protection & Permanency
Ensuring Cultural Competency and Diversity in the Child-serving Community
Collaborating with Organizations Dedicated to Children and Families in New Jersey

Session 5: Train the Trainer – Empowering the Parent Trainer Graduation

On day 1, prior to the start of training, participants complete a questionnaire for each of their children with special needs that asks about their family and the child. Several of the questions are typical demographic questions (e.g., race, income), while other questions ask about the parent and the child's involvement in services or systems (e.g., mental health services, justice system). The focus of this report is on the items within the questionnaire that ask about the

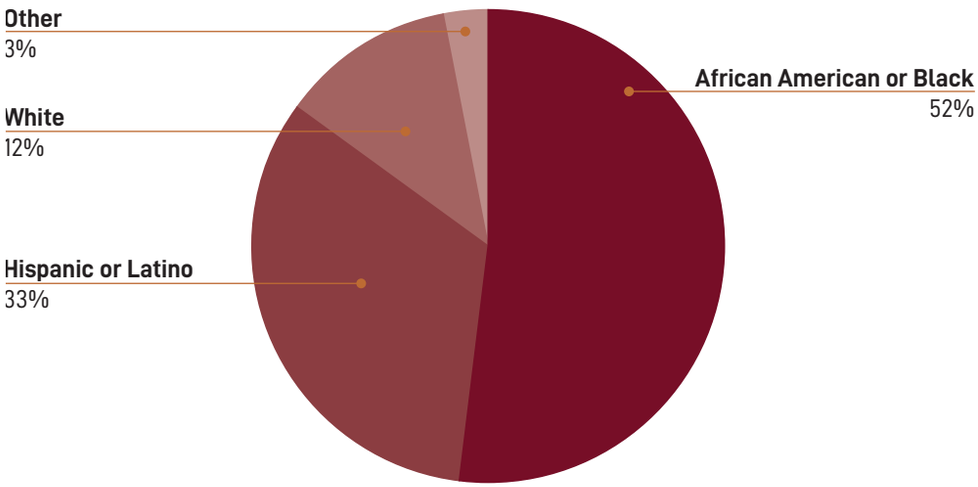
child's well-being, the parent's/caregiver's engagement with professionals and the system, and the perceived quality of services. Answers to these three groups of questions are re-evaluated about six months to one year after training and compared to the responses given on day 1, prior to training, to evaluate the effect of training on these parameters. These questions are answered on a scale from one to three where 'one' generally indicates a negative or undesirable response, and 'three' generally indicates a more positive or desirable response.

Participants

In terms of race/ethnicity, the majority of the families who participated in the PPA training had children who were Black or African American (52%). The second largest race/ethnicity for the children of the families who participated in the training was Hispanic or Latino (33%), followed by White (12%), and Other (3%).

Figure 1. Demographics of PPA Participants

Children's Race Ethnicity of the Families that Took the PPA Training



A small portion of these parents and caregivers were directly referred to NJPC by organizations including the child welfare and criminal justice systems. However, the vast majority of parents and caregivers who participated in PPA training were directed there through self-referral, referral from past trainees, and as a result of NJPC outreach efforts.

PPA Training Outcomes – Quantitative Measures

Results of ongoing surveys conducted by NJPC before and after PPA training, representing 342 children over a number of years, demonstrate significant and desirable outcomes for the youth and their families. After completing the training, parents and caregivers reported increased levels of satisfaction with the services and their ability to navigate the system. The data reported in this section represents a subset of the total number of participants over several years that the PPA training has been offered. The reported results are limited to those who completed a questionnaire at the time of the training ***and*** also six to twelve months after receiving the training.

The arithmetic means of the PPA training variables, with values of 1, 2, or 3, were calculated using R-Statistical Software. The values were derived from the results of the PPA questionnaire administered prior to the start of training ("before") and six to twelve months after training ("after"). The sixteen variables reported on in the following sections are grouped into three categories, reflecting the well-being of the child, family involvement, and perceived quality of services.

