Evaluation of The Arc of Pennsylvania's Initiative to Address COVID-19 Disparities
among People with Disabilities

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## **Executive Summary**

During the COVID-19 pandemic, individuals with disabilities in Pennsylvania experienced mental and physical health issues, lack of access to vaccination and testing sites, improper staff support, financial insecurity, and cultural or linguistic barriers. The Pennsylvania Department of Health aimed to address the disparities related to COVID-19 among Pennsylvanians living with disabilities by funding The Arc of Pennsylvania (The Arc of PA). The Arc of PA is an advocacy organization that serves individuals with intellectual and developmental disabilities via statewide program implementation of healthcare initiatives, policy analysis, grassroots advocacy, and other crucial services. It represents over 8,000 members through 33 local chapters. The Arc of PA focused on Strategy 3: Build infrastructure support and Strategy 4: Mobilize partners and collaborators. Subsequently, The Arc of PA established a Statewide Task Force (SWTF) and 13 Regional Community Workgroups (RCWGs) to raise awareness of health disparities related to COVID-19 in the disability community, develop strategies for multi-sectoral alignment, and build capacity to address such issues.

The Research & Evaluation Group at Public Health Management Corporation (PHMC), in collaboration with the National Network of Public Health Institutes (NNPHI), evaluated The Arc of PA's SWTF and the RCWG efforts. The Arc of PA placed this partnership initiative within Strategy 3. Focusing Strategy 3, PHMC conducted an evaluation with quantitative and qualitative methods, including five interviews with SWTF members, four with RCWG leaders, four with RCWG members, and one focus group with three staff from The Arc of PA, and secondary analyses of programmatic documents to answer the following questions:

- 1. How effective was the initiative in developing new and strengthening existing partnerships?
- 2. To what extent did multi-sectoral collaborations a) contribute to perceived increase of the public's awareness of COVID-19 disparities in the disability community and b) increase partners' capacity to address these disparities?
- 3. What contextual factors, including barriers and facilitators, did The Arc of PA experience in establishing new partnerships and bolstering existing partnerships?
- 4. How did Arc of PA implement and modify its efforts and products to fit accessibility standards, audience needs, and setting?

This evaluation revealed that the partnership initiative was effective in developing new and strengthening relationships across diverse sectors, locally and statewide. Three-quarters of RCWG members and 45% of SWTF members were new partnerships that The Arc of PA developed through this initiative. The partnership initiative involved multiple sectors, including nonprofits, healthcare, government, and education. Furthermore, interview participants reported that the partnership initiative operated effectively at both local and state levels and shared that increasing the diversity of members included in the partnership initiative helped to break down silos and merge local disability advocacy networks.

The evaluation also showed that there were several impacts of the partnership initiative. Interview participants reported their understanding of disability issues and disparities, resources, and networks grew. Participants also shared that in building new relationships through the partnership, they had expanded networks to call upon when navigating healthcare access barriers. Participants reported

disseminating initiative products with their vast networks, which has the potential to impact community awareness of available COVID-19 resources for individuals with disabilities. Participants also described various changes in their practices, which focused on improving health and accessibility of their services. Finally, some partners shared the perception that this initiative contributes to increased readiness to address health disparities in the disability community.

Participants identified key procedural and cultural facilitators that led to the success of the partnership initiative. These facilitators included professional facilitation and organization, meeting accessibility, and a collaborative culture of respect and trust in partnership meetings. Consistent engagement was the biggest barrier to the partnership initiative. To encourage participation in the partnership initiative, The Arc of PA implemented various accommodations, such as flexible meeting times, sharing materials and meeting schedules in advance, and providing ASL interpreters and closed captions during Zoom meetings. Furthermore, The Arc of PA applied multiple modifications to its products (e.g., *Barriers* and *Recommendations* reports) to increase accessibility to a wide array of audiences. These modifications included offering reports in multiple languages, including Braille, offering plain language versions, using person first language, and including mixed mediums (e.g. written, video, and pictures).

The results of this evaluation help to establish best practices of high-achieving partnerships that focus on improving health outcomes and reducing disparities in the disability community. These results can also inform approaches to advancing preparedness in the disability community in the event of future health emergencies.

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#### Introduction

#### Background

The Centers for Disease Control and Prevention's (CDC) National Center for State, Tribal, Local, and Territorial Public Health Infrastructure and Workforce (Public Health Infrastructure Center) awarded funding to 108 health departments as part of the National Initiative to Address COVID-19 Health Disparities Among Populations at High-Risk and Underserved, Including Racial and Ethnic Minority Populations and Rural Communities. The National Network of Public Health Institutes (NNPHI), in partnership with CDC, collaborated with OT21-2103 grant recipients to conduct evaluation studies of novel or emerging practice (NEPS) activities within the funding's grant strategy areas. The OT21-2103 four strategy areas are COVID-19 mitigation, data collection and reporting, infrastructure support, and mobilizing community partnerships. These evaluations have been led by contracted evaluation partners and overseen by NNPHI and CDC.

The purpose of the NEPS evaluation studies is to understand and build evidence for novel and emerging practices implemented under the OT21-2103 grant strategies and disseminate these findings to improve capacity and services that address health disparities related to COVID-19. The OT21-2103 recipients who volunteered to participate in NEPS have been identified as implementing either novel or emerging practices based on operational definitions of best, promising, emerging, and novel practices created in the development of the online repository of COVID-19 best practices with CDC during the project's first year. The NEPS evaluation studies employ the RE-AIM framework, focusing on the Effectiveness and Implementation of RE-AIM dimensions to enhance the knowledge base regarding novel approaches to decrease COVID-19 disparities and increase health equity.

The Pennsylvania Department of Health (PA DOH) is a recipient of the OT21-2103 grant. PA DOH is a cabinet-level government agency in Pennsylvania that aims to promote healthy behaviors, prevent injury and disease, and assure the safe delivery of quality healthcare for all people in Pennsylvania."¹ For the OT21-2103 grant, PA DOH awarded funds to The Arc of Pennsylvania (The Arc of PA). The Arc of PA, the Commonwealth's expert in the disability field, is an advocacy organization that serves individuals with intellectual and developmental disabilities (IDD) across racial, ethnic, and geographic populations. It represents over 8,000 members through 33 local chapters. The Arc of PA implements statewide healthcare initiatives, provides crucial services, and conducts policy analysis and advocacy to address disparities among Pennsylvanians living with disabilities.

Given the OT21-2103 goal of reducing disparities associated with COVID-19, PA DOH was focused on serving the most vulnerable communities, particularly individuals with disabilities. Individuals with intellectual disabilities were 2.5 times more likely to contract COVID-19 and 5.9 times more likely to die from the infection when compared to the general population.<sup>2</sup> In Pennsylvania, during January and August 2020 of the COVID-19 pandemic, individuals with disabilities, particularly those from historically marginalized and rural communities, face heightened inequities, including lack of access to vaccination and testing sites, improper staff support, financial insecurity, and cultural or linguistic barriers to care due to the COVID-19 pandemic.<sup>3</sup> In order to address disparities related to COVID-19 among Pennsylvanians living with disabilities, PA DOH funded The Arc of PA to bring together disability and healthcare provider stakeholders at the local and state levels, develop an education campaign, and create disability-specific recommendations for PA DOH's COVID-19 Health Equity Response Team.

#### **Evaluation Purpose**

The Arc of PA focused on Strategies 3 and 4 of the OT21-2103 grant, including Strategy 3: Build, leverage, and expand infrastructure support and Strategy 4: Mobilize partners and collaborators. This evaluation focuses on Strategy 3. The purpose of this evaluation is to assess how partnerships were implemented to build capacity for improved health outcomes among individuals with disabilities and how effective those partnerships were in building capacity. Arc of PA implemented Strategy 3 by establishing and expanding state and regional partnerships to raise awareness of health disparities and gaps related to COVID-19 in the disability community, develop strategies, and build capacity to address such issues. The Arc of PA's intended goals of this partnership initiative were to 1) shed light on the health disparities facing the disability community, particularly during public health emergencies, 2) bridge the gap between healthcare providers and the disability community, and 3) ensure that in future emergencies, information is accessible and reflects the disability community.

## Description of Practice

The Arc of Pennsylvania is a statewide nonprofit advocacy organization that promotes the human rights of people with intellectual and developmental disabilities and supports their inclusion and participation in their community. The Arc of Pennsylvania comprises 33 local chapters and represents more than 8,000 members (demographic information of its members is unavailable). The Arc of PA's innovative practice centers on leveraging partnerships to improve health equity in the disability community (referred to as "partnership initiative"). To this end, The Arc of PA established a Statewide Task Force (SWTF) and 13 Regional Community Work Groups (RCWGs) to increase awareness of the COVID-19 barriers the disability communities face at the state and local levels and to identify potential solutions and best practices for future emergencies. This evaluation focuses on the partnership initiative. The partnership initiative is described in detail on pg. 8. In addition to establishing and maintaining the SWTF and the RCWGs, other key activities included Listening Tours, public reports, and a media campaign. These activities are detailed below and are referenced throughout the report. An initiative timeline is depicted in Figure 1.1.

