



# The Case for Studying Peer Support in Pediatrics

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# The Case for Studying Peer Support in Pediatrics

## Introduction

1. Since the beginning of time, parents have wondered if they were “doing it right” when it comes to raising children.
2. They’ve been looking for people who’ve done it before to point them in the right direction.
3. For parents of children with special needs, finding people to ask who have similar experience is more difficult.



# Why do a literature review on peer support in pediatrics?

- There has been a great amount of research done on peer/caregiver support in the adult world of chronic illness.
  - Peers for Progress among other groups.
- While we believe many findings from those studies can inform pediatric peer support, we also believe there are some issues unique to pediatrics that those studies don't address.
- To build a solid foundation for peer support that can be measured, we need to know what has been done in the way of research in this field so that we:
  - Don't "re-invent the wheel."
  - Learn from and give credit to those who have already broken ground in this field.
  - Find common themes in what is being done.



# Methodology

- Multiple search engines
  - Pubmed, NIH, NIMH, Google, Facebook Groups, Wikipedia
- Multiple search terms
  - Peer support, Caregiver support, Parent support, Families of CYSHCN, Caregiver mental health
- Conducted 11 needs assessment interviews with advocates from disease states across neurology spectrum; assessed disease state peer support needs vs. community wide needs
- Conversations with People in the “Special Needs” community



## Specific Search Results

- PubMed/NIH Search

- Parent Support - >144,000 hits
- Caregiver Support – 33,514 hits
- Peer Support – 30,455 hits
- Caregiver Mental Health – 7,520 hits
- Families of CYSHCN – 13 hits

- NIMH Search

- Parent Support - 459 hits
- Peer Support - 315 hits
- Caregiver Support - 94 hits
- Caregiver Mental Health - 75 hits
- Families of CYSHCN - 0 hits



## Specific Search Results

- Google Search
  - Parent Support - 158,000,000 hits
  - Caregiver Support - 31,000,000 hits
  - Caregiver Mental Health - 26,000,000 hits
  - Families of CYSHCN - 221,000 hits
  - Peer Support - 72,000 hits
  
- While providing very little useful data, this search reflects the need for defining what we are talking about!



## Specific Search Results by Number

- Facebook Groups who offer support to families in either formal or informal ways number in the 100's.
  - Most groups are closed with a formal “acceptance process.”
  - All of the closed groups have a group gatekeeper who monitors page activity and conversation.
  - While the leaders can describe what they do in providing support, few have a formal definition or offer training to those providing support.



## Specific Search Results

- Wikipedia
  - “Peer Support” has a page with 1 paragraph on “special needs.” No reference to childhood conditions. Most of the contents related to addiction recovery or PTSD.
  - Categories that don’t have a Wikipedia page
    - “Caregiver Support”
    - “Caregiver Mental Health”
    - “Families of CYSHCN”
    - “CYSHCN”
- Wikipedia has a page on everything! To have nothing in these areas is telling.





# General Themes

- The case for Peer Support is well-documented for adults experiencing chronic illness.
  - A search for “peer support” in PubMed yielded:
    - >30,000 hits
    - When the word “pediatric” was added, >1,400 results
    - When “CYSHCN” was added, 0 results
- Peer Support is effective (Sokol, 2016):
  - Across health topics
  - For populations that are “hardly reached”
  - For populations who may struggle with low health literacy

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106(7), e1-e8. doi:10.2105/AJPH.2016.303180.



## General Themes

- Peer Support played a major role in reducing the feeling of isolation, commonly associated with anxiety and depression. (Fisher, 2015; Schilling, 2014; Sokol, 2016).
- Peer Support was found to be especially beneficial for three “hardly reached groups”. (Sokol & Fisher, 2016)
  1. Individuals with low health literacy, self-efficacy skills, and education levels.
  2. Individuals of lower socio-economic status.
  3. Individuals who have little social support or are isolated geographically.