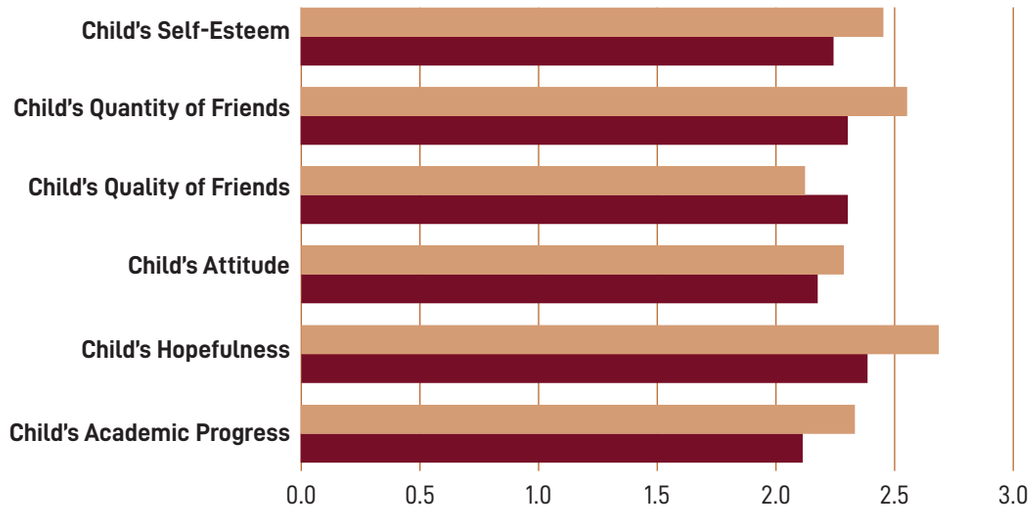
Paired t-tests were conducted using R-Statistical Software to determine the significance of differences between the "before" and "after" responses. Using a threshold of p-values that are less than 0.05, all differences in means were deemed to be statistically significant.

Child's Well-Being

Six of the questions on the NJPC survey of PPA training participants relate to the child's well-being, asking about their academic progress, their friends, and how they feel about themselves and the future. As shown in Table 1, the respondents indicated on average, that their childrens' well-being improved six to twelve months after the training. The largest gain was in "Child's Hopefulness," while the perception of their "Child's Quality of Friends" declined. In general, the caregivers' assessments of their children's well-being was more positive after the PPA training than before they completed the training.

Table 1. Child's Well-Being

Child's Well-Being



	Child's Academic Progress	Child's Hopefulness	Child's Attitude	Child's Quality of Friends	Child's Quantity of Friends	Child's Self-Esteem
After Training Mean	2.33	2.68	2.28	2.12	2.55	2.45
Before Training Mean	2.11	2.38	2.17	2.30	2.30	2.24

Scales used for Child Well-Being Measures:

1 → **2** → **3**

Child's Self Esteem		
Self-hating	Average for Age/Gender	Self-loving
Child's Quantity of Friends		
No Friends	Some Friends	Many Close Friends
Child's Quality of Friends		
Very Dissatisfied	Somewhat Satisfied	Very Satisfied
Child's Attitude		
Negative	Average for Age/Gender	Positive
Child's Hopefulness		
Hopeless	Average for Age/Gender	Hopeful
Child's Academic Progress		
Very Dissatisfied	Somewhat Satisfied	Very Satisfied