- Listening Tours: sessions in which SWTF and RCWG members collected qualitative data from
  impacted community members about the challenges they experienced accessing healthcare
  and social services during the COVID-19 pandemic, the strengths of the community and
  systems that serve them, and solutions for improved outcomes. Content from the Listening
  Tours was integral to the Barriers and Recommendations<sup>4</sup> reports and was used to inform
  and guide discussions in the SWTF and RCWG meetings.
- Publicly facing key reports and accompanying fact sheets: The Arc of PA and the SWTF created the following reports which were informed by the RWCG and the Listening Tours- 1) the Barriers<sup>3</sup> report, which sheds light on the challenges the disability community faced during the COVID-19 pandemic, and 2) the Recommendations report, which identifies key recommendations for PA DOH.
- Media campaign: The Arc of PA developed and administered a media campaign to promote COVID-19 services and resources via digital and radio advertisements. The campaign featured individuals with disabilities and targeted the disability community and communitybased service providers in Pennsylvania. The messages focused on dispelling COVID-19 myths, building trust, and communicating information on testing and vaccination in English and Spanish. Figure 1.2 shows examples of the digital advertisements.

Figure 1.1 Initiative Timeline

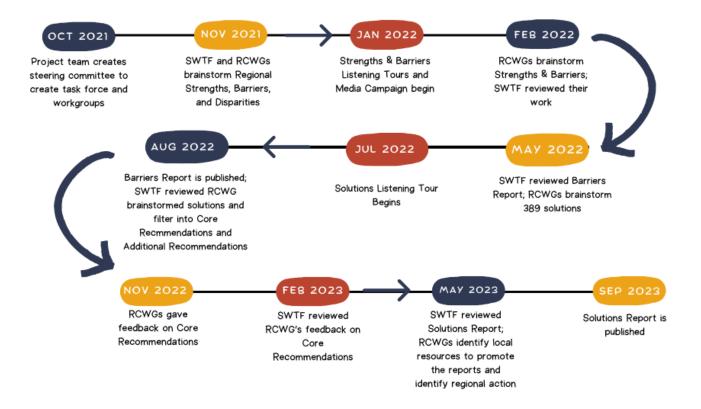


Figure 1.2 Media Campaign Advertisement Examples





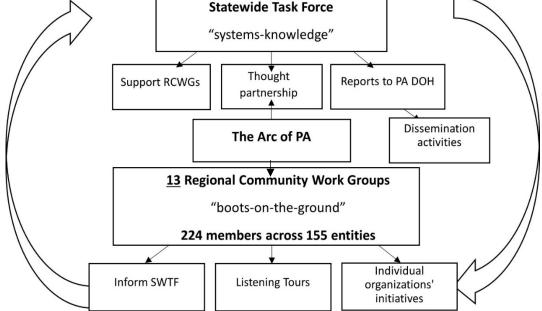
For the partnership initiative, The Arc of PA created a steering committee to initiate the SWTF and RCWGs and to outline clear guidelines and responsibilities for each entity. The Arc of PA served as the conduit between the two entities and ensured they were working in concert. The Arc of PA and SWTF members worked together to recruit additional individuals to the SWTF. Ten different Arc chapters managed 13 RCWGs. RCWG leaders were responsible for recruiting members to their individual workgroups. The Arc of PA hired a professional facilitator for the SWTF and supported the RCWGs with a "train the trainer" approach to facilitation and other resources, including a robust compendium of organizations from which to recruit.

The SWTF was predominantly made up of statewide entities, such as provider associations and hospital and education enterprises with expertise in systems and policy. The SWTF was charged with: 1) identifying disparities, inequities, and best practices impacting the disability community throughout the COVID-19 pandemic, 2) developing solutions for the current pandemic and future health emergencies, and 3) producing reports on barriers and recommendations and disseminating them to the Pennsylvania Department of Health and other policymakers. The RCWGs were typically comprised of local government agencies, non-profit, organizations, and health care providers that serve the disability community. RCWG members have expertise in direct service and local community experience. The RCWGs were responsible for: 1) conducting regional listening tours to identify local disparities and gaps in services related to COVID-19 in local disability communities, 2) providing recommendations to the SWTF, and 3) developing local strategies to increase equitable access to COVID-19-related services and mitigation efforts. While there is overlap and distinction in the activities each entity undertook, the SWTF and the RCWGs work in concert, their activities building off each other's. For example, the SWTF used RCWG-identified recommendations to inform Core Recommendations for the report to PA DOH.

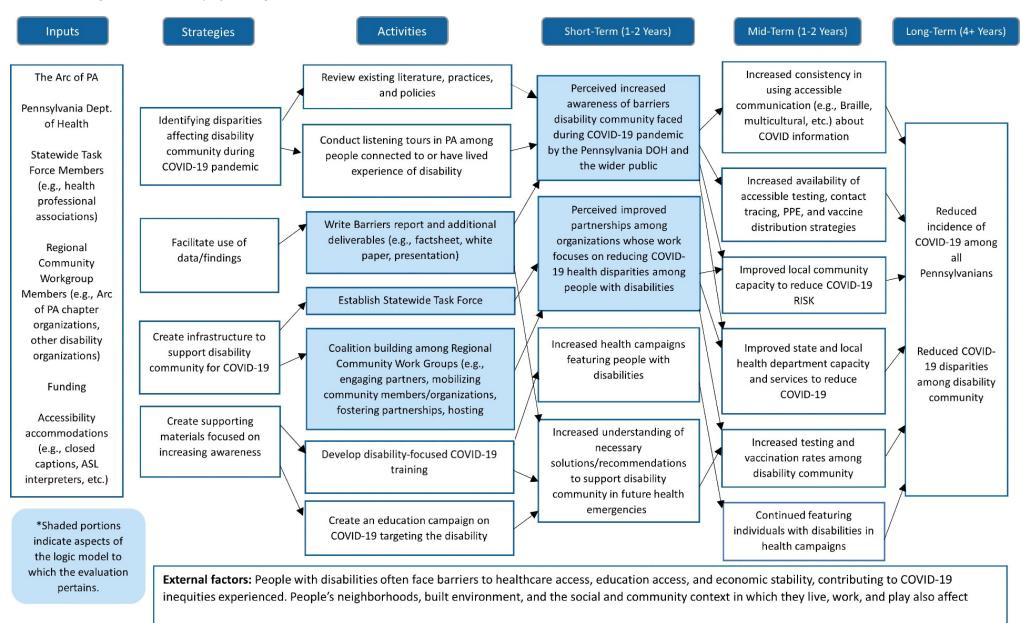
Figure 1.3 depicts the partnerships in the initiative, the main activities of each entity, and the relationship between them. The Arc of PA is positioned in the middle of the diagram as the mediating organization between the SWTF and RCWGs. The boxes beneath the SWTF and RCWGs reflect their primary activities. The two large arrows on the sides of the entire image signify that the SWTF and RCWGs worked in tandem, their activities informing each other's.

Figure 1.3 Structure of The Arc of PA Partnership to Reduce Health Disparities in the Disability Community

Statewide Task Force



### Logic Model/Theory of Change



## **Evaluation Design**

Primary and Secondary Evaluation Question(s)

PHMC collaborated with The Arc of PA to identify evaluation questions, aligning with the RE-AIM framework. The Arc of PA was interested in evaluating their partnership initiative, particularly in learning what worked well, the impact of the partnership initiative, and what can help other entities better serve the disability community. PHMC also reviewed The Arc of PA's existing documents to identify the short-term outcomes that could be assessed in the evaluation (see Logic Model). Next, The Arc of PA and PHMC jointly agreed upon assessing how the partnerships were implemented to build capacity for improved health outcomes among individuals with disabilities and how effective those partnerships were in building capacity. The effectiveness questions align with select short-term outcomes; the implementation questions align with understanding how the partnerships were developed and sustained. Each evaluation question, as shown below in Table 1.1, contains two to four sub-questions.

