# Developing a Statewide Peer Support Network for Individuals Who Are Blind or Low Vision

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**Abstract**

This article looks at experiences of setting up and maintaining peer support groups in two states with long-standing peer support networks for seniors who are blind or low vision (B/LV).

## Introduction

Vision loss often impacts an individual's daily living, psychosocial functioning, and emotional health. Research points to people who are blind or low vision (B/LV) experiencing social isolation resulting from a variety of factors. Isolation can lead to anxiety, concerns about the future, or depression (Horowitz et al., 2000). Adjusting to vision loss is a process that, when supported appropriately, can mediate potential negative impacts and create opportunities for psychological growth and social connection (Nyman et al., 2012).

Sanecki et al. (2021) explain that it is important for clients to have support networks in addition to their health and rehabilitation care providers. Many older adults face compounding challenges due to experiencing vision loss and aging. The Big Data Report found that individuals aged 65 and older with B/LV were about twice as likely to experience other health conditions than were individuals in the same age group without blindness or vision impairment (VisionServe Alliance, 2022). Additionally, a recent national survey found that rates of loneliness have increased among older adults from 2018 through 2023 (Institute for Healthcare Policy Innovation, 2023). Social distancing required during the COVID-19 pandemic may have contributed to feelings of isolation, making the topic of increasing opportunities for peer support more pertinent for individuals who are B/LV.

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Peer-focused programs can expand the individual's resources and networks of emotional support and help improve confidence in daily living skills. Individuals who are B/LV may benefit when they are connected with a peer who has shown resilience and adapted well to their vision impairment (Sanecki et al., 2021). Additionally, some evidence points to the effectiveness of social interventions in reducing social isolation and loneliness for older adults (Hoang et al., 2022; Jansson et al., 2018).

## Peer Group Models

The term peer support group can be defined differently, depending on the organization and the staff's perception of what peer support groups should include. A peer support group may be educational, social, skills-focused, or therapeutic, and in some cases, may incorporate aspects of more than one focus.

- An **educational support group** typically features a presentation from an outside presenter. Presentation topics may relate to vision impairment or blindness, or they may be a topic of interest to the group.
- Support groups that have a **social focus** often include a community outing or recreational activity.
- A support group with a **skills focus** will provide opportunities for hands-on learning and practice using adaptive strategies.
- The **therapeutic support group** provides an opportunity for participants to share feelings and experiences related to their visual condition.

In addition to the various focuses a group might incorporate, the group may be led by a professional from a sponsoring organization or by one of the members of the group who is themselves B/LV. Since support groups for individuals who are B/LV naturally include others with vision impairments, peer support occurs between the group participants. However, some may consider only groups led by peers to be peer support groups. Additionally, the professional leading the group may be B/LV, filling both the roles of professional and peer. There is no evidence to tell us if one of these models or focuses is most effective. Anecdotal feedback suggests that each model can be beneficial.

## Barriers

Despite the benefits of peer support groups for individuals who are blind or low vision, many agencies do not intentionally develop or maintain a network of peer support groups. In some areas, a professional may have a passion for peer support groups and start one or more, but most times, it is not part of an organized effort by the agency. When asked why programs do not have an organized plan for peer

support groups, several barriers are frequently mentioned: challenges with transportation for participants to attend the group (Harshbarger, 1980; Nyman et al., 2012; Sanecki et al., 2021; Winer, 1982), identification of qualified peers to lead a group (Winer, 1982), and the time required for training of volunteer leaders and regular check-ins to maintain their continued commitment (Sanecki et al., 2021; Winer, 1982). Additionally, barriers may include the perceptions by professionals that starting and maintaining a peer support group is time-consuming and dependent on volunteer peer leaders who may encounter health or other difficulties, which may impact their ability to sustain their leadership commitment. Even when an agency makes a concerted effort to start groups, that effort is not always maintained.

Noting these various challenges, two programs were identified that serve individuals 55 and older who are B/LV. These programs have maintained state-wide peer support group networks over many years. Key personnel from these programs were interviewed to learn what procedures and supports they use to keep their peer support networks thriving.

## Georgia

Project Independence, Georgia's program serving individuals 55 and older who are B/LV, has maintained a network of more than 25 active peer support groups. According to the Project Independence program manager (personal communication, October 28, 2021), who is employed half-time to oversee services provided to those 55 and older in Georgia, the idea for the peer support group network started with one group led by a peer volunteer. After observing the success of this one group, the program manager had the six agencies who contracted Project Independence services each identify one to two consumers to participate in a 3-day training. Project Independence partnered with a disability rights and peer support group advocate at a local center for independent living (CIL) to provide the training. Project Independence covered the cost of the training as well as travel, hotel, and food for the training. Since the pandemic, this training is provided virtually at a cost of $350 per participant (personal communication, March 19, 2024). After these initial groups started, Project Independence found that additional peers were also interested in starting groups. Interested leaders were asked to identify a meeting place for their group, recruit participants for the group, talk with other active leaders to learn about the role, and attend other support groups to observe. New leaders were sent to the 3-day training. Completing these prerequisites ensured that interested leaders had the time and ability to lead a group.