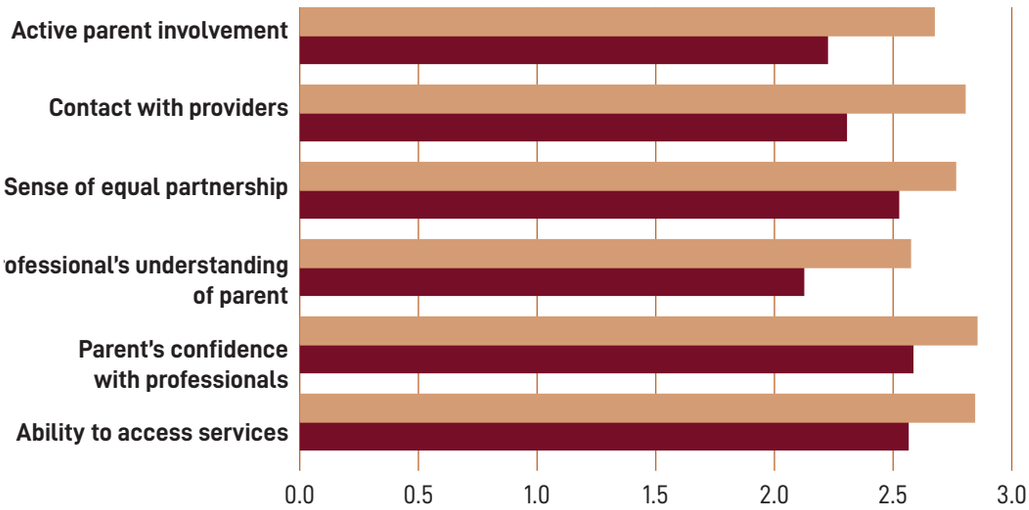
Parents/Caregivers Involvement

The responses to questions about the parents' and family's involvement with the services and system of care indicate that on average, respondents already had a good level of contact with providers and active involvement in the decision-making process, and they felt that professionals had a good understanding of them. The pre-training level of these variables ranged from 2.52 to 2.58 on a three-point scale, trending closer to "usually" than "sometimes." The largest changes in levels of involvement variables were with regard to ability to access services, parent's level of confidence with professionals, and sense of equal partnership with the professionals, with gains of .45, .50, and .45, respectively. The results indicate that trainees had a much better opinion of their ability to advocate for their children after training and that this likely translated into their success at obtaining services that would better help their children and family. Because a majority of participants in NJPC's PPA training are minorities as indicated in Figure 1 above, this increase in access indicates mitigation of typical disparities in access to care.

In addition to unequal access to mental health resources based on demographics and lack of awareness (National Council for Mental Wellbeing, 2018), unequal access to mental health resources may also be due to the stigma surrounding mental health illnesses (Stuart, 2016). The magnitude of this stigma may vary across communities depending on factors such as access to educational resources. The stigma associated with mental illness is worrisome since it may prevent or delay medical treatment upon the onset of illness, and may result in aggravated symptoms. PPA training helps to reduce the stigma associated with mental health through education about symptoms, diagnoses, and available resources, as well as with the support of presenters and other attendees who are in similar situations.

Table 2. Parent and Family Engagement

Parent/Family Engagement



	Ability to access services	Parent's confidence with professionals	Professional's understanding of parent	Sense of equal partnership	Contact with providers	Active parent involvement
After Training Mean	2.67	2.80	2.76	2.57	2.85	2.84
Before Training Mean	2.22	2.30	2.52	2.12	2.58	2.56

Scales used for Parent/Family Involvement Measures:

1 → 2 → 3

All Questions

Rarely	Sometimes	Usually

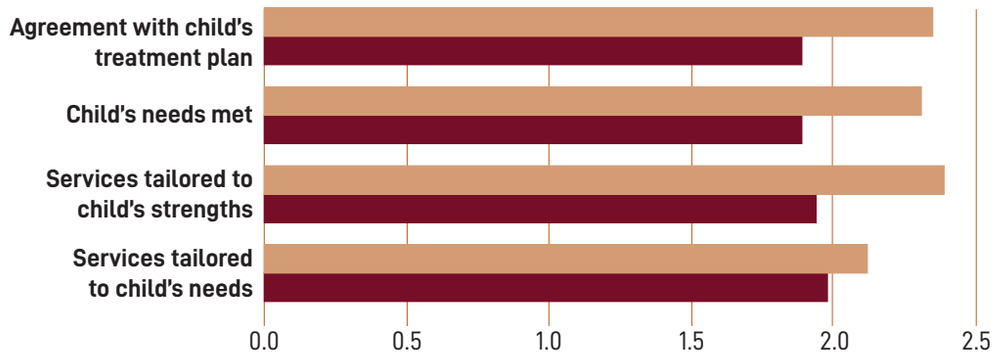
Perception of Service Quality

Four questions ask respondents to indicate whether they agree with the treatment plan designed for their child and how often they perceive the services provided to be adequately meeting the child's needs in alignment with his or her strengths and needs. With regard to the treatment plan, prior to training, parents and caregivers somewhat agreed with the treatment plan with an average response of 1.98. After training, however, there appears to be more disagreement with the plan with an average response of 2.44. It is likely that after learning more about the nature of their child's disability and the possible services available, respondents were not satisfied with the planned treatment.

From the patient perspective, being treated as an individual is a vital component to the patient experience. This is why it is essential to tailor health services to each patient's specific needs. Factors such as medical history, family dynamics, and diverse demographic and cultural upbringing come into play when tailoring these services. By recognizing the unique experience for each patient, healthcare providers are able to acknowledge a patient's experiences, hopes, and expectations. Prior to the PPA training, respondents on average felt that services were not quite meeting their child's needs, nor were they aligned with the child's strengths and needs, with ratings all below 2, "sometimes." After PPA training, respondents had a more favorable perception of the services provided to their children with the average evaluations ranging from 2.31 to 2.39. It is not clear that the services themselves improved in quality as a result of greater parental involvement, or that just the perception of the quality improved. Regardless, there was improvement in the parents' satisfaction level with the services being provided after PPA training.

Table 3. Perceptions of Service Quality

Perceptions of Service Quality



	Services tailored to child's needs	Services tailored to child's strengths	Child's needs met	Agreement with child's treatment plan
After Training Mean	2.33	2.68	2.28	2.12
Before Training Mean	2.11	2.38	2.17	2.30

Scales used for Perception of Service Quality Measures:

1 → **2** → **3**

Agreement with Child's Treatment Plan

Yes	Somewhat	No

Child's Needs Met

Rarely	Sometimes	Usually

Services Tailored to Child's Strengths

Rarely	Sometimes	Usually

Services Tailored to Child's Needs

Rarely	Sometimes	Usually

Within the context of larger system involvement, results also showed that participation in PPA training resulted in decreased youth involvement in juvenile justice and child welfare systems (National Juvenile Justice Evaluation Center, 2014, p. 4). This is significant because decreased involvement in these systems results in families being able to stay together and avoids children being placed outside of their communities. Decreased involvement with juvenile justice also alludes to less violence throughout the community, leading to reduction of childhood trauma. Finally, decreased involvement in the welfare system allows children to avoid the foster care system and reduces the incidence of family separation. Further analysis showed an increased involvement of youth in special education and mental health services after PPA training compared to before training. This increase in involvement of care is critical since early intervention is key to preventing more serious problems later in life.

The significant desirable outcomes following NJPC's PPA training demonstrate the value of engaging parents and caregivers in a meaningful way to help them navigate the systems available to support them and their children. Graduates of PPA training are more knowledgeable about their children's diagnoses, the services available, and how to fully participate in decisions and plans for the benefit of their children. Beyond the boundaries of their own families, graduates are equipped to teach other parents what they have learned, help influence policy, and be agents of change.

PPA Training Outcomes – Personal Stories

The previous sections presented the numbers associated with training outcomes. While the quantitative results are impressive, the true impact is revealed through the personal stories and triumphs of the PPA graduates. The short narratives below are examples of how the PPA Training Program has changed the lives of children and their families. Note that while the stories are real, the names of the individuals have been changed to assure the anonymity of the individuals involved.