Table 1.1 Primary and Secondary Evaluation Questions

Primary Evaluation Questions	Secondary Evaluation Questions
Effectiveness Q1: How effective was the initiative in developing new and strengthening existing partnerships?	<ul> <li>How many new and existing partners were involved in the initiative?</li> <li>How diverse was the membership (with respect to various characteristics, such as sectors, geography, populations served, types of service, etc.) because of The Arc of PA's strategy?</li> <li>To what extent were partner organizations engaged in the initiative?</li> </ul>
Effectiveness Q2: To what extent did multi-sectoral collaborations a) contribute to perceived increase of the public's awareness of COVID-19 disparities in the disability community and b) increase partners' capacity to address these disparities?	<ul> <li>To what extent did partners disseminate products from the initiative, and what was the potential reach of those dissemination efforts?</li> <li>To what extent was there a perceived increase in the community-at-large's awareness of disparities related to COVID-19 among individuals living with disabilities?</li> <li>In what ways did the partners' capacity to address exposed disparities in the disability community increase?</li> </ul>
Implementation Q1: What contextual factors, including barriers and facilitators, did The Arc of PA experience in establishing new partnerships and in bolstering existing partnerships?	<ul> <li>How did The Arc of PA define success in partnerships?</li> <li>What factors (promoting, inhibiting, and contextual) impacted partnerships, and in what ways?</li> </ul>
Implementation Q2: How did The Arc of PA implement and modify its efforts and products to fit accessibility standards (e.g., closed captioning, representative images, etc.), audience needs (e.g., language, medium, etc.), and setting (e.g., partners' culture, sector, etc.)?	<ul> <li>How did The Arc of PA engage and sustain new and existing partners, and to what extent did their strategy vary based on the partnering organization?</li> <li>How did The Arc of PA modify its efforts to meet accessibility standards and audience needs?</li> </ul>

#### **Evaluation Methods**

This evaluation involved collecting and analyzing primary, qualitative data and examining secondary data via document review. PHMC conducted five interviews with SWTF members, four with RCWG leaders, four with RCWG members, and one focus group with three staff from The Arc of PA. These interviews explored how the partnerships were formed, implemented, and sustained, as well as the impacts of these partnerships, with respect to perceived increase in community awareness of COVID-19 disparities among the disability community and increased capacity to address these disparities. Additionally, PHMC reviewed the following programmatic documents: attendance logs for 13 meetings (Appendix I), six records of SWTF meeting minutes, eight progress reports and organization initiative reports, and 12 impression and click reports (Appendix J). Furthermore, PHMC conducted an accessibility review of The Arc of PA's key initiative reports (Appendix K) and an online organization scan to understand SWTF and RCWG partners' characteristics, such as target population, sector, and geography (Appendices G and H). The programmatic documents offered data on the implementation and effectiveness of the partnership initiative. A timeline of the evaluation can be found in Appendix A.

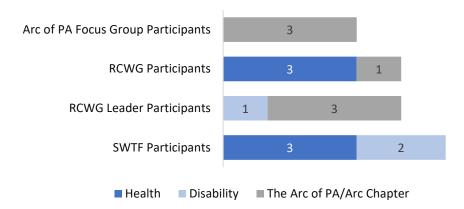
The Arc of PA and PHMC collaborated throughout the various stages of the evaluation. The Arc of PA described what they wanted to learn from the evaluation, and PHMC worked to align that aspiration with the RE-AIM framework, outcomes that could be observed, and the partners' resources and capacity. The Arc of PA provided secondary data documents and answered questions as they arose. PHMC created the interview guides, which The Arc of PA reviewed. The recruitment strategy, another collaborative effort, is described below. The Arc of PA reviewed this evaluation report as well.

### Participant Recruitment & Criteria

Throughout this evaluation report, interview participants and focus group participants are referred to as "participants." The term "members" refers to all members of the SWTF and RCWGs. The Arc of PA collaborated with PHMC to use purposive sampling to identify potential participants. The Arc of PA created a list of potential participants, stratified according to group affiliation, role, and whether they had lived experience with a disability. PHMC recommended that participants range in organizational characteristics and initiative engagement levels to capture diversity in experience. The Arc of PA then ranked their preferred candidates to interview and offered alternates in case those were unavailable to participate. Selected participants were those identified by The Arc of PA, who responded to PHMC's recruitment efforts, and who were available and interested in participating in the interviews.

PHMC conducted interviews and focus groups with 16 total participants, including five interviews with SWTF members, four with RCWG leaders, four with RCWG members, and one focus group with three staff from The Arc of PA. Figure 1.4 depicts the sector makeup of the interview and focus group participants, which shows that the health and disability sectors were represented in the interviews. Additionally, 12 of the 16 participants reported whether they had lived experience with disabilities, and among those 12 individuals, 4 shared that they had this lived experience.

Figure 1.4 Number of Interview and Focus Group Participants in Health, Disability, and Arc Sectors



Description of Data Collection Tools, Indicators, or Artifacts

Four interview guides were created to collect perspectives from The Arc of PA members, SWTF members, RCWG leaders, and RCWG members (Appendices B-E). All four interview guides include questions related to four broad domains aligned with the RE-AIM Framework evaluation questions, including organizational details/background, depth and strength of partnerships, and evidence of enhanced capacity. The interview guides also included questions to capture respondents' efforts to advance health equity for persons with disabilities in Pennsylvania. The questions varied for each role-specific guide, such that no more than nine people were asked the same question. The Arc of PA staff members were asked about building partnerships, whereas the SWTF and RCWG groups were predominantly asked about the engagement in the partnership and evidence of enhanced capacity. RCWG leaders were asked about the facilitation of workgroup sessions and organizational progress, whereas RCWG members were asked questions about their participation and contributions in meetings. All interviews were conducted virtually and recorded via Zoom. Interviews were transcribed via Scribie.

Additionally, the evaluation team reviewed secondary data from The Arc of PA, including RCWG and SWTF attendance logs (Appendix I), SWTF meeting minutes and progress reports, and media click and impression reports (Appendix J). The websites of RCWG and SWTF organizations were reviewed for the organization scans (Appendices G and H), and *What We Know Now, Fact Sheets, Barriers,* and *Recommendations* reports were assessed for accessibility tools and modifications (Appendix K). Table 1.1 details the evaluation questions and the secondary data used to explore those questions.

Table 1.2 Secondary Data used to Explore Primary and Secondary Evaluation Questions

Secondary Data	Primary and Secondary Evaluation Questions	
RCWG and SWTF attendance logs	How many new and existing partners were	
	involved in the initiative?	
	To what extent were partner organizations	
	engaged in the initiative?	
SWTF meeting minutes	To what extent were partner organizations	
	engaged in the initiative?	
Organization Scan	How diverse was the membership (with respect	
	to various characteristics, such as sectors,	
	geography, populations served, types of service,	
	etc.) because of The Arc of PA's strategy?	

Secondary Data	Primary and Secondary Evaluation Questions
	To what extent did partners disseminate
	products from the initiative, and what was the
	potential reach of those dissemination efforts?
The Arc of PA progress reports	In what ways did the partners' capacity to
	address exposed disparities in the disability
	community increase?
	How did The Arc of PA modify its efforts to
	meet accessibility standards and audience needs?
Organization initiative reports	In what ways did the partners' capacity to
	address exposed disparities in the disability
	community increase?
Usage reports from media company	To what extent was there a perceived increase
	in the community-at-large's awareness of
	disparities related to COVID-19 among individuals
	living with disabilities?
The Arc of PA public reports	How did The Arc of PA modify its efforts to
	meet accessibility standards and audience needs?

#### Analytic Plan

Interviews were analyzed using Dedoose software. The investigative team conducted a thematic analysis of the primary data, as outlined by Lester et al.<sup>5</sup> First, the team created a codebook based on emergent themes identified in the transcripts. In this process, three team members looked at the same two transcripts from the RCWG interviews and created separate codebooks, which were then merged to create a cohesive codebook. The project director reviewed the codebook and added codes and descriptions based on emerging themes from the SWTF interviews. The original three team members practiced applying the codebook to a new RCWG interview and amended codebook definitions. All team members participated in coding the remaining transcripts; all transcripts were double-coded. Coders resolved discrepancies on a case-by-case basis. The codebook is available in Appendix F. Intercoder reliability was not conducted, given the double-coding and discrepancy-resolution process.

The team identified which codes corresponded with the proposed evaluation questions. Individual team members analyzed and summarized the main findings within a particular code. Analysis included examining the sub-themes within a code and the prominence of those sub-themes; assessing the number and types of participants who discussed each sub-theme; and exploring how themes and sub-themes were related. The full team met weekly to discuss, reflect upon, and further develop findings iteratively.

Regarding secondary analysis, excel databases were created to catalog data. Senior project staff revised document review plans as they were developed and applied. Descriptive statistics (e.g., frequencies) were analyzed and reported on the data reviewed in the RCWG and SWTF attendance logs, usage reports from The Arc of PA's media company, and in conducting the organization scan and review of The Arc of PA's products for accessibility. Reports for the organization scans, attendance analysis, impression and click analysis, and the product accessibility review are included in Appendices G-K, respectively.