Fisher, EB, Ballesteros, J, Bhushan, N, Coufal, MM, Kowitt, SD, McDonough, AM (2015). Key features of peer support in chronic disease prevention and management. *Health Affairs*, 34(9), 1523-1530. doi:10.1377/hlthaff.2015.0365

Shilling, V. et al. (2015). Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41(4), 537-546. doi:10.1111/cch.12222.

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106(7), e1-e8. doi:10.2105/AJPH.2016.303180.



## General Themes

- Qualitative studies generally reflect parents benefit from this type of support across conditions and the ways support is delivered.
- Qualitative evidence that does exist consistently suggests that parent to parent support is beneficial (Schilling, 2013).
  - 89% of parents receiving peer support found it helpful, but “helpful” is not defined.
- Quantitative studies provide inconsistent evidence of positive effects. (Schilling, 2015)
  - “The current lack of understanding can be attributed to a ‘no one size fits all’ approach to providing peer support and the strong emphasis on a family-centered design.”
  - “Identification of ‘gaps’ in our understanding yield opportunities for continued research.”

Shilling, V, et al. (2013). Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology*. 2013. 55, 602-609. Mac Keith Press.

Shilling, V. et al. (2015). Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41(4), 537-546. doi:10.1111/cch.12222





# Literature Review Findings



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## Methodology

- Schippke J, Provvidenza C, Kingsnorth S. (2017) reported these findings:
  - Four data bases searched – Medline, PsychINFO, Embase, CINAHL
  - Internet search of peer reviewed literature also performed.
  - Of 1,402 unique records identified, only **one** focused exclusively on peer support interventions for families of children with disabilities.

Schippke J, Provvidenza C, Kingsnorth S. (2017). Peer support for families of children with complex needs: Development and dissemination of a best practice toolkit. *Child Care Health Development*. 43(6);823-830. doi: 10.1111/cch.12494. Epub 2017 Jul 18.

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223

Shilling, V. et al. (2015). Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41(4), 537-546. doi:10.1111/cch.12222.



# Key Functions Found in Effective Peer Support in Adults (Sokol and Fisher, 2015)

- In a review of 14 additional studies, authors found that the content of Peer Support was more important to successful outcomes than who provides it.
- 4 Key Functions of Peer Support –
  - Assistance in daily life management
  - Social and emotional support
  - Linkage to clinical care and community resources
  - Ongoing support that reflects the lifelong nature of chronic disease
- When these 4 functions were present, **94%** of participants reported significant change favoring peer support.

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106(7), e1-e8. doi:10.2105/AJPH.2016.303180.



## Peers for Progress (Sokol and Fisher, 2016)

- Authors reviewed 47 studies attempting to measure the value of peer support.
- Per review, authors developed a definition of peer support:
  - “Emotional, social, and practical assistance provided by nonprofessionals to help people sustain health behaviors.”

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106(7), e1-e8. doi:10.2105/AJPH.2016.303180.



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## Insights into caregivers

- Studies consistently show that stress is higher for parents of children with disabilities (Gerstein, 2009).
- At the same time, some of these caregivers show greater resilience and an ability to thrive in the midst of these challenges.
- Characteristics of resilient caregivers (Luthar, 2003):
  - Psychological well-being
  - A supportive partner or intimate relationship
  - A positive parent-child relationship

Gerstein, et al. "Resilience and the course of daily parenting stress in families of young children with intellectual disabilities." Intellectual Disabilities Resource. December 2009; 53 (12); 981-997.

Luthar, S. Resilience and Vulnerability: Adaptation in the Context of Childhood Adversities. New York: Cambridge University Press; 2003.





# Peer Support for Caregivers of CYSHCN (Shilling, 2015)

- Author reviewed 17 papers
  - “There is ample evidence that parents of children with special needs are at risk of physical and psychological health problems, which are both pervasive and likely to worsen over time.”
  - “Recognizing the expertise of parents is a fundamental concept in family-centered services.”

