

Executive Summary: (Draft: v1.0)

Parent to Parent USA: A Narrative Literature Review*

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Introduction

A review of research literature was conducted to answer three questions related to Parent-to-Parent programs that assist families of individuals with disabilities and/or special healthcare needs:

- 1) What are the organizational structures and resources that sustain programs described above?
- 2) What are the interactions and programmatic content found in those programs?
- 3) What training is provided for Support Parents participating in those programs?

Approach

A total of 42 studies were identified for review, published between 1985 to 2025. The majority concentrated on data from programs within the United States, although some reported on the international expansion of P2P programs. Most studies relied on “qualitative” data gathered through interviews, focus groups, questionnaires, or case studies. A smaller number relied on more structured “quantitative designs” that systematically examined program effectiveness and outcomes. A third category of studies included previously published literature reviews.

Highlights

Across these methodologies and settings, research findings consistently documented the emotional, informational, and social benefits of peer support for parents navigating complex care systems. Similarly, across the 40-year span of these studies, participants routinely reported a reduced sense of parental isolation with increased empowerment, stress management, and access to resources. Recent studies also highlighted the adoption of digital delivery methods, the programmatic inclusion of cultural and linguistic diversity, and cross-system collaboration.

Organizational Structures and Resources

Initial surveys of P2P programs described them as informal, volunteer-driven organizations, with most directors being parents themselves. Groundbreaking research conducted at Kansas University and the University of California in the 1990s promoted the growth of more formally structured P2P programs and provided empirical justification for specialized staff roles and the adoption of evidence based best practices.

Financial support for P2P programs began to shift from local donations and small grants to various forms of state, federal, and philanthropic funding. Formal organizational structures and professional staff became more common, along with an increase in institutional affiliations with hospitals, universities, and state agencies.

While the literature reviewed offered valuable insights into the nature and general evolution of Parent-to-Parent programs, empirical evidence was often lacking on how specific organizational structures, staffing models, and funding mechanisms influenced program outcomes. A mix of cross-site, and site-specific, experimental studies can help fill this gap.

Programmatic Interactions and Content

Studies showed program content has been primarily provided through one-on-one peer matches involving a “Support Parent” and a “Requesting Parent,” with the peer matches being based on a combination of factors, including having children with similar disabilities, shared lived experiences, comparable family structures, geographical proximity, and cultural or linguistic backgrounds. A sense of perceived similarity between matched parents resulted in more meaningful and supportive relationships.

Some programs included specific requirements for the frequency of parental interactions, while others offered ongoing, flexible parental contacts through a variety of means. Even within this variety, the content of P2P programs remained consistently focused on providing a combination of emotional, informational, and instrumental support.

Participating parents reported reduced feelings of isolation, along with an increased sense of self-awareness, parental empowerment, and more confidence in their interactions with medical and educational professionals, in addition to feeling more emotionally supported by their peers, as compared to health professionals who mostly focus on physiological information.

Face-to-face peer interactions were common features of early P2P studies. However, participants accommodated phone, email, and social media interactions as those methods became more prevalent to reduce barriers of time and space. Online methods proved to be as effective as face-to-face interactions, especially when interactive and well-facilitated. However, concerns about their ability to build reciprocal peer relationships and parental resiliency have been noted.

Although the literature reviewed provided rich and detailed descriptions of the interaction patterns and content of P2P programs, few studies examined *how* current modes of engagement translate into measurable family or child outcomes. Greater focus is also needed on cultural responsiveness, parental readiness, and socioeconomic conditions that affect program interactions.

Training Provided for Support Parents

Studies reviewed found the readiness, training, and ongoing support of individuals serving as Support Parents were essential in successful P2P programs. The length of training programs varied widely. Some programs offered as little as five hours of training, while others required up to 40 hours of training delivered over a 10-week period.