## **Evaluation Findings**

Effectiveness Question #1: How effective was the initiative in developing new and strengthening existing partnerships?

This evaluation question and its sub-questions touch upon the number of new and existing partners, diversity in the partnership initiative, and engagement of partners.

Nearly Two-Thirds of Partnerships Members were New Partners

According to the organization scans (Appendix G-H), the SWTF included 31 members across 23 organizations. There were 13 RCWGs, which included 224 members across 155 entities and organizations. Table 1.3 depicts the proportion of organizations in the RCWGs and the SWTF that were new relationships formed during the initiative or were pre-existing partnerships, for each sector category. Overall, nearly three-quarters of RCWG organizations (n=114) were new partners, and two-thirds of SWTF organizations (n=15) were new partners. For both the RCWGs and the SWTF, all the healthcare partners were new relationships, and the majority of members in the government sector were also new. This reflects one of the main intentions of this initiative. In the RCWGs, the majority of advocacy/nonprofit and education members were also new relationships. One-half of the education partners in the SWTF were new as well. The proportion of new partners is significant, as The Arc of PA strived to expand its relationships and the sectors with which it worked through the OT21-2103 grant.

Table 1.3 RCWG and SWTF Organizations by Sector and New or Existing Status

	RCWG Members		SWTF Members			
Sector	Total	New	Existing	Total	New	Existing
Advocacy/Nonprofit	31%	90%	10%	39%	23%	77%
Government	19%	77%	23%	18%	67%	33%
Healthcare	18%	100%	0%	18%	0%	100%
Arc	10%	0%	100%	12%	0%	100%
Education	12%	92%	8%	12%	50%	50%
Other	7%	0%	100%	n/a		
Faith-based	4%	0%	100%	n/a		
Community center	2%	100%	0%	n/a		
Corporate	0.6%	0%	100%	n/a		
Total	100%	74%	26%	100% 65% 35%		

#### There Were High Levels of Diversity Among the SWTF and RCWG Members

Participants consistently reported that diversity was important to bring various views and perspectives to the partnership members. For example, several participants revealed that diversity was one of the key drivers in recruitment. Participants shared how they leveraged their existing networks to merge "pockets of work" and how they recruited non-disability stakeholders as a means of breaking down silos. The organization scan revealed that members of the SWTF and RCWGs represent diverse sectors as shown in Figures 1.5 and 1.6. In both, nonprofit sectors held the largest proportion of representation.

Figure 1.5 Sectors of SWTF Member Organizations

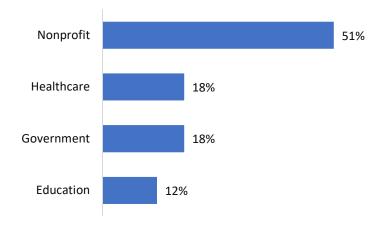


Figure 1.6 Sectors of RCWG Organizations

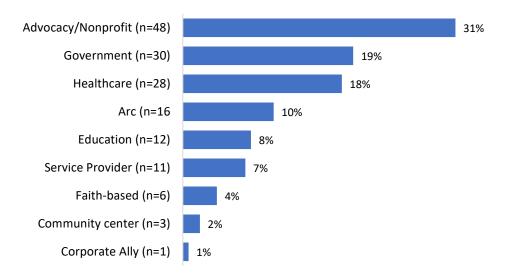


Figure 1.7 depicts the breadth in the geographic reach and service areas of the SWTF and RCWG organizations. RCWG organizations served 70% of counties across Pennsylvania. The areas served below align with the general service area of all The Arc of PA chapters. The counties in darker shading were served by a higher number of RCWG organizations, which corresponds with population density to some degree (e.g., Montgomery, Philadelphia, and Allegheny counties), but not exclusively. Figure 1.7 shows the locations of SWTF organizations, which were concentrated primarily in the central and southeastern regions. However, most served the entire state of PA.

Erie Susquehanna McKean Warren Bradford Tioga Potter Crawford Wayne Forest Wyoming Cameron Sullivar Elk Venango Lycoming Mercer Clinton Luzerne Montour Columbia Clearfield Centre Union Butler Carbon Northumberland Armstrong Snyder Northampton Beaver Mifflin Juniata Indiana Lehigh Blair Allegheny Dauphin Lebanon Berks Huntingdon Bucks Westmoreland Washington Montgomery Cumberland Lancaster Philadelphia Bedford Fulton Franklin Delaware Favette York Adams Greene RCWG Counts

Figure 1.7 Number of RCWG Organizations Serving PA Counties and SWTF Organization Locations

#### Partner Diversity and Community Involvement Were Essential to Partnership Effectiveness

Statewide Task Force Organization Addresses

1 - 2 organizations
3 - 5 organizations
6 - 10 organizations
11 - 17 organizations
18 - 25 organizations

Participants also reported that diversity was essential in the effectiveness of the partnership initiative meetings and during the Listening Tours. SWTF members and RCWG participants explained that by having input from various sectors and persons with disabilities who shared their expertise and personal experiences, their own awareness of disability issues and available resources increased, and they felt more engaged in and committed to the partnership initiative. One respondent noted:

"Everybody was pretty engaged. You would bounce around the room, and you would hear from those different healthcare perspectives or public health perspectives." – RCWG Leader

"The richness of the different backgrounds and experiences really shaped the project well. We had several individuals with disabilities whose voices were really critical to this [project]. We really take that "it's not about us without us" approach. In using that approach, every group and every person's voice was heard." – SWTF Member

An important aspect of partnership diversity was community involvement. Participants defined community involvement as engaging individuals with disabilities, as well as the providers and staff who worked directly with those individuals. SWTF and RCWG members described how they incorporated community input from the Listening Tours into the products The Arc of PA created. This community perspective was very powerful for participants. Ultimately, the community input shaped partners' work, expanded their understanding of disabilities, and deepened their commitment to the project.

"[The Listening Tour stories] were presented to us early in the project. And I feel like that almost gave us our lens. It gave us our why. It's important to have that why when you're doing something. I mean, at face value, everybody knew to some degree what the why was. But until you heard those community stories, we didn't understand the depth of the why." – SWTF Member

"And again, you asked, 'Were folks with an intellectual disability involved in the report?'
Absolutely. You got to see all those firsthand accounts, and that's how they were built into each of the recommendations, which was a cool way to present the work." – RCWG Member

Of note, 10% of RCWG members reported having a disability, and another 5% indicated they were family members or care providers of individuals with a disability. The Arc of PA, as well as partnership members, felt that having individuals with direct disability experience involved in the partnership initiative was essential and used phrases such as, "Nothing for us without us." Additionally, the majority of RCWG members (73%) directly served individuals with disabilities, providing services to those with an intellectual/developmental disability, autism spectrum disorder, deaf/hard of hearing, blind/visually impaired, and people who have physical disabilities.

#### There Were Sufficient Attendance & High Levels of Engagement in Partnership Initiative Meetings

A component and precursor to engagement is attendance in partnership meetings. As such, attendance logs were reviewed by the project team (See Appendix I). Across all RCWGs and the six sets of sessions, there were a total of 349 meetings. Every RCWG member attended at least one RCWG session during the initiative, with the highest attendance recorded at the first meeting and decreasing over the course of the sessions. Seven of the 13 RCWGs were represented at each workgroup session. For the SWTF, on average, 18 members attended per meeting; four organizations were present at each meeting, all from the Nonprofit/Advocacy sector. Although attendance varied throughout the initiative, particularly among the RCWGs, participants shared that attendance was sufficient and allowed ample engagement, as described below.

SWTF and RCWG members reported high engagement in partnership meetings, much of which focused on sharing perspectives and expertise related to the topic at hand and assisting with developing the *Barriers* and *Recommendations* reports. This was confirmed in the analysis of the SWTF meeting minutes (RCWG minutes were not reviewed, as this was beyond the scope and resources for the evaluation). SWTF meeting minutes showed that members were engaged in thought partnership in each meeting and more than any other type of activity, including recruitment efforts, promotion of resources, or collection of data. Nearly all participants described engagement as actively sharing and participating in group conversations. Participants also talked about how they felt their voice was heard and their opinions mattered. Several participants noted that the conversations in meetings were very active. SWTF members, in particular, felt very involved in decision-making.

"For the first time, I didn't feel that the process [of being involved in a collaborative effort] was being slowed by the typing, no, it actually increased, because [the facilitators] were so on top of controlling and focusing us on and using [the chat feature] and contributing. And then coming back and bringing us together in the meeting to say, this is what we noticed during those breakouts." – SWTF Member

"The meeting group that I was involved with were 100% engaged and respectful of the comments and the feedback that any and all participants provided. There was a sense of camaraderie, we're all here for the same purpose, the same goal...And periodically, we were reminded that the information we provided in our workgroup is leaving the workgroup and going higher to the [SWTF] to be looked at and analyzed. When the report came out two weeks ago,

that's where you kind of read it and smiled to yourself, and you're like, yeah, I remember that we talked about that. And it's great that they made that a recommendation." — RCWG Member

Effectiveness Question 2: To what extent did multi-sectoral collaborations a) contribute to perceived increase of the public's awareness of COVID-19 disparities in the disability community and b) increase partners' capacity to address these disparities?

