

A photograph of a man with short dark hair, wearing glasses and large white over-ear headphones. He is smiling broadly and looking down at a laptop screen. He is wearing a light-colored, possibly olive green, long-sleeved shirt. The background is a blurred indoor setting, likely a home office or living room.

# Online Peer Support Networks As a Mental Health Tool for Parents of Children Struggling with Mental Illness and Substance Use

May 2022

# Background

In 2020, 1 in 6 adolescents between 12 and 17 years of age experienced a major depressive episode, and 1 in 3 young adults between 18 and 25 years of age experienced a mental illness (Substance Abuse and Mental Health Services Administration, 2020).

Suicide remains the second leading cause of death among people aged 10 to 34 (National Institute of Mental Health), and the proportion of mental health related emergency room visits by adolescents between 12 and 17 years of age increased by 31% from 2019 to 2020, as the COVID-19 pandemic and isolation took a toll on youth mental health (Yard et al., 2021). Understanding how to best support youth mental health is perhaps more crucial now than ever before. Despite this, many families continue to struggle with mental health issues in silence, while there are an increasing number of families all around them who can relate. Parents of struggling youth are more likely to experience reduced well being and elevated psychological distress (Sartore, Pourliakas, & Lagioia, 2021), however they often lack the tools and support to recognize, value, or attend to their own mental health needs (Olex, 2018). Having access to online peer support, in combination with other mental health services, might be one such way of connecting parents with knowledge, support, and community to help them feel less alone, and to learn how to better support their children struggling with mental health concerns. This is the mission of Other Parents Like Me (OPLM, LLC), a mental health organization seeking to provide this critical support that has long been absent in the landscape of online peer support services (PSSs).

Peer support has a long history, both formally and informally. As applied to mental health support, “peer support” generally refers to the process by which individuals with lived experience of a mental health condition support others dealing with similar experiences (Ibrahim et al., 2020). This support can exist in the form of knowledge or resources, peer connection, or emotional support. Peer support can be informal support between friends, or more formal support, with employment of peer support workers (PSWs) in mental health services. PSSs as an aspect of mental health services go back several centuries (Shalaby & Agyapong, 2020) as a method of connecting those with shared experiences and fostering a sense of community and mutual understanding.

Online peer support networks (PSNs) provide a uniquely accessible form of mental health support that can be utilized alongside other healthcare services to provide connection, informational resources, and a feeling of being less alone.

In this way, they can be beneficial for individuals looking for peer support for a health issue, a substance use disorder, or any number of stressors. In the landscape of online PSNs, and in research concerning online PSNs, there is a gap in understanding and meeting the needs of parents seeking peer support in relation to the mental health struggles of their children. The mission of Other Parents Like Me as a peer support network is to address this gap, and to create a space where parents can find the support they need as they and their families move from crisis to healing. In building an understanding of how best to support parents through this journey, it is imperative to use existing research and resources to inform best practices, and to understand how online PSNs more broadly can best support parents in crisis.



In thinking about what makes online PSNs maximally beneficial to those who are part of such online communities, it is important to understand the documented experiences of those using online PSSs alone or in combination with other mental health services; the different types of PSSs and PSNs; who uses online PSSs and PSNs, and how the user base is growing and changing; how the COVID-19 pandemic has shaped the landscape of online mental health services; and what the future of online PSNs might look like.

“I feel the parents on these meetings can relate better than any other interpersonal interaction I have.”



Jennifer

“Having others share their experience deepens my own...as a result of these meetings my relationship with my son has changed.”



Marcie

“These meetings are life changing, in terms of how I view myself, my relationships and the world.”



Michael

# Peer Support Online

Though PSSs have a long history, the landscape of PSSs has been dramatically altered by the availability of many forms of peer support online. When speaking of online PSSs and PSNs, it is helpful to first understand the following distinctions:

1

Forums versus support groups

Peer support online can look like many things, from a Facebook group centered around a shared health experience, to a structured support group with private access and video meetings. Things like Reddit groups or Quora conversations on a topic would be considered forums rather than support groups, and there is a body of research dedicated to understanding how use of forums and social media peer support impacts mental health. These forms of peer support tend to be more accessible, but also more publicly visible and unmoderated. Research suggests that such peer-to-peer support without professional input has limited effectiveness, and respondents to surveys on peer support forums gave majority feedback that the involvement of professionals to either participate or offer a “safety net of passive monitoring” would be beneficial (Milne et al., 2016).