Mary

Through the training, Mary learned how a good IEP (individualized education program) could help her son avoid institutionalization. She also learned how to avoid triggers for her son's bad behavior. After reaping the benefits of PPA for herself, Mary now supports other families. She advocates for early comprehensive medical and psychological exams for children to correctly identify causes of disruptive behavior. She focuses her assistance on the child and the family. She knows that parents have to be healthy and strong so they can advocate for and participate in their children's care.

Laura

When the school recommended special education for her son, Laura did not understand much of what the professionals were saying and she kept quiet in the meetings. After PPA training, Laura knew much more about the IEP process. She was able to hold the school accountable and to effectively advocate for her son. The PPA Training Program also motivated and equipped Laura to help other parents so they would know where to turn for help.

Nancy

Many years ago, as a young widow with five children, Nancy gained significant benefit from participating in the PPA Training Program. Armed with new knowledge about mental health and special education, she was able to secure specialized resources for her children. She became a full partner in supporting their positive growth and development after a traumatic family loss. Learning more about the CSOC in New Jersey allowed her to push through the system when she received an initial "no" to a request. Having a community and learning from other parents in similar situations has been a blessing that NJPC provided. Nancy has become very involved with the organization and now supports many families so they too can access critical services for their children.

Michelle

Michelle took custody of her five-year old granddaughter, Tina, twenty years ago. During her elementary school years, Tina was a good student but she exhibited extreme behavior that concerned Michelle. The family sought and received counseling for Tina for several years but it didn't get to the root cause of the behavior. Michelle then found the PPA Training Program. There, she learned much more about underlying mental-health causes of behavior, about IEPs, and how to advocate for her granddaughter. Michelle also learned how to avoid certain triggers that tended to make matters worse. With greater knowledge and skills, Michelle pushed for her granddaughter to be placed in a therapeutic high school. After failing all her courses at her previous school, Tina thrived at her new school. She went on to attend college and recently graduated with a degree in Sociology. Michelle's dedication was rewarded by seeing her granddaughter succeed and enjoying their positive relationship now. She pays it back by applying what she learned to help other families in similar situations.

Cynthia

Many years ago, Cynthia lost custody of her young children to her mother. Cynthia's mother attended the PPA Training Program to better equip her to advocate for her grandchildren. Cynthia was also prompted to attend when she saw the materials at her mother's home. She learned more about her own mental health challenges and through role playing exercises was better able to understand her mother's perspective. Since graduating from the PPA Training Program, Cynthia has been able to help other parents. Because she speaks fluent Spanish and English, she has been an asset to the NJPC, allowing them to assist even more parents. In addition to using the skills and knowledge gained through the PPA program to help many families, Cynthia is better able to support her grown daughter who has a mental health diagnosis, and helps to raise her grandchild.

Each of these personal stories shows that the PPA Training Program has been instrumental in changing the lives of children for the better. Parents and caregivers who participate in the program become well-informed partners with professionals to ensure their children receive the services they need. Because the PPA program is built on a model of parent engagement and mutual support, many graduates are motivated to help others in similar situations. The "train the trainer" component of the program results in a positive reinforcement loop, amplifying the benefits of PPA training well beyond the initial impact on a participating family.

Potential Sources of Error and Limitations

Questionnaires completed prior to the Professional Parent Advocacy Training Program and six to 12 months after the program were submitted for 342 children. Within the questionnaires, there were some missing responses for some of the individual items of interest, reducing the sample size for some variables to less than 342. Participants were limited to evaluating the items on a three-point scale. There were not opportunities to add qualitative remarks to provide context or explanations for their quantitative responses.

Another source of limitation is that the responses were the result of the attendees' own self-reflection and assessment. There were no independent assessments of the child's well-being, effectiveness of services, or parent's participation in the care process. There is always potential for respondents to misunderstand the meaning of the question they are being asked. For future training sessions, independent measures of outcomes would be beneficial when assessing the effectiveness of PPA training.