Engagement in the partnership initiative, through meeting attendance, participation in meeting activities and discussion, and information sharing and dissemination, led to several outcomes. These outcomes, displayed in Figure 1.8, include strengthened relationships, participants' increased awareness of COVID-19 disparities in the disability community, and changes in partners' practices. Participants believed the biggest impact pertained to strengthening relationships, as their ability to address the needs of the disability community improved through these stronger, expanded networks. Participants reported that their own awareness of COVID-19 disparities in the disability community increased and shared their belief that awareness in the community-at-large also increased. The interviews and document review also revealed important changes in partners' practices. These outcomes overlapped with one another, and partners believed that these outcomes contributed to a stronger foundation for increased readiness to address health disparities among the disability community. Each of these impacts is described more fully in the narrative below.

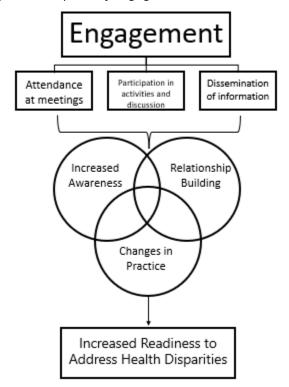


Figure 1.8 Impacts of Engagement in the Partnership Initiative

Community Awareness: Catchment Areas of Partnering Organizations Indicate Potential for Dissemination of The Arc of PA's Efforts in Pennsylvania

The Arc of PA encouraged partners to disseminate products, information, and resources from the initiative to increase the public's awareness of COVID-19 disparities in the disability community. The Arc of PA did not track members' dissemination activities during the initiative; thus, the evaluation is not

able to serve as a conclusive depiction of all dissemination work. However, data from the secondary data review and the key informant interviews help to highlight the potential dissemination impacts of The Arc of PA's work.

All SWTF interview and The Arc of PA participants reported they shared the *Barriers* and/or *Recommendations* reports with their colleagues and networks. Some RCWG participants did the same. Most participants also indicated that they disseminated resources from the media campaign and other initiative-related information in platforms, such as newsletters, lectures, and even through radio advertisements. Progress reports revealed that The Arc of PA gave presentations, participated in radio interviews, and disseminated the key reports via online publications and newsletters. It is important to note that these interviews occurred just as the *Recommendations* report was released and that, to date, dissemination is ongoing; see *Figure 1.1* for reference. As a result, a few participants noted that they had dissemination plans in progress. There was also the suggestion that a formal dissemination plan for major products, like the *Recommendations* report, would be very helpful.

The organization scans (Appendix G-H) for SWTF and RCWG member organizations show the potential for dissemination in the broader community. The catchment areas of the organizations indicate the possible geographic reach of partners' dissemination activities. The member organizations' core services present another way to consider potential dissemination. That is, organizations offering services such as policy, advocacy, and education, have the capacity to include and spread initiative findings, products, and efforts through those service arms. Of note,

- 14 of the 23 SWTF organizations have catchment areas that serve the entire state of PA, with three additional organizations serving surrounding states as well (New Jersey, Maryland, New York, and West Virginia) and one organization with nationwide reach.
- 70% of counties in PA were served by at least one RCWG member organization, and 40% of counties were served by three or more RCCWG organizations. 30% of counties were not served by any RCWG member organizations.
- 11 SWTF organizations provide policy and advocacy services, and 8 organizations offer training programs.
- In the stratified RCWG sample, 64% offered COVID-19 information and resource sharing, which aligns with the initiative's goal of providing resources to the disability community.

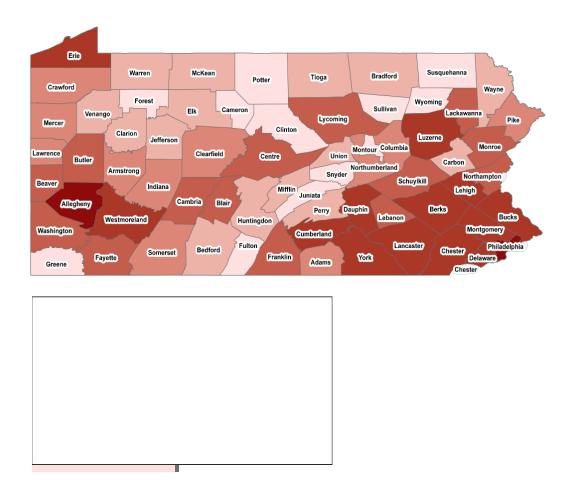
#### Community Awareness: Millions of PA residents were exposed to The Arc of PA's media campaigns

Furthermore, the evaluation team reviewed reports from The Arc of PA's media company to report on public engagement with and reach of the initiative's media campaign. The evaluation team compiled data on "impressions" and "clicks." Impressions in this context are defined as the number of times an advertisement is seen or heard. Clicks are measured by the number of times the static ad was clicked on for more information. As a proxy for public engagement with the campaign, the Impressions and Clicks Report (Appendix J) indicates the potential for increased public awareness of COVID-19 resources geared towards the disability community. Key findings include:

- Total impressions for the English audio advertisements were 17,834,143
- Total impressions for the Spanish audio advertisement were 2,865,145
- Total clicks for English static ads were 226,455
- Total clicks for Spanish static ads were 49,659

Figure 1.9 shows that counties from the Southeast region consistently had a high volume of clicks, compared to other regions. Allegheny and Philadelphia counties had the highest click volume compared to all other counties. Additionally, seven of the 48 counties that the Arc of Pennsylvania identified as "rural" clicked on the digital resources more frequently than the other counties.

Figure 1.9 Media Campaign Clicks by County



Participants' Awareness of Disparities in the Disability Community and Related Resources Increased

Despite a limited view of dissemination activities, most participants described increased awareness as an outcome of the initiative, particularly their own enhanced understanding of disparities in the disability community, as well as awareness of additional resources and networks to bolster their own efforts. Some participants also felt that the initiative, specifically the reports and media campaigns, illuminated the health disparities facing the disability community for the public at large, particularly among health care and service providers. However, given the early stage of the initiative, the impacts of dissemination that can be detected are nascent. Therefore, participants predominantly discussed a growth in their awareness of disability issues. Given the participants' spheres of influence and leadership positions, particularly in the SWTF, changes in partner awareness have the potential to trickle out to community-wide awareness.

Most participants shared that their perspective on disability issues had expanded because of their involvement with the partnership initiative. Participants described filling gaps in their knowledge of disability issues and having a greater understanding of the intersection of social determinants of health and disability, as well as broader insight into the array of disabilities people have. SWTF members appreciated learning more about how disability issues impact their specific field. RCWG members described gaining a more holistic perspective and learning about how other sectors overlap with disability services. This expanded awareness covered disability needs, healthcare, transportation, finances, education, insurance reimbursement, food insecurity, social isolation, and self-advocates.

"It was really nice to be able to hear about what's going on in terms of transportation and living space and financial aspects in the area of intellectual disability, since that's not something I always talk about every day. So that kept me engaged... you had your little lane that you worked in, but this [Work Group] call really looked at all lanes... And over time you learned, well, my healthcare possibly does impact our conversation about transportation during the pandemic. Now that I know about transportation, as I practice clinically, I'm gonna think differently when I have a patient who needs to go to physical therapy." — RCWG Member

"The Arc of Pennsylvania, our focus has always been on individuals with intellectual disabilities. So to be able to be disability inclusive and talk to people that have vision issues or hearing issues, physical disabilities, that was a big learning curve for us. And it's great to be able to have that perspective as well." — The Arc of PA Staff Member

Awareness grew in a few other areas as well. Some participants described having a greater appreciation of the lived experiences and personal stories of individuals with disabilities. The Arc of PA reported having increased awareness of work happening in the Arc chapters. RCWG members, in particular, shared a better understanding of local resources, services, and networks. Finally, some participants also reported an improved understanding of how they fit into disability work (their "stake in the game") and of accommodations that increase accessibility.