Leaders who completed the training were identified as "certified." Existing peer support groups were brought into the network, and their leaders, both sighted and vision

impaired, were included in Project Independence's ongoing communication and trainings. Biannual in-person trainings were set up for leaders. During the pandemic, the ongoing trainings were held virtually for two hours each quarter. The program manager collected information about community activities, disability information, and free training opportunities; they regularly sent this list to the peer support network. Project Independence's program manager credits this cross-agency collaboration and ongoing training and support as an important factor in Georgia's success in growing and maintaining support groups. Other organization support groups included the local chapters of the American Council for the Blind, the National Federation of the Blind, and the Veterans Administration.

The peer groups set up by Project Independence were varied in format. One group leader (personal communication, December 6, 2022) shared that her group met for 90 minutes monthly. The first part of the meeting was a check-in time, allowing participants to share about how things were going with them. The second half of the meeting was a presentation, either by the group leader or by an invited presenter. The leader stated that she always provided resources about upcoming events and information of interest.

Early in the peer group network development process, it was decided to offer peer leaders a small honorarium. The original peer group leader purchased snacks for the group out of her own money, and it was hoped that other leaders could have the flexibility to do the same if this token amount was provided. Although an honorarium of $100 per monthly meeting was available, after a time, most of the peer leaders no longer requested it.

## New Jersey

The peer support group network in New Jersey has a long history dating back to the 1980s. In 2005, the person interviewed for this article (personal communication, March 1, 2022), began coordinating peer support groups for individuals who were B/LV through a CIL. The support groups she coordinated were in central and northern New Jersey. With funding changes, the staff working with the support groups were eliminated at the CIL. The interviewee reported that she encouraged peer group leaders to continue meeting. After several years of advocating for the peer support groups, the interviewee was hired by the New Jersey Commission for the Blind to again work with the support groups. In this position, as a full-time social worker, she oversees the more than 50 groups that meet throughout the state of New Jersey. The network of peer support groups is called ASPIRE, standing for Assistive Support Programs for Independence Renewal and Education. The interviewee asserted that support groups backed by the Commission for the Blind would

keep the support groups focused on topics relevant to adjustment to blindness and low vision.

The social worker identifies regional areas for new groups and may include the new leader in helping locate the meeting space. She prefers peer support group leaders to be B/LV due to the shared lived experience with group members. In some cases, such as at assisted living facilities, the leader is a social worker from the facility and is more likely to be sighted. In some cases, the leader identifies a group participant and makes them a co-leader. However, even in cases with a sighted group leader, the social worker noted there can be significant benefits as group members share their compensatory strategies with one another.

After an interview to assess the appropriateness of an individual as a group leader and informing them of the responsibilities, the new leaders are provided a short document entitled "Role of a Group Facilitator." The social worker also regularly attends meetings to support the new leader. She encourages new leaders to call interested individuals to build relationships with them. This usually results in getting new individuals to start attending the group. The interviewee pointed out that although peer support leaders may be unsure at first, they often gain confidence as they learn to facilitate the group. Two ongoing trainings are provided each year for all group facilitators. Since the pandemic, these trainings are now virtual, which the social worker reports are easier to facilitate, preferred by group leaders, and less costly to the Commission.

The ASPIRE groups are each unique, so new referrals are matched with a group that is the best fit for the consumer's life situation, such as age or employment status. Many peer support group leaders invite speakers to present on various topics selected by the facilitator. The interviewee also discussed that many of the groups still meet virtually, but she believes the in-person meetings are more beneficial. For example, group participants are responsible for their transportation to attend the group. This practice in travel, along with group interactions, often has a significant impact on the confidence of participants.

## Discussion

Despite the various focuses and formats of peer support groups, the key element seems to be introducing individuals who are B/LV to each other. The disability of blindness or low vision is low incidence, resulting in affected individuals rarely meeting each other without an intentional meeting. Project Independence and ASPIRE used similar strategies to start and maintain peer support groups within their states. Potential leaders were identified and screened, with both groups asking the potential leader to participate in group setup and training to demonstrate their

ability and commitment. Both states provide ongoing support and training for peer leaders. Regularly bringing the peer leaders together demonstrates that the program values the peer leaders' efforts, provides an opportunity for networking among peer leaders, and stimulates growth in leadership and fresh ideas that can benefit their groups. It is noteworthy that, despite the initial training for peer leaders being very different—Project Independence provides a formalized training while ASPIRE uses individualized mentoring—both peer support group networks have connections to the methodology used by CILs.

## Conclusion

Peer support groups for individuals who are B/LV have been recognized as beneficial across many decades when provided in various formats and held in a variety of locations (rural, urban, virtual, etc.). Although many programs that serve individuals 55 and older with B/LV have limited resources, these two programs, Project Independence and ASPIRE, have demonstrated that intentional guidance and training can result in a thriving peer support group network. On-going training seemed to be an essential common thread that kept the two networks strong. Additionally, initial training and support were needed to set the new groups on a successful trajectory. More research is needed to identify best practices for group format, inclusion of family members, group size, essential training and support needed, and desired qualities for group leaders.

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