The content of training typically included a mixture of communication and empathy skills, role-playing and relationship-building, understanding the need for confidentiality and personal boundaries, and fostering self-awareness and cultural sensitivity. Practical content often included information about available community resources and guidance on navigating complex systems,

such as schools, health care, and legal supports, alongside disability-specific information relevant to participating families.

Initially, Support Parent training was informal, conducted face-to-face in small groups facilitated by peers with similar lived experiences. Over time, training became more formalized, grounded in evidence-based practices, and more often delivered by a paid staff member. Eventually new forms of online, virtual, and blended training methods met the needs for increased accessibility and flexibility. A related training issue concerned the lack of technology training and role clarity prevalent among Support Parents.

From their perspective, Support Parents reported a reciprocal benefit from taking part in their training, including improvements in their own communication skills, confidence, emotional well-being, and a deepened sense of empowerment.

Despite the substantial evidence describing Support Parent training, gaps exist in the empirical understanding of what constitutes the most effective training content, delivery format, and duration. Studies incorporating mixed-methods and longitudinal, experimental designs are needed to evaluate how specific training strategies influence both the quality and effectiveness of Support Parent training and how that training affects desired parental outcomes.

Discussion

Drawing on forty-two studies conducted over four decades, our findings illustrate the dynamic evolution of P2P programs from informal, community-driven initiatives to structured, evidence-informed programs integrated within an array of institutional frameworks.

P2P programs have developed multi-layered staffing models that blend the strengths of personal lived experience with professional oversight. Support Parents are still at the core, but their work is increasingly supported by program coordinators, coaches, cultural brokers, and allied health professionals.

Early programs in the 1980s and 1990s relied on one-to-one, in-person peer matches, reflecting the relational, community-based origins of P2P support. As programs expanded in the 2000s and 2010s, technology-enabled interactions began to reshape P2P engagements. Additionally, today's programs are increasingly reaching out to linguistically and culturally diverse populations adopting programs and practices that are responsive to their unique needs

During this period of evolution, the field matured. Its practices grew more complex. Yet, it stays grounded in its founding principles of providing emotional, informational, and instrumental support for parents of individuals with disabilities or special healthcare needs. That support is delivered through a variety of peer-to-peer interactions.

This historical progression from localized one-to-one support to multi-modal, technology-enhanced networks illustrates how P2P programs have stayed grounded in empathy and shared experiences while evolving to meet the changing social and technological realities of families. The adaptability of these interaction models underscores the resilience and relevance of peer support as both a personal and systemic resource for families navigating disability and chronic care.

P2P Research Next Steps

In addition to the research recommendations associated with the three specific questions central to this review and discussed above, two thematic recommendations are offered here.

1. **Reexamine and validate evolving program practices.**

Engage P2P program directors, researchers, agency leaders, and key stakeholders in a systematic examination of current and emerging P2P practices. This work should document their prevalence, assess their application to the wide variety of P2P programs, and evaluate their effectiveness in relation to the foundational principles of the P2P model. The results could inform the development of an updated and empirically validated set of *best practices* to guide the next generation of P2P programs reaching millions of families annually.

2. **Strengthen collaboration between researchers and program managers.**

Establish formal processes that better connect the community of P2P researchers with program administrators to identify immediate and emerging programmatic challenges, improve the translation of research into practice, and enhance the operational effectiveness and sustainability of P2P programs across diverse contexts.

Conclusion

Future research should build a stronger evidence base for P2P programs by testing specific program components, finding key mediators of success, and examining how P2P programs can meet changing technological environments and the needs of increasingly diverse families.

The structure, programming, and training of volunteers in Parent-to-Parent programs have evolved significantly and this evolution will continue. As P2P programs face new social, technological, and political challenges, maintaining an ongoing commitment to rigorous, collaborative, and inclusive research will be essential. Such inquiry will ensure that future iterations of P2P programs stay faithful to their founding principles and responsive to the complex realities of the families they serve.

**The full text and supporting citations for this review can be found on Parent to Parent USA's website; <https://www.p2pusa.org/>*