



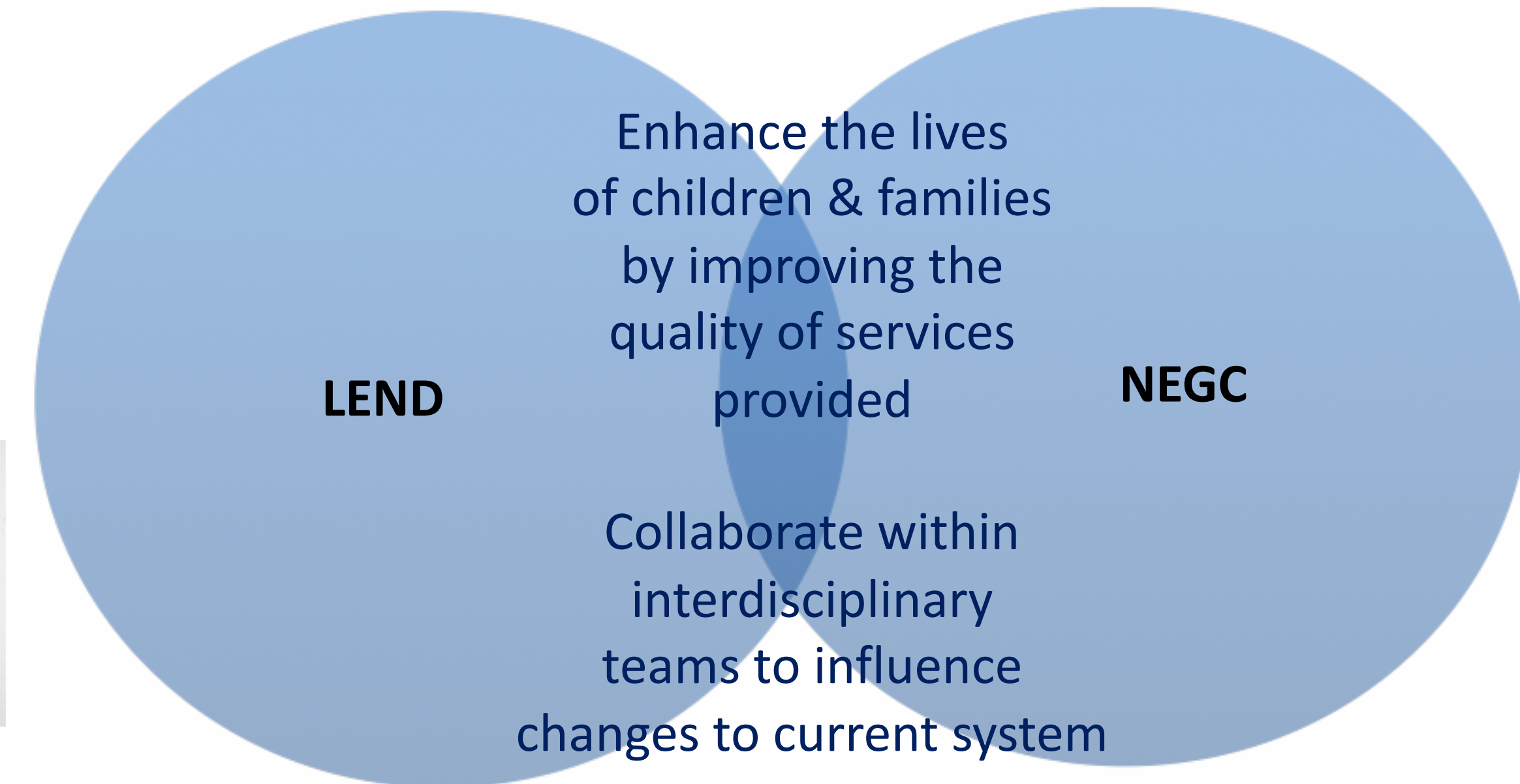
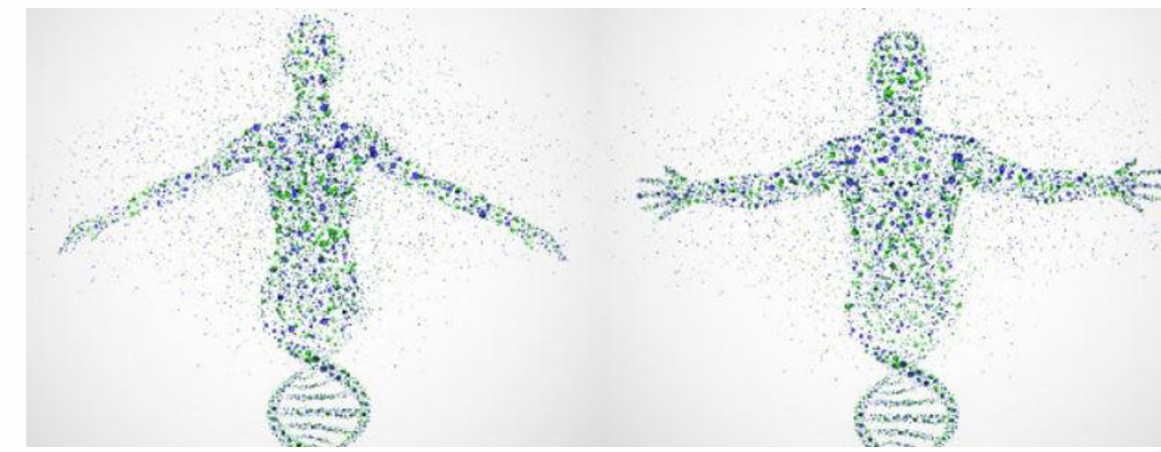
Raven Vigars, MS OTR/L

