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Parent Peer Models for Families of Children with Mental Health Problems

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An estimated 1.9–6.1 million children between the ages of 3 and 17 have a diagnosable mental health condition including anxiety, depression, and oppositional defiant disorder [1]. The intractable and chronic nature of many mental health disorders, coupled with a lack of appropriate treatment and support, have a deleterious impact upon a child's educational and occupational functioning,

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J. D. Avery (ed.), *Peer Support in Medicine*,
https://doi.org/10.1007/978-3-030-58660-7_7

relationships, and physical, emotional, and behavioral health [2–4]. Child-onset mental health difficulties also have a significant impact upon the family. Alongside parenting challenges associated with their child's mental health problems, caregivers are tasked with overseeing and advocating for their child's treatment needs in a barrier-laden service system [5, 6], yet they often lack their own emotional support and information about resources, services, and information about treatment options for their child [6]. These difficulties, coupled with experiencing burden, stigma, and blame for their child's condition [5, 6], puts caregivers at high risk for stress, strain, and emotional distress [5, 7–12].

Supporting caregivers is of paramount importance for the health and wellbeing of the entire family; reduction in parental stress, for example, not only enhances the emotional health of parents but is also associated with improvements in therapeutic outcomes among youth [13]. However, the child mental health system has historically subverted caregivers' needs, and their involvement in treatment has been primarily to support the child [14]. In the 1980s, a new model of service delivery was formalized in which parent peers, defined as trained parents/primary caregivers of children with mental health needs, provided similarly situated families with an array of services such as emotional support, information about mental health and treatment, and linkages to services for the child and themselves [14]. This chapter provides an overview of parent peers and the services they provide, including the multiple theories underlying parent peer support programs, evidence supporting these models, and future directions for the field.

Qualifications and Roles

Parent peers are referred to in the literature as peer support specialists, peer and parent advocates, family peer advocates, and family or parent advisors. By definition, a parent peer has to have had lived experience as the primary caregiver for a child with a mental health problem and has navigated the child-serving system [14–17], as it is their lived experience that is believed to

make them uniquely qualified to engage parents and caregivers facing similar issues [18, 19]. Additional criteria vary but may also include age and educational requirements (e.g. being 18 years of age or older and having a high school diploma), completion of trainings, holding a valid credential, and prior paid or volunteer experience working or volunteering providing peer parent support [20].

Unlike other peer models, parent peers focus on the parent/primary caregiver and support them to take an active role in decision-making, navigating services, and developing their capacity to meet the needs of their child and family. This often occurs in collaboration with clinicians and other providers who are focused more centrally on the child's treatment needs. Within this capacity, the roles that parent peers assume are multifaceted, yet comprised primarily of providing education and information, facilitating linkages to supports, and providing emotional support, skill development, and advocacy.

By way of example, Hoagwood and colleagues [14] conducted a review and synthesis of family support programs and found that peers engage in services which include: informational/ educational support (for example, providing families with information about resources that may be available to them); instructional/ skills development (for example, coaching caregivers on effective ways to address their child's behaviors); emotional and affirmation support (promoting caregivers' feelings of being affirmed and appreciated); instrumental support (such as providing concrete services); and advocacy (such as assisting parents to understand their rights and advocate effectively for the services their child is entitled to.)

Formal training programs for these roles are beginning to emerge. Rodriguez and colleagues [21] describe the development and evaluation of a professional program to enhance parent peers' professional skills, called the Parent Empowerment Program (PEP). The PEP training was originally designed as a 5-day in-person training and currently consists of a combination of online self-learning modules followed by a two-day in-person training and a series of 12 weekly group coaching calls. PEP training fulfils the training requirement for the New York State Family Peer

Advocate Credential (FPA). Approximately 400 individuals currently hold a valid FPA Credential [22]. Evaluation of the training program provided systematically collected information about peer activities over time. It indicated that the job functions of parent peer workers include provision of information/education, advocacy, tangible assistance, and emotional support, but that emotional support and service access issues appear to be a key focus of the peer's role.

Theory

Often, reports of any peer-delivered intervention do not state an explicit theory about the mechanisms underlying how it will impact the outcomes under investigation, but rather center around a series of values, ideas, and beliefs [23]. Without an underlying theory, it is difficult to know if these mechanisms are being carried through into practice, which can lead to a lack of congruence between design, implementation, and evaluation [23]. Therefore, theories are necessary to understand how parent peer programs are intended to work, along with the expected intermediate and long-term changes in caregiver, child, and family outcomes.