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223

Shilling, V. et al. (2015). Peer support for parents of disabled children part 2: how organizational and process factors influenced shared experience in a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41(4), 537-546. doi:10.1111/cch.12222



## Peer Support for Caregivers of CYSHCN (Shilling, 2015)

- Subsequently, authors found these outcomes for parents receiving peer support:
  - **Reduced isolation** – having access to a parent who shares a similar life experience reduces the feeling of being alone.
  - **Emotional stability** – the opportunity to “offload” some of the emotional burden in a judgement-free zone was valuable in managing the ups and downs that come with CYSHCN.

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223



## Shilling 2015 Findings cont'd

- Common components found in successful peer support efforts (Schilling, 2015):
  - **Shared experience** was seen as a necessary component of peer support by all participating groups.
  - A **safe, supportive environment** that allowed parents to speak freely without fear of judgement.
  - **Continuity** – getting to speak with the same person over time – allowed trust to be built.
  - **Training** – equipped workers with fundamental skills and taught how to set appropriate boundaries.
    - The importance of these 2 areas (along with others) is also found in a study on the Parent Engagement and Empowerment Program (Rodriguez, et al. 2011).

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223



## Common Components, cont'd.

- **Mutual Support of Support Givers** – having opportunity to share experiences was not only beneficial to parents, but also for those offering support to families.
- **Ongoing Supervision** – to help offset the emotional burden of providing peer support, regular supervision to process experiences and their impact on the provider was seen as valuable in maintaining emotional well-being and preventing burnout.

Shilling, V. et al. (2015). Peer Support for parents of disabled children part 1: perceived outcomes of a one-to-one service, a qualitative study. *Child: Care, Health & Development*, 41 (4), 524-536. doi:10.1111/cch.12223



# Peer Support Interventions for Parents and Caregivers of Children with Complex Needs (Schippe J, Provvienza C, Kingsnorth S, 2017)

- Found that benefits of peer support include:
  - Emotional support and hope
  - Reduction of Isolation and stigma
  - Improved advocacy and self-efficacy
  - Information about specific disabilities
  - Practical ways to find and gain access to resources
    - Did not address the strategies for how to create these benefits in families.
- Supports the need for further study to determine effectiveness of various structures and strategies.

Schippe J, Provvienza C, Kingsnorth S. (2017). Peer support for families of children with complex needs: Development and dissemination of a best practice toolkit. *Child Care Health Development* 43(6);823-830. doi: 10.1111/cch.12494. Epub 2017 Jul 18.



# Parent Engagement and Empowerment Program (Rodriguez, et al. 2011)

- Mission: improve children's mental health in New York State.
- Program study targeted improving parent self-efficacy for caregivers of children with serious emotional needs.
- Train Family Peer Advocates (FPA)—
  - 40 hours of formal training
    - ❖ Training areas – listening, engagement, boundary setting, family empowerment, priority setting, specific disorders, mental health system
  - Bi-weekly consultation for 6 months following training
- FPA's focused on providing emotional support and assisting with service access issues.
- Outcomes reflected greater parent efficacy and empowerment.

Rodriguez, J, et al (2011). The Development and Evaluation of a Parent Empowerment Program for Family Peer Advocates. Child Family Studies. 20(4) 397-405. doi:10.1007/s10826-010-940504.



# “It’s a marathon, not a sprint” (Ryerson Espino SL, Kelly EH, Rivelli, A, Zebracki K, Vogel LC, 2017)

- Study of unmet needs and support preferences of caregivers of children with spinal cord injury (SCI)
- Looked at 2 types of stressors:
  1. Those associated with SCI
  2. Those associated with other areas of the caregiver’s life
- Families reported experiencing isolation and a desire for additional support from professionals and peers.
- Families receiving peer support reported less isolation and better communication with professionals.
- No strategies for producing these outcomes were listed.