"I remember the task force meeting where one of the members – you could see the light bulb go off in him. Like, oh wait, I'm training people. I can have the perspective of disability inclusion when I'm training new [health care workers]. Even if that's the only thing we get out of this entire project, what ripples that one person can make with just that one changed perspective, just that one person, was pretty powerful." – The Arc of PA Staff Member

"I honestly think probably the most effective thing for me that really resonated with me was hearing the individual stories of the people and their lived experiences. I don't think I could have participated in the way that I did if I didn't have that lens that was beyond my own. I know those stories, I know people have those needs, but hearing the depth of the stories and just the impact that they had, I don't think... I think that really was a spark behind it." – SWTF Member

#### Relationship Building was the Biggest Impact of the Initiative Overall

Participants shared that the biggest impact of the initiative overall was the building and reinforcing of strong relationships between stakeholders. In fact, The Arc of PA identified relationship-building as a primary vision of this initiative, as well as one of its biggest successes, particularly for RCWG members. Many participants expressed that new relationships with partners and the local community had been created because of this initiative. Several others discussed bringing existing networks into the partnership initiative for a new, unified effort.

In particular, RCWG members discussed building a network that one could "call upon" to help navigate healthcare access barriers or mobilize for future public health emergencies affecting the disability community. Because of these relationships, participants gleaned and shared newfound information about initiatives and resources within their immediate network or incorporated them into their practice.

"We saw a lot of partnerships within regional community work groups that as a statewide chapter we probably wouldn't see otherwise. So, some of the regions have a lot of partnerships with faith communities and their local governments agencies or local department of health or county governments. I mean, that's always been the vision of the grant, building those relationships would be the byproduct of the grant. So that the next time something happens,

they have these connections within their region so that they know exactly who to talk to. They already have a relationship with those people." – The Arc of PA Staff Member

"When you're doing things in a time of crisis, things get overlooked and it's not as organized. And that's exactly what happened during the pandemic. Now, we have an organized group of people who've worked with The Arc of Pennsylvania, who could be called on at any moment if there is a need to mobilize around some kind of public health issue." – RCWG Member

#### Most Participants Shared Various Changes in Practice as a Result of this Initiative

The Arc of PA reported several significant changes to their practice that have increased their capacity to address COVID-19 health disparities in the disability community. The Arc of PA noted building new partnerships with organizations in the health sector, including the Pennsylvania Department of Health, the Hospital Association of Pennsylvania, Woods Services, and the Special Olympics Pennsylvania. The Arc of PA intends to continue working with these partners and felt that they could call upon them for help or to mobilize in the event of a future public health emergency. The Arc of PA believed that creating the *Barriers* and *Recommendations* reports is a measure of the success of these newfound partnerships.

The Arc of PA also noted that the grant helped expand their reach and expertise. Examples include hiring bilingual employees to reach Spanish-speaking populations and improving their accessibility practices for disability needs outside their intellectual developmental disability expertise. The Arc of PA hired a consultant to improve plain language on their website, create an accessible PowerPoint template for SWTF presentations (now the organization standard), and include a video medium for the *Recommendations* report to increase accessibility. Furthermore, because of this grant initiative, The Arc of PA reported that it has gained credibility and expertise in the health sector and has related to the health sector as a partner instead of as a critical adversary, as one of The Arc of PA staff members describe below. As part of their "new frontier" to focus more closely on health disparities, The Arc of PA has initiated applying for new health grants, hosting a Health Equity Summit in 2024, continuing to create educational training and curriculum for health professionals, and amplifying disability inclusion to the Pennsylvania Department of Health.

"This grant has enabled us to put down the pitchforks and torches because we've got the credibility now behind us and we've got all of this work that we've done so we can sit at the table in a whole different light [with] the Department of Health. I really believe that we are going to continue to be that go-to resource, whether it's the governor's office or Department of Health or one of the associations." – The Arc of PA Staff Member

Nearly all participants shared various changes in their organizations' practices because of this initiative, which focused on activities aimed at improving health, as described in Table 1.4. This was also found in the review of the initiative and progress reports. Participants discussed creating and continuing health promotion programming to address COVID-19 disparities and to improve overall health within the disability community. Participants also reported hiring staff and creating departments to support new health-focused efforts. SWTF and RCWG members noted improvements to healthcare delivery within their organizations and individual practices. SWTF and RCWG members reported changes within their organizations that indicated a greater understanding of disability inclusion, the intent to prioritize accessibility measures, and efforts to start new projects and studies inspired by the grant.

Table 1.4 SWTF and RCWG Changes in Practice to Improve Capacity Aims

Aims	Strategies	Examples		
New activities	Health promotion	<ul> <li>Accessible COVID-19 vaccination clinics</li> </ul>		
aimed at	programming for COVID-19	<ul> <li>Free COVID test distribution</li> </ul>		
improving	and overall health	<ul> <li>Cooking classes and food box distribution</li> </ul>		
health,		<ul> <li>Dental clinics</li> </ul>		
inspired fully		<ul><li>– 'Wellness Wednesdays' (group exercise)</li></ul>		
or in-part by	New staff roles and	<ul> <li>Hiring a Director of Healthcare Advocacy program within</li> </ul>		
the grant	department to expand	regional Arc chapter		
	health efforts	<ul> <li>Building marketing/communications department for outreach</li> </ul>		
	Improvements to healthcare delivery	<ul> <li>Streamlined referral systems for disability-friendly providers and clinics</li> </ul>		
		<ul> <li>Expanded neurodiversity work in medical centers</li> </ul>		
		<ul> <li>Healthcare provider training curriculum development and implementation</li> </ul>		
		Considering accessibility and social determinants during		
		patient encounters		
Organizational	Demonstrate greater	Incorporating Barriers report recommendations into		
changes focused on	awareness of disability inclusion	hospital's equity efforts		
disability	Inclusion	Intent to recruit, support, and retain diverse staff  OCIVIC Leader in its and leave to recommend and the second state of		
inclusion		RCWG leader joined local emergency preparedness		
merasion	Accessibility practices to	committee to lend perspective/expertise  - Continuing use of telehealth and Zoom		
	ensure inclusion	Prioritizing accessibility in information dissemination (i.e.,		
	Charle melasion	plain language, Braille, video mediums, considering		
		disability community in lay results dissemination)		
	New studies/projects	Securing new funding for disability-focused projects		
	inspired by grant project	because of demonstrated need		
		<ul> <li>Proposal directly benefiting/focusing on disability</li> </ul>		
		population; considers disability inclusion		
		<ul> <li>Collaborating with new partners from initiative on future</li> </ul>		
		projects		

Participants shared the following regarding new activities conducted to promote health:

"Normally, The Arc doesn't do cooking classes and provides a box of food to go with that cooking class. But people are still experiencing food disparities and social isolation...So it's incorporating what we learned of the disparities during [partnership] conversations that we've implemented in our programs now offered at The Arc." – RCWG Leader

"[In] the last two years, we were able to shape arguments to grant funders...and now we've hired a full-time director for the [healthcare advocacy] program. Our program has quite literally gone up to the next level...It's increased our capacity." — RCWG Leader

Participants also described organizational changes focusing on disability inclusion:

"Out of meeting with the Allegheny Health Department, I now serve on the local emergency preparedness committee, which is wild...[To] be there and have a presence to make sure the experience of the disabilities community continues to be lifted and dealt with and addressed."

- RCWG Leader

"We're doing a pilot study right now about lay results dissemination, and we're doing focus groups to learn from community members about what formats work... it means we need to keep in mind all populations, including folks with disabilities." – RCWG Member

#### Participants Reported Increased Readiness to Address Health Disparities in Disability Community

There is early indication of this initiative building readiness to address health disparities in disability community. However, compared to the other themes related to increased capacity, participants discussed readiness less frequently, which aligns with the timing of the evaluation as well. One Arc of PA staff member noted that the Barriers report, which demonstrated needs to address health disparities in the disability community, and the Recommendations<sup>5</sup> report, which included prioritized recommendations, gave the state of Pennsylvania "a framework" of what to do to reduce disparities. A few participants noted that they were better positioned to handle specific issues with their clients and patients, such as being able to recommend appropriate resources and information. Participants also described concrete improvements among specific healthcare providers who were both internal and external to the partnership initiative, such as improved networks of disability-inclusive healthcare providers. One interviewee commented, "it [the initiative] will make life better for my patients." Another participant mentioned that the National Institute of Health's designation of people with disabilities as a population with health disparities was a sign that "the culture is shifting" to address these longstanding inequities and viewed this initiative as part of the wave bringing about this shift. Similarly, there was an emergent consensus that momentum was building around disability equity and that this work was integral and in tandem with that momentum.