Unmoderated peer support groups are support groups where there is no moderator present in the space to guide the conversation, moderate dialogue to make sure accurate information and resources are provided, and to keep the environment safe and open. Unmoderated groups are more likely

2

Moderated vs unmoderated peer support spaces

to be anonymous and publicly visible, which adds another layer to the distinction. Generally, studies of members of unmoderated PSNs for mental health have generated mixed results, with those reporting more positive experiences with the Internet peer support groups also reporting greater levels of psychological distress than those reporting less positive experiences (Kaplan et al., 2011).

In studies of adverse events in moderated PSNs, occurrence of adverse events has been shown to be low, even for those who experience the spaces as neutral rather than helpful (Easton et al., 2017). Within moderated PSNs, research has also been done to better understand how members of online PSNs perceive guided chats compared to unguided chats (O’Leary et al., 2018). Guided chats were thought to provide solutions to problems and new perspectives, and were perceived as “deep.” Unguided chats offered a source of personal connection on shared experiences, and were perceived as “smooth” (O’Leary et al., 2018). Overall, there is a general lack of research on the topic of online PSNs (Eysenbach et al., 2014), and comparatively more research on forums and unmoderated spaces than moderated spaces.

3

Anonymous versus not

# Who Utilizes Online Peer Support Services?

Use of online PSNs over the past several decades has been documented by limited research surveys, reflecting a user base that is largely white, female, and middle-aged. Of such surveys, the majority are self-reports concerning online PSN members who utilize online PSNs for their own mental health struggles, rather than in relation to a loved one. However, there are an increasing number of online peer support communities for family members and loved ones of individuals struggling with mental health issues, substance use, chronic illness, etc.

Research specific to parents who utilize online PSNs in relation to their children is limited, and mostly reflects the experiences of parents of disabled children (Bray et al., 2017; Kaplan et al., 2011; Shilling et al., 2015). The experiences of parents seeking peer support in relation to children struggling with mental illness and substance use are less documented, and there is a gap here in understanding demographic data more broadly for those who utilize PSNs in relation to loved ones. Social support from parents can be a critical determinant of adolescent mental health (Helsen, Vollebergh, & Meesus, 2000) and parents who are getting peer support themselves may be better able to in turn provide support for their children. Because there is a gap in data on the experiences of parents who utilize online PSNs in relation to their children's mental health or substance use struggles, information from studies of PSNs for parents of disabled children might be a useful proxy in understanding the needs of parents seeking or involved with PSNs related to their children's mental health struggles or substance use.

## DEMOGRAPHICS

Between 2004 and 2010, it was estimated that three out of 1000 adults in the United States sought online peer support for mental health problems each year (DeAndrea & Anthony, 2013), with individuals with depression and/or psychological distress being over-represented among those seeking online peer support. This study found significant associations between seeking online peer support and college education, age being non-Hispanic white, and being female.

A more recent study of online peer support communities found that amongst 369 respondents, the mean age was 49, 85% were non-Hispanic white, and 77% were female (Merchant et al., 2022). Of this sample, 34% self-reported having depression, 25% self-reported having PTSD, and 20% self-reported anxiety-related conditions.

## ONLINE PEER SUPPORT USE AND THE COVID-19 PANDEMIC

This study by Merchant et al. (2022) also documented use of online peer support communities before and after the onset of the COVID-19 pandemic, and results demonstrated an increased utilization of online peer support communities on multiple levels: first, those accessing online support communities multiple times a day increased from 13% to 27% of the sample after March 2020. Second, there was a 50% increase in the number of respondents who accessed online support communities at least once per day (from 42% to 65%). Third, there was a 15% increase in the number of respondents who accessed online peer support communities at least once a week (from 80% to 92%) (Merchant et al., 2022). Of this survey sample, there was a positive association between frequency of use and self-reported benefit to mental health after adjusting for demographic factors.

Over the course of the COVID-19 pandemic, numerous mental health services have either pivoted to an online format, or were launched in response to the mental health crisis.