A theoretical basis for understanding the potential effectiveness of peer support has been offered in the literature to a limited extent. One theory is Festinger's Social Comparison Theory. This theory postulates that individuals self-evaluate based on the comparison of their own beliefs and desires against those of another person's [24]. It proposes that individuals seek to improve their self-esteem and enhance themselves by making comparisons with others [25]. Within the context of peer support, vulnerable or at-risk individuals work with peers who have made successful changes, thereby encouraging comparison and positive behavior change [26]. Moreover, people are more likely to compare themselves to another when they perceive the person to be similar to themselves. Parent peers may be perceived by individuals to be more similar than a traditional clinician, due to their shared lived experience. This shared connection may provide common ground between the two individuals upon which to change [26].

A second theory which may provide a theoretical rationale for the value of peer support is Bandura's Social Learning Theory. This theory posits that behavior is learned from the environment through the process of observational learning [27]. In other words, desirable behaviors are modeled and the effects of these behaviors can be determined in the process of observational learning. These observed and newly learned behaviors can then serve as a guide for future action [26]. Within the context of peer support, parents have the opportunity to observe new behaviors through role modeling from a parent peer [28], which may enhance the caregiver's confidence, perceived empowerment and sense of personal agency.

Rogers' Diffusion of Innovation theory [29] has also been offered as an explanatory framework for peer support. This theory explains how an idea or new behavior gains momentum and is "adopted" by others. Adoption of new or innovative behaviors relies on the perception that they are superior to current behavior, that they align with one's values, and that there are opportunities to observe what happens when others adopt the new behaviors. Although specific to youth peers, an Australian study that aimed to identify the key features, impacts, and outcomes associated with peer-based programs draws on this theory to explain how, in a group peer program, long-standing or negative attitudes or beliefs can change through exposure to positive coping strategies adopted by credible and positive peer role models. New innovative and acceptable behaviors that were adopted in their youth peer-based program included improved help-seeking behavior, pro-social behaviors, and alternatives to risk behaviors [30].

Aside from specific theories, key components that are responsible for the positive impacts of peer support have been identified in the literature. Because of their personal experience, parent peers have credibility and are able to engender trust. Shared experiences also enable parent peers to adopt a nonjudgmental attitude [31]. In the case of parent peer programs, these trusting relationships can assist caregivers in becoming more actively engaged in their child's services [32–37]. In this same way, parent peers are often seen as authentic because they can relate to common challenges and have found their way to support their child and family

to move forward in positive ways. This lived-experience helps the families be hopeful that things can get better.

Research Evidence

The diversity of roles and settings in which parent peers work is reflected in the research about these models. A synthesis of this literature identifies four main foci: (1) the feasibility and acceptability of peer programs; (2) mental health services utilization, (3) caregiver and family processes, and, (4) symptoms and functioning.

Feasibility and Acceptability

Feasibility and acceptability studies primarily test innovative models in which the program is being delivered in a new setting or the role of the peer deviates from the typical services they offer. A consensus of these studies suggests that parent peer programs are highly feasible to deliver and perceived as being acceptable from the perspectives of caregivers and peers. For example, Acri et al. developed and tested a detection and outreach model in which parent peers screened caregivers for symptoms of depression, provided information about mental health and treatment, connected at-risk caregivers to mental health services for a formal assessment, and using an evidence-informed approach, taught caregivers how to be empowered participants in their treatment. This model was tested both in freestanding family support organizations, which serve caregivers of children with emotional and behavioral problems [38, 39], and in the child welfare system [15, 40]. In both studies, results showed the intervention was highly feasible to deliver, based upon metrics including number of sessions completed, fidelity to the intervention, and attendance, and acceptable from the perspectives of parent peers and caregivers in that peers felt comfortable delivering the intervention and caregivers viewed parent peers inquiring about their mental health favorably. Moreover, Butler and Titus [16] found a preventative

peer-delivered parenting intervention delivered in primary care settings for families of preschool youth at risk for behavior problems was feasible for parent peers to deliver as measured by the number of physicians who referred caregivers to peers, the number of peers who completed the training and caregiver attendance. And, January et al. [5] found that a telephone intervention for caregivers of children at risk for behavioral or emotional problems was delivered with fidelity, which is an important criterion for assessing feasibility.