### Background:

The NEGC focuses on improving the health and social well-being of those with inherited conditions through various means of collaboration. Stakeholders involved include public health professionals, private health professionals, educators, consumers, and advocates across New England. Together they work to create opportunities for individuals with genetic conditions to reach their fullest potential.

### The goal of the stakeholder survey:

- ❖ Provide an overview of stakeholders' perceptions of the NEGC's progress over the year
- ❖ Identify organizational needs to improve quality of services
- ❖ Discuss recommendations made by stakeholders to achieve the NEGC's mission and vision



### Results:

- ❖ 150 email invitations were sent out between February 2016 and March 2016 to stakeholders of the NEGC
- ❖ 43 provided responses (28% response rate)

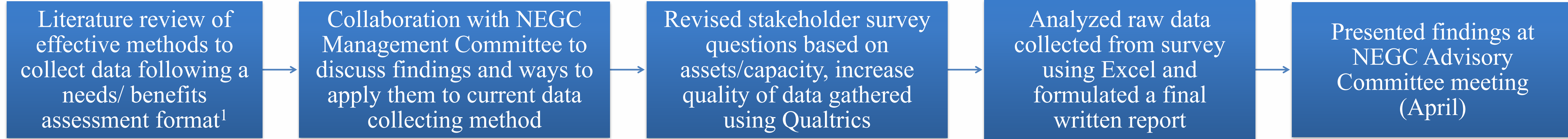
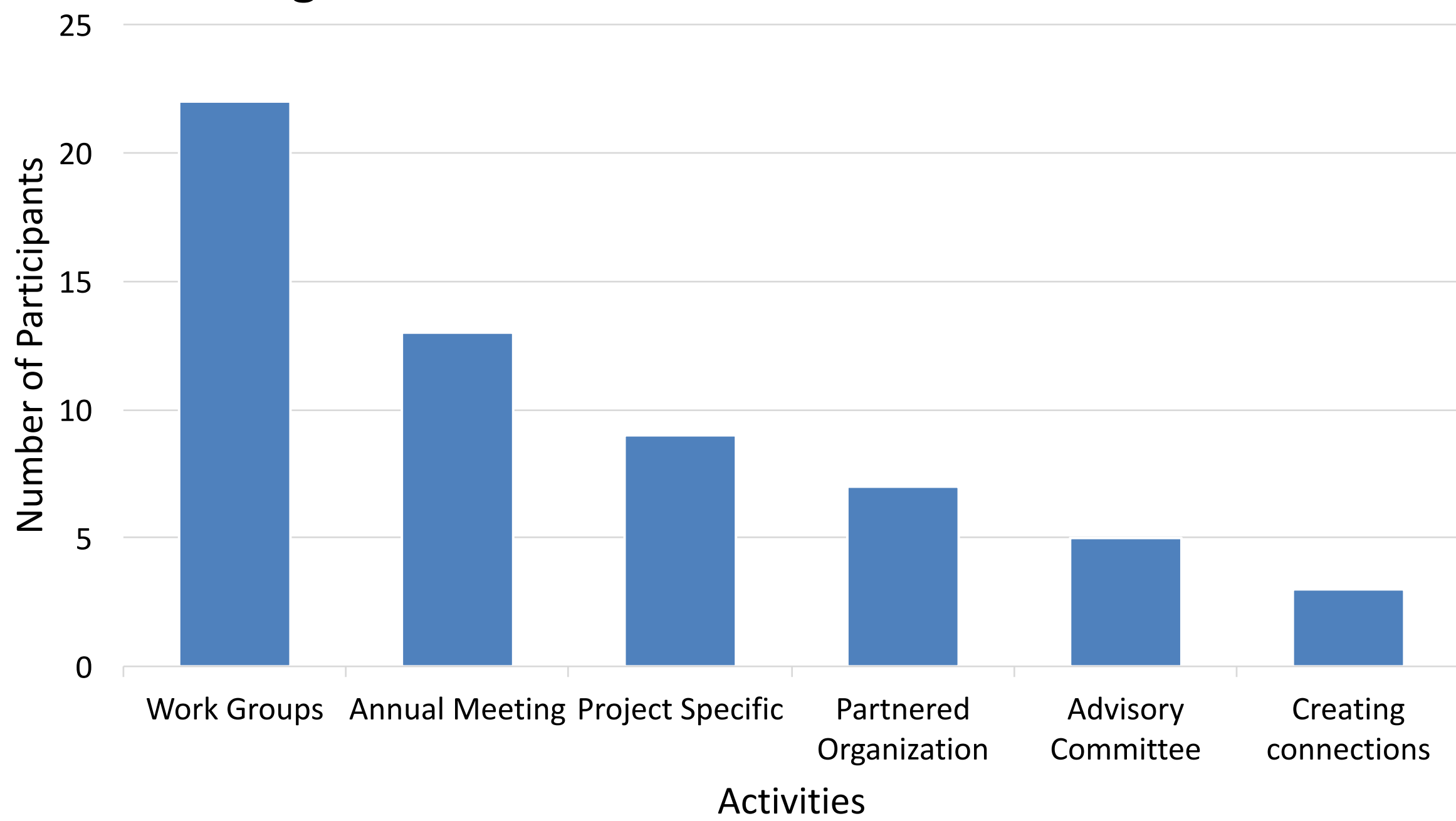


Figure 1: Members' Involvement in the NEGC



### Recommendations for Follow Up:

- Effectivity of answering questions → directing towards additional resources, connecting with other stakeholders, videos on website
- New topics: Disseminating information to specific audiences, connect families (support group), state advocacy → podcasts
- Continue to promote familiarity with mission statement → short videos/ podcasts regarding current projects/ activities
- Improve outreach to new members → introductory/ welcome packet
- Low response rate to survey → survey, meetings within workgroups/ advisory, incentives

### Leadership Takeaways:

*“The saying “it takes a village” resonates well with my experience working with the NEGC and my personal experience as a paraprofessional. No single person can make a difference, you need many voices to create an impact. The NEGC stakeholder survey gave me the opportunity to hear the many voices supporting the organization and understand the various perspectives represented. As a leader, this experience encouraged me to represent the views of others in reaching a shared vision by compiling stakeholders’ view points and presenting them to organizational leaders to enact change. I learned to be concise and informative with my reports and embrace feedback as a way to enhance my effectiveness as an active team member.”-Raven Vigars*

1. Source: Altschuld, J. W., Hung, H. (., & Lee, Y. (2014). Needs Assessment and Asset/Capacity Building: A Promising Development in Practice. New Directions for Evaluation, 2014(144), 89-103. doi:10.1002/ev.20105.