Ryerson, E, Kelly E, Rivelli A, Zebracki K, (2017). Spinal Cord. 2018 Mar;56(3):284-294. doi: 10.1038/s41393-017-0022-6. Epub 2017 Nov 30.



## “Communication and Exchange of Specialized Health-Related Support Among People with Experiential Similarity on Facebook” (Gage-Bouchard EA, LaValley S, Mollica M, and Beaupin LK, 2017)

- Facebook offers people with similar experiences the ability to connect
- Support contained highly specialized health-related information
- Parents exchanged emotional support
- Found that the ability to connect with another person experiencing similar, rare circumstances overcame the absence of “face to face” interaction

Gage-Bouchard EA, LaValley S, Mollica, M, Beaupin LK (2017). Communication and Exchange of Specialized Health-Related Support Among People With Experiential Similarity on Facebook. *Health Communications*. 2017 Oct;32(10):1233-1240. doi: 10.1080/10410236.2016.1196518. Epub 2016 Aug 2.





## When peer support did not go well (Schilling, 2013)

- The family being offered support saw the provider as a “bad match.”
- The supporter struggled to maintain emotional separation.
- The supporter gave bad or outdated information.
- The supporter shared too much personal information – “over-sharing.”
- Lack of time – with limited resources, parents prioritize caring for their child over caring for themselves.

Shilling, V, et al. (2013). Peer support for parents of children with chronic disabling conditions: a systematic review of quantitative and qualitative studies. *Developmental Medicine & Child Neurology*. 2013. 55, 602-609. Mac Keith Press.





# Discussion



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# Conclusions worth consideration

- Peer support appears to be a way of improving health outcomes among groups that are hard to reach through conventional approaches (Fisher, 2015).
- In terms of reducing disparities and broadening the reach of health care, not only does peer support appear to be effective among those hardly reached, but evidence also indicates that it may be more effective among these groups (Sokol, 2016).

Fisher, EB, Ballesteros, J, Bhushan, N, Coufal, MM, Kowitt, SD, McDonough, AM (2015). Key features of peer support in chronic disease prevention and management. *Health Affairs*, 34(9), 1523-1530. doi:10.1377/hlthaff.2015.0365

Sokol, R, Fisher E. (2016). Peer support for the hardly reached: A systematic review. *American Journal of Public Health*, 106(7), e1-e8. doi:10.2105/AJPH.2016.303180.



## A word about Facebook Groups

- Facebook groups led by parents living the experience have become a popular resource for families.
- The leaders of these groups have worked diligently to go beyond the knowledge of just personal experience.
- However, anyone can start a group. And a young, unknowing parent may choose a resource based on the order it pops up in a Google search, not knowing what to look for in terms of quality.



# What's Next for Peer Support in Pediatrics

- While the stories we hear from caregivers and providers indicate value in this work, we need more than those stories for peer support to grow in credibility.
- We need a shared definition of peer support that allows for more effective scientific measurement.
- We need opportunities to measure the effectiveness of peer support and the specific elements that the data to date shows to be important.
- We need to develop formal training around these elements shown to be effective in supporting caregivers to better prepare those working in peer support and to support them in being seen as part of the professional team and not “just a parent.”
- We also need opportunities to measure peer support in the variety of settings that it is now offered – hospitals, primary care and specialty clinics, and virtually through online portals and social media platforms.
  - This would allow comparison of effectiveness in different environments.
  - This would allow for testing of different strategies for usefulness in different settings.



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## Resource

- Peer Support Toolkit is available free online at:
- [https://hollandbloorview.ca/Assets/Evidence%20to%20Care/Peer%20support%20toolkit/EtC\\_PeerSupport\\_Section1\\_FA.pdf](https://hollandbloorview.ca/Assets/Evidence%20to%20Care/Peer%20support%20toolkit/EtC_PeerSupport_Section1_FA.pdf)







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