Discussion

The results of participants' evaluations of the PPA Training Program show that educating and training parents about mental health, available services, and effective ways to interact with the system bring about positive effects on access to quality care, increased engagement of caregivers, and enhanced well-being of the affected children. NJPC training programs have the potential for even broader reach. Historically, each instance of the full training program has cost approximately $5,000 to deliver to 25 parents in one location. The training programs are free to participants which increases access for parents and caregivers of children struggling with their mental health. In the advent of the COVID-19 virus and restrictions on in-person gatherings, the NJPC has developed alternative delivery methods that would support widespread implementation of the training program, throughout New Jersey and in other parts of the country. With additional funding, NJPC has the opportunity to produce similar beneficial results in many more communities, helping other jurisdictions to leverage their systems of care for the health and well-being of more children and their families.

The positive impact of PPA training was significant in a status quo environment, pre-COVID 19. The pandemic's effect on school routines and access to in-person services only enhances the imperative for parents and caregivers to be well-informed advocates for their children. Even for children without the added burden of mental health issues, school closures and remote learning have posed unprecedented challenges for children, parents, and teachers. These school closures have been especially disruptive for students and their families as more responsibility is given to students and parents to successfully complete the curriculum. Additionally, on-line learning has made disparities in access to technology more apparent. It is important to consider the implications these closures have had on children's mental health in New Jersey and across the United States.

Prior to the coronavirus pandemic, it is estimated that 17.1 million children in the United States have or had a psychiatric disorder (Child Mind Institute, 2015) and this number is projected to increase following the pandemic. Although most children may not suffer deleterious psychological outcomes, the impact of prolonged lack of socialization, skill-based learning, and reduced physical activity may increase children's emotional distress (Stark, White, Rotter & Basu, 2020). The resulting increase in child mental illness is still to be determined after the COVID-19 pandemic. However, large-scale disasters, including mass shootings and natural disasters, are often accompanied by increases in depression, post-traumatic stress disorder (PTSD), substance use disorder, a broad range of other mental and behavioral disorders, domestic violence, and child abuse (Galea, Merchant & Lurie, 2020).

Although it has been difficult for all children, children who have been diagnosed with a mental illness are finding it especially difficult to get a valuable education due to the lack of supplemental resources that may have been available to them in in-person environments (Patel, 2020). It is noted that schools serve as a source for mental healthcare and an implication to school closures is temporarily decreased access to these resources. School-employed professionals may include school psychologists, counselors, social workers, and nurses. According to a handout from the National Association of School Psychologists (NASP, 2021), "Research shows that students are more likely to seek counseling when services are available in schools." This is especially important in rural areas where schools may provide the main source of mental health resources for the community (NASP, 2021). Many families involved in NJPC training indicated that school counselors are part of a child's care-team. In consideration of this, PPA training has become even more crucial as a result of the pandemic, supporting families of children with known behavioral and mental health challenges and families of children who develop issues as a result of the new environment.

In light of the effects of COVID-19 on the overall mental health of children, PPA training is a cost-efficient and effective tool to serve large numbers of parents and caregivers. The Train the Trainer aspect expands the instructional base to accommodate growth in demand. The training also sets a standard for informational instruction that can be used by the New Jersey Department of Children's System of Care in a proactive way. NJPC recommends the New Jersey Department of Children & Families incorporate parent advocacy training into its introduction of families to involvement in the system. By providing parental education on the appropriate subject matters and empowering them in their decisions for their children, negative outcomes may be avoided or reduced.

The New Jersey Parents' Caucus also recommends a state standard for a Parent Advocacy Certification. The standard should include a minimum length of time of 30 instructional hours, a list of required topics in the training materials (information about government programs, mental health diagnosis and what they mean, etc.), and a final certification test. A standard system like this is in the state's best interest to allow them to demonstrate progress against their core values of providing care that is family driven, youth guided, individualized and community based, and culturally and linguistically competent. 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 should seek to rigorously document evidence of the positive correlation between parental education and system efficiency and effectiveness. The favorable results achieved by NJPC thus far are cause for optimism that similar efforts on a broader scale will bring us closer to the ideals envisioned over 35 years ago for children's mental health care.

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