Others such as OPLM were committed to being an online community from the beginning, and found the COVID-19 pandemic reaffirming their mission to provide a virtual space for peer support. The global



mental health impact of the COVID-19 pandemic (Suresh, Alam, & Karkossa, 2021) has given rise to broader conversations around mental health, and the lack of accessible and effective options for accessing mental health support, especially as some in-person services have struggled to effectively move to an online-model. These circumstances have highlighted the utility of online-accessible mental health supports, and the need for more research to be done on the subject of online PSNs.

### Benefits of Online Support Communities:

Feeling less lonely, isolated or judged

Reducing distress, depression, anxiety or fatigue

Being able to talk openly and honestly about your feelings

Improving skills to cope with challenges

Staying motivated to manage the situation and/or stick to treatment plans

Gaining a sense of empowerment, control, or hope

Improving understanding of a situation and your own experience with it

More frequent or flexible participation

Opportunities for people who may not have local face-to-face support groups

A degree of privacy or anonymity

Source: <https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655>

# Barriers and Facilitators of Positive Peer Support Network Experiences

In studies of both moderated and unmoderated PSN interactions, a number of factors have been highlighted as either making for a positive experience with a PSN, or not.

Respondents to a survey on peer-support discussion boards identified positive personal change, supportive social interactions, and opportunities to express their feelings as some positive aspects of the online boards (Griffiths, Reynolds, & Vassallo, 2015). Some identified disadvantages were perceived disadvantages of board rules or moderation, unhelpful social interactions or contact with other members, and technical obstacles to using the board.

These results vary from other forms of online PSNs, given the differing structure of an online discussion board compared to virtual support group meetings, or other forms of peer support; however, many of these advantages and disadvantages are likely to overlap with moderated focus groups, particularly regarding technological barriers. While online PSNs have the benefit of being widely available geographically,

and being available at all hours of the day, this also means that a stable internet connection; access to a phone, computer, or tablet; and, in some cases, a private space to take meetings, might still be significant barriers to use. Likewise, relationships with moderators may also play an important role in whether an individual experiences a PSN as beneficial, with negative experiences with moderators making it feel harder to connect with the group, and positive experiences in turn allowing individuals to feel more comfortable participating in the space, which might contribute to a more positive experience with a PSN overall. Surveying members about their experiences with moderators might be one way of understanding how interactions with moderators factor into satisfaction with the PSN overall.

## OUTCOMES OF POSITIVE EXPERIENCES WITH ONLINE PEER SUPPORT NETWORKS

Understanding the effects of online PSNs on mental health is complicated by a lack of data (Eysenbach et al., 2014) available on the subject, particularly when it comes to moderated PSNs used by parents. Information on what makes for a beneficial experience with a PSN is largely known from limited surveys on the subject, and, when it comes to parents, much of the data relates to parents of disabled children. In comparison, there is shockingly little data on the experiences of parents of children struggling with mental illness or substance use. What is known from survey data concerning parents of disabled children can still be helpful in understanding the experiences more broadly of parents utilizing PSNs in relation to their children.

From survey research on online PSN use by parents of disabled children, data has been disaggregated to understand whether mothers and fathers perceive different benefits to participating in online PSNs (Niela-Vilén

et al., 2014). Mothers reported that online PSNs provided them with emotional support, information, and membership in a social community. Fathers also commented on the access to helpful information, as well as humorous communication with other fathers. Mothers were more likely to utilize online PSNs overall. Both mothers and fathers who utilized online PSNs also found them to be useful sources of informational support that were accessible regardless of geography or time constraints (Niela-Vilén et al., 2014).

Other studies of PSN use by parents of disabled children have found that shared experience is perceived as central to effective peer support, and for finding support in other aspects of online PSNs (Shilling et al., 2014). Participation in online PSNs enabled parents to learn from the experiences of others, speak freely in a safe and non-judgemental environment, and receive support and encouragement. Parents receiving support reported greater emotional stability, personal growth, and reduced isolation after engaging with online PSNs.

Parents acting as PSWs also reported positive outcomes from their participation in the PSNs in the form of mutual support and feeling like they were helping others, though there was potential of creating an emotional burden and time constraint for supporting parents if they in turn were not properly supported (Shilling et al., 2014).