"[RCWG Leader] just asked that question this morning, if we all felt that we were starting to gain some traction in disability work, specifically intellectual disability work. And we all responded, yes, like we felt that in the past year, we're seeing a lot of forward movement...! think the work that's being done – we're just beginning to see the reward of it, and that it's happening and there may be a shift in culture... The work that we're doing here, the recommendations that were made are having a positive impact on raising visibility for this population." – RCWG Member

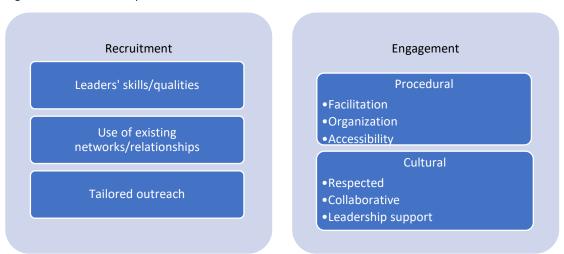
"I think [the initiative] is a great model and certainly highlights a problem that has been on a lot of people's minds. We have clear health disparities demonstrated, which now I guess people are publicly acknowledging at the federal level, that disability is a health disparity with the recent changes that were announced this week from the NIH policy statement. But [the reports] provided real, concrete examples. Like, this could happen to someone that you love... it just makes it more relevant. And when you read those reports, it's hard to ignore the impact it had on individuals, and it would be hard for me to imagine that that feels okay for folks in a decision-making capacity." – SWTF Member

Implementation Question 1: What contextual factors, including barriers and facilitators, did The Arc of PA experience in establishing new partnerships and in bolstering existing partnerships?

#### Structural and Cultural Facilitators Led to Productive Engagement

Distinct components facilitated the partnership initiative at initial recruitment and during the ongoing engagement phases of the partnership initiative, as depicted in the image below (Figure 1.10). Participants described three key factors that led to successful recruitment in the workgroups: skills and qualities of the person conducting the outreach, use of existing relationships and networks, and tailoring of outreach efforts. During ongoing engagement, participants described procedural and cultural factors facilitating partnership activity. These factors worked together to instill a deep commitment to the initiative among its members.

Figure 1.10 Partnership Facilitators



Recruitment was one of the main tasks of RCWG leaders. As such, these factors were discussed more often and in greater depth in RCWG interviews. However, SWTF participants also discussed the use of existing relationships and tailored outreach. At recruitment for SWTF and RCWG members, participants shared that recruitment leaders, or their organizations (including The Arc of PA), had strong reputations, were able to foster trust and relate authentically to their colleagues, and were expert community organizers. Participants also described using their robust professional and personal relationships and networks to facilitate recruitment. While this recruitment facilitator did not immediately lead to new partnerships, it brought colleagues together in different ways, working towards a new goal. Finally, participants discussed how they tailored their outreach, appealing to individuals' unique motivators and being "person-specific" regarding how an individual's role in the community would enhance the initiative.

"It was intentionality and persistence in outreach... It was also the success of folks that knew me and knew my track record, to be honest. You have those already existing relationships and connections that you build upon, and in doing so, bring energy and enthusiasm to it in terms of the important need of this and really being about honoring the story." - RCWG Leader

"We framed this as an opportunity for our [existing] Cities of Inclusion group to contribute to a policy initiative. And everybody in the group was excited about that...to have input that can make its way up to the Office of Health Equity." - RCWG Leader

During the implementation of the SWTF and the RCWGs, participants reported procedural and cultural factors that facilitated their ongoing engagement. The main structural factors included the high-quality facilitation of the meetings, the way they were organized, and their accessibility. Both RCWG and SWTF participants described these same facilitators, yet the facilitation and organization of the meetings were discussed more fervently in the SWTF interviews. SWTF participants described the tremendous skill of the meeting facilitators. Several SWTF participants shared that this coalition was one of the more successful ones in which they have participated.

"The process was fabulous. The facilitator was incredible in getting people's ideas... and helping us hone in on the top three priorities. The work that came out as a result of that process is commendable." - SWTF member

Participants described the meetings as highly organized. Participants used words, like "on-task" and "action-oriented." Meeting documents and agendas were shared in advance, minutes were distributed in a timely manner, and there was a good "flow" of activities. SWTF participants went a step further, sharing that meetings included scaffolding from previous meetings and from the RCWGs' work and included rigorous and iterative processes to move towards known milestones. Participants also shared that the accessibility of the meetings facilitated their ongoing participation, which included reasonable time commitments, flexible meetings, knowing the schedule in advance, and an effort to accommodate members' schedules.

"This is one of the better well-run and organized ones that I have participated in. One of the things that I thought they did a good job of is with the structure of the meetings. We would talk theoretically about whatever the topic was, but then we would get down to, 'Okay, now let's translate that to a practical model that would create an action around and move the theory into practice.'" - SWTF member

Participants reflected that the culture within the meetings was as important as the structure. Nearly all participants expressed that they felt listened to, valued, engaged, respected, trusted, and that they were collaborating within a safe space.

"The facilitator was deliberate about making sure that folks who were on the call had the opportunity to speak and were listened to and the information was being synthesized." - RCWG Member

"We really made it clear that everybody's opinions were valuable. We listened to every person that participated. A lot of times when people would say things, it would be an 'and.' We added to it because the richness of the different backgrounds and experiences really shaped the project well." - SWTF Member

Participants described how the collaborative nature of the meetings facilitated a high level of engagement. This was particularly pronounced among SWTF participants, who shared that a unified vision and purpose were established early in the process. This common goal helped SWTF deprioritize individual agendas and strengthen their commitment to the initiative.

"Even though we may have had different reasons for being there, I think we were so unified in our cause of making this better. We were all driven by that recognition that what happened should not be repeated." - SWTF member

Participants characterized a culture of support that enabled their engagement. Some RCWG participants named support from the workgroup leader and their organization's leadership as crucial factors in their participation. A few SWTF participants also shared that The Arc of PA's support and facilitation was integral to the process.

These procedural and cultural facilitators led to high levels of commitment among members. RCWG participants described being driven to affect systemic change. SWTF participants shared a similar motivation of wanting to achieve impact and success. Some SWTF members also shared a deep sense of pride and ownership in this work, enabling their ongoing dedication.

"I believe every [SWTF] participant was like – please, put my name on this [report]. This is ---- good work that we did. Even though we were a task force and it was led by The Arc of PA, we really felt committed to the work and part of the work." - SWTF member

#### Inconsistent Engagement was the Biggest Barrier in the Partnership Initiative

The most frequent barriers centered on challenges engaging people in the partnership initiative. RCWG participants noted that some individuals and organizations were too busy to engage in the initiative, even if they wanted to participate. Examples included physicians, direct care staff, members from marginalized communities, and family members/caregivers of individuals with disabilities. Difficulties engaging adequate numbers of participants and having participants consistently attend partnership meetings can impact the quality of participation in meetings, such as having to repeat previous discussions and not being able to proceed to the next activity, as mentioned by one RCWG member. Other RCWG members named examples of organizations that showed a lack of organizational capacity, including program funding restrictions and leadership changeover leading to inability to participate or disinterest in participation. One Arc of PA staff member also recalled that the lack of organizational leadership support for RCWG facilitators impacted their ability to engage people in workgroup sessions. This finding contrasts with the facilitation experience present for SWTF members. Furthermore, a few RCWG members and Arc PA staff noted that, during the height of the COVID-19 pandemic and coinciding with the direct support professional staffing shortage, it was very difficult for Arc chapters to participate.

"I feel like our work group was kind of small. I wish we [could] have had more people involved...And it's not from lack of us trying to get people into the work group. I think people are just busy. And you always find that once you're over a crisis, people are moving on instead of taking that time to really analyze what happened during it, so we can make sure it doesn't happen again." - RCWG Member

Implementation Question 2: How did The Arc of PA implement and modify its efforts and products to fit accessibility standards (e.g., closed captioning, representative images, etc.), audience needs (e.g., language, medium, etc.), and setting (e.g., partners' culture, sector, etc.)?

One of the evaluation sub-questions focused on modifying efforts according to partners' culture or sector. This occurred within recruitment and outreach efforts, as described in the *Facilitators* section of this report, particularly by RCWG leaders. This evaluation did not discern other modifications made by The Arc of PA regarding partner characteristics.

Accessibility was a theme throughout the key informant interviews and cut across multiple interview topics. In interviews, participants discussed the role of accessibility concerning community involvement, changes in their practices, awareness among partners and the community at large, barriers, and facilitators. They described accommodations for partnership members and individuals with intellectual, vision, hearing, and physical disabilities. Specifically, they mentioned accessibility considerations in initiative activities, like the Listening Tours, SWTF and RCWG meetings, and other efforts, such as research recruitment. Participants discussed how the partnership initiative informed new and ongoing accessibility efforts in education dissemination, COVID-19 services including but not limited to testing and vaccination, and other healthcare activities (e.g. provider training). During partnership meetings, accommodations included: (1) flexible meeting times; (2) accommodating schedules; (3) sharing meeting schedules in advance; (4) allowing partnership members and community members to contribute via Zoom; (5) sharing materials in advance with partnership members; and (6) providing ASL interpreters and closed captions during Zoom meetings.