Mental Health Services Utilization

Peer-delivered services also appear to facilitate treatment utilization for caregivers. For example, caregivers at risk for depression who participated in Acri et al. [38, 39] detection and outreach model and reported a strong working alliance with their parent peer were also more likely to access mental health services and reported fewer perceived barriers to help seeking (Hamovitch et al., in press). This finding is consistent with results of Radigan et al. [41] study, which surveyed over 1200 caregivers across New York State who had accessed public mental health services and found that caregivers who worked with a parent peer attended more mental health sessions for themselves than caregivers who did not utilize parent peer services, and evidenced significantly greater satisfaction with services and overall satisfaction as well.

However, the evidence isn't quite as clear for child service use. Specifically, Hoagwood et al. [14] reviewed two published studies that examined child treatment engagement: The first found the parent peer program, which aimed to facilitate treatment utilization prior to beginning Oregon's Early and Periodic Screening, Diagnosis, and Treatment Program, was associated with the child's initial engagement into treatment, but had no impact upon ongoing use of services or attendance [35]. The second study, which tested Parent Connectors, a telephone-based program for caregivers of children receiving special education and who had emotional problems, did not find any discernible impact of the peer program upon the child's utilization of treatment [42].

Caregiver and Family Processes

Studies of caregiver and familial processes also vary. Specifically, Hoagwood et al. [43] Parent Empowerment Program, which aimed to train parent peers to empower and activate caregivers to engage their children into mental health services, found no impact upon caregiver strain or empowerment, while Kutash et al. [42] Parent Connectors found significant improvements from pre- to posttest on family empowerment, but only among those who were experiencing the high levels of strain. Further, Koroloff et al. [35] found that the EPSDT pretreatment program was associated with slight improvements in the caregiver's sense of empowerment comparative to a matched comparison group. And, January et al. [5] found significant pre- to post-improvements in the caregiver's perception of social and concrete (e.g., access to supports and resources) as a result of a peer parent support program delivered by phone.

Child and Caregiver Symptoms and Functioning

A synthesis of this literature suggests that peer models are associated with multiple, positive outcomes for children and their caregivers. Results of a recent randomized controlled trial of a parent peer-delivered educational and supportive group for ethnically and racially diverse families of children with autism spectrum disorder found that caregivers in the intervention condition exhibited significant improvements in knowledge about autism and reductions in caregiver stress in comparison to caregivers receiving treatment as usual (referrals to services in the community) [44].

Additionally, studies of peer-delivered parenting programs found several improvements in child and caregiver outcomes. In comparison to a waitlist control group, for example, caregivers who received a peer-delivered parenting program evidenced significant improvements in their concerns about their child and parenting, and their children showed significant improvements in behavior, although there was no difference between this group

and a waitlist control group regarding parent stress [45]. Butler and Titus [16] found a peer-delivered parenting skills intervention was associated with significant improvements in parent-reported behavior problems and parenting stress and competence from pre- to posttest, although the frequency of their preschool child's behavior problems was not significantly impacted. And, Chacko et al. [46] who examined a parent peer-delivered parenting program for families of children with ADHD found that the intervention, coupled with medication, was linked to improvements in child behavior symptoms and functioning as well as reductions in parenting stress and improved parenting behavior. However, neither Hoagwood et al. [43] nor Kutash et al. [42] found improvements in child behavior or emotional functioning due to the Parent Empowerment Program training or the Parent Connectors programs, although the primary targets for these interventions were caregiver empowerment, activation, and support, and not child emotional health or functioning.

Taken as a whole, the emerging research on parent peer models is favorable; peer-delivered interventions appear to be feasible to administer and acceptable to key stakeholders, facilitate service use by caregivers to address their own behavioral healthcare needs, increase caregiver knowledge, and improve child and caregiver emotional health and functioning. To this latter point, parenting skills programs appear to be the most effective for decreasing mental health symptoms, improving the child's functioning, reducing caregiver stress, and enhancing parenting.

Future of Peer Programs

Peer-delivered services have expanded dramatically both in the United States and globally [47]. Peer parents assume a range of roles and are embedded in a variety of settings, most states have established credentialing requirements, and parent peer delivered services are, or will soon be, a billable service under Medicaid across the United States [16, 48]. The research on parent peer models is encouraging and shows several areas of growth, including detection and outreach models for caregivers at risk

(e.g., Acri et al. [38, 39]), integrated and co-located models [16, 46], and preventive programs for at-risk youth [5]. Efforts such as these illustrate the growth and promise of parent peer models for families of children with mental health difficulties.

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