## ONLINE PEER SUPPORT SERVICES IN COMBINATION WITH OTHER MENTAL HEALTH SERVICES

When understanding what factors tend to contribute to the most positive mental health outcomes for members of online PSNs, data suggests that utilizing online PSNs in combination with other mental health services seems to create a beneficial balance of peer support and more formal support. A systematic review of online peer support interventions for those struggling with a mental illness found that involvement in PSNs combined with evidence-based practice interventions resulted in statistically significant improvement in psychiatric symptoms (Fortuna et al., 2019). There is limited data available on the mental health impacts of those who utilize online PSNs without utilizing other mental health services, with outcomes differing between studies focused on social media, forums, or moderated PSNs. Overall, though, involvement in online PSNs in combination

with more formal mental healthcare interventions may provide the greatest level of support for individual struggles with mental illness or other stressors (Niela-Vilén et al., 2014).

Indeed, in a survey of individuals who utilize online PSNs, 81% of respondents expressed interest in accessing psychoeducational and mental health services via online peer support communities (Merchant et al., 2022). Further, engagement in online PSNs is associated with seeking formal mental healthcare after discussion with peers online (Naslund et al., 2016). In this way, involvement in online PSNs can help individuals to feel empowered and informed, and give them the confidence to make mental healthcare decisions.



# Other Parents Like Me (OPLM, LLC) and the Landscape of Online Peer Support Networks

Other Parents Like Me launched during the COVID-19 pandemic to address a critical gap in the online peer support landscape: providing an online platform and virtual community that is designed to create a safe space for parents of children struggling with mental illness or substance use.

As the COVID-19 pandemic has highlighted worsening global mental health, particularly amongst youth, the need for services that support parents' healing so that they might better support their children is essential. OPLM's mission is to give parents the support they need as they and their families move from crisis to healing. Recent research has highlighted aspects of online PSNs that can maximize benefit to community members, including having moderated sessions, associated support directories and informational resource libraries, and availability regardless of time zone and geography. This knowledge has informed the design of OPLM, which offers virtual peer support meetings on a variety of topics, early in the morning to late at night (allowing community members from around the country and in different time zones to meet and connect), and prioritizes the building of a resource library and support directory to provide community members with up-to-date information and access to additional forms of mental health support.

OPLM utilizes the Peer-Parent model to connect community members with peer support on a variety of topics in order to foster community support and connectedness. As a member of the online peer support landscape responding to an urgent need to support struggling parents, OPLM is committed to being informed by developing research on online PSNs, and guiding the company's future in alignment with emerging knowledge. An important part of this growth will involve surveying community members to routinely examine the efficacy of the peer support network, and identify areas where growth or additional support is needed. As OPLM and similar organizations grow alongside developing research, incorporating this new knowledge into organizational models will be critical in continuing to facilitate effective peer support online, and in eliminating as many barriers to access as possible.



# The Future of Online Peer Support Services

Online peer support networks provide the unique potential for creating spaces for mutual support that can be accessible regardless of geography or time zone, and involvement in online PSNs, particularly in combination with other mental health services, can help individuals to feel more supported, and less alone in their mental health journeys.

The utility of online mental health support services has been highlighted by the effects of the COVID-19 pandemic on mental health, for both youth and adults. For individuals seeking peer support for their own mental health concerns, or in relation to those of a loved one, peer support networks can provide community support and a space to be open about one's experiences around others who can relate.

As the mental health impacts of COVID-19 on youth become more well known, accessible mental health support services for youth and their families may become more essential than ever. Though online mental health services for youth struggling with a mental health issue or substance are improving and becoming better documented, support services for their parents are less common, as is research concerning them. The effect of social support from parents on youth mental health is well documented, and parents addressing their own mental health needs may be better able to support their children. This is where organizations like Other Parents Like Me come in.

The future of peer support for both youth and parents may see a more robust online community of peers looking to receive and provide support for one another; this future will likely also include online peer support networks that exist in partnership with more formal mental health services, or that have support directories and resource directories available for community members. Use of online peer support networks is steadily increasing, particularly in response to the COVID-19 pandemic, and more research is needed to understand the needs of online PSN community members, and what peer support networks can do to provide the most beneficial experience to members, as research and peer support networks grow together.

Other Parents Like Me is committed to responding to developing research and feedback from community members to provide the most effective space for parents of struggling youth to come together and move from crisis to healing, knowing that they are supported, seen, and that they are not alone.

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