The evaluation team reviewed the initiative's five key products to assess modifications around language, accessibility, and medium. This brief report is found in Appendix K, highlights of which are discussed below. The Accessibility Assessment included the review of the *Barriers* report and factsheet,

the *Recommendations* Report and factsheet, and an infographic detailing existing research on healthcare disparities the disability community faced. All of these products are public-facing documents; the *Recommendations* report is geared towards PA DOH and a set of recommended changes it can implement. The assessment examined the use of modifications in language, medium, and accessibility. Table 1.3 displays the language, medium, and accessibility modifications the evaluation team assessed in the five products.

Table 1.5 Product Modifications Reviewed in the Accessibility Assessment

Language	Medium	Accessibility
Number of languages offered	Number of	Braille, available by request
Plain Language:	mediums used	WCAG Accessibility standards (Web Content
used or offered in addition to		Accessibility Guidelines 2.0 AA <sup>6</sup> )
technical language		- 4 Principles: Perceivable, Operable,
Inclusive language:		Understandable, Robust
used person-first language*		- Assistive technology compatibility:
		alternative text for non-text elements,
		accurate tagging, etc.

<sup>\*</sup>Use of person-first language (e.g., person with a disability) or identity-first language (e.g., disabled person) is an ongoing discussion within the disability community.

This assessment revealed several important findings, including the sheer number of modifications in the products.

- Modifications increased and improved over time.
- Main products for public distribution (e.g., *Barriers* and *Recommendations* reports) had the most modifications, reflecting prioritization in resource allotment.
- Language: All products used inclusive language; some products were translated into Spanish and Mandarin; and the main products were offered in plain and technical language.
- Mediums: Products used written, pictures, graphics/data visualization, and video mediums (audio was not used).
- Accessibility: All products met WCAG Understandable and Robust principles, which aligns
  with The Arc of PA's expertise in Intellectual and Developmental Disabilities. WCAG
  Perceivable and Operable principles, which include text alternatives, color contrast, and
  navigation elements, were met less frequently.
- Products often went beyond standards to include plain language and technical language, QR codes (and use instructions) for additional/easy information access, Braille copies of reports by request, and availability of an online report flipbook.

For many participants, the use of these accommodations was novel and impressive. However, it is noteworthy that one participant shared there are always more ways to increase accessibility. For example, while Zoom allowed participants from all over the state to collaborate safely, the technological demands were great. Having to toggle between multiple screens and go in and out of Zoom rooms can limit full participation for individuals with disabilities, although The Arc of PA tried to limit breakout room navigation for individuals with accessibility needs.

#### Conclusions

#### Summary of findings

The Arc of PA's vision of the grant was for disability advocates to build relationships with non-disability stakeholders. The evaluation reveals that relationship-building was the biggest impact of the initiative overall. Relationships were strengthened at both the local and state level. Participants deeply valued the diversity of relationships built, such as merging "pockets of work," collaborating with non-disability stakeholders to break down silos and expanding networks for future assistance and mobilization. This evaluation also found that expanded relationships led to changes in practice, which could potentially increase partners' capacity to address health disparities affecting the disability community. Participants reported that their awareness of disability issues and available resources increased, which they also disseminated within their networks. Participants were inspired to develop health initiatives and implement organizational changes, including increasing accessibility accommodations.

The value of community input in this initiative cannot be understated. The Listening Tours infused direct community input into identifying barriers and recommendations for subsequent reports. Partnership members who have disabilities or care for and serve the disability community shared their experiences in partnership meetings. This community involvement expanded partners' awareness, shaped their work, and deepened their commitment to the project. As one member said, it gave them their "why."

Specific structural and cultural elements in partnership meetings were crucial to the partnership functioning effectively. Procedural components, particularly in SWTF meetings, included high-quality facilitation, clear organization, and accessibility for participation. SWTF and RCWG members highlighted the culture fostered in partnership meetings, which created a safe space where participants felt listened to, valued, engaged, respected, and trusted. Meeting leaders were credited with establishing this positive, collaborative culture. These structural and cultural facilitators led to productive engagement in partnership meetings.

#### Lessons Learned

From the evaluation, we identified key ingredients that assisted in making this partnership initiative successful, which included diversity in membership, community involvement, and within the partnerships themselves, professional facilitation, inclusive practices to increase engagement, and a culture of respect and collaboration. This project can be a model for other statewide Arc organizations addressing health disparities in the disability community. Reducing COVID-19 disparities also requires the inclusion of the disability population, which has only recently gained traction. This initiative and the findings from this evaluation demonstrate the need to address disparities in the disability community and the use of partnerships to confront inequities.

The evaluation team notes several limitations to this evaluation. The qualitative component of the evaluation examined participants' perceptions of the effectiveness and implementation of the initiative. The evaluation team was not able to determine the effectiveness of the strategy because baseline data was not collected at the start of the initiative, and there was no available comparison group. Additionally, The Arc of PA was responsible for choosing representative participants for the evaluation team to interview according to group affiliation, role, and whether they had lived experience

with a disability. Since the evaluation utilized this purposive sampling method, selection bias in choosing participants may have influenced the results. Another limitation was designing and conducting the evaluation after the initiative was nearly finished. It is important to plan an evaluation at the outset of an intervention to collect the appropriate data needed. However, the evaluation has many strengths owing to its primary and secondary data collection design. The evaluation team assessed evaluation questions from multiple sources and incorporated secondary data to allow for a broader analysis of the RE-AIM Framework. The team also captured perspectives of all roles within partnerships. Finally, the evaluation included four primary questions, which allowed for a thorough analysis of the initiative.

The Arc of PA learned from this evaluation that it accomplished its objectives of recruiting participants from diverse sectors and creating a state-wide partnership. Moving forward, The Arc of PA identified which tactics worked best to unite multi-sector stakeholders at the recruitment and engagement stages. Examples include appealing to individuals' motivations and offering flexibility in participation avenues. Additionally, this evaluation has helped to identify what characteristics/traits of participants are needed in a coalition to make collective change, such as ensuring diverse representation, including community involvement, and having a firm commitment to disability advocacy/openness. The Arc of PA plans to disseminate the findings through the SWTF and RCWGs and with other statewide and regional stakeholders. The Arc of PA will continue strengthening and expanding relationships with multi-sectoral partnerships and employing accessibility practices to ensure inclusion in the initiative and the dissemination of its findings.

#### Sustainability and Future Plans

The Arc of PA plans to review the evaluation findings to inform ongoing health equity initiatives, including the 2024 Health Summit and other statewide and regional initiatives. The *Recommendations* report provides the Pennsylvania Department of Health with a framework for reducing disparities in the disability community, and The Arc of PA will continue to advance its adoption. Regarding the sustainability of efforts, The Arc of PA is interested in using the work to sustain existing relationships and continue the initiative's momentum. Examples include implementing recommendations across the state, connecting with new stakeholders, and advocating for effective policy recommendations. The Arc of PA is currently assessing potential grant opportunities to fund these efforts. Furthermore, the Arc of PA will continue holding consistent meetings with the SWTF and is interested in connecting RCWGs and identifying successful RCWG models. To ensure that the relationship between PA DOH and The Arc of PA continues, The Arc of PA staff are advisory members of PA DOH's COVID-19 Health Equity Response Team. PA DOH shared that it is open to The Arc of PA continuing activities via a grant extension.

The evaluation findings contribute to the evidence base regarding novel and emerging practices to reduce COVID-19-related disparities by identifying best practices for creating, strengthening, and utilizing partnerships to address COVID-19 disparities in the disability community. This evaluation identifies specific facilitators at the partnership recruitment and engagement stages that help ensure productive working groups and describes an effective structure for interwoven local and statewide partnerships. It also highlights the importance of including diverse sectors and the voice of the community in such partnerships. Partnership initiatives can prevent gaps in services, alleviate health disparities in the disability community, and improve readiness to respond to future health emergencies.

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Appendices.

# Appendix A.

Timeline.

## Original Timeline (May 23, 2023)

Related Activities	Timeline	Person(s) Responsible	Evidence of Completion
Meetings			·
Meet monthly with The Arc of PA and PA DOH (additional meetings scheduled as needed)	Jan 2023 - Nov 2023	Project Manager	Meeting minutes
Meet biweekly with NNPHI	Jan 2023 – Nov 2023	NNPHI	Meeting minutes
Products			
Develop evaluation plan, steps 1-4	Mar 31, 2023	PHMC team	Evaluation plan submitted
Develop a data management plan	June 5, 2023	PHMC team	Data management plan submitted
Complete Interim Progress Report	May 22, 2023	Project manager	Progress report submitted
Submit a draft final report	Sept 25, 2023	PHMC team	Draft final report submitted
Complete final report	Nov 6, 2023	PHMC team	Final report submitted
<b>Evaluation Activities</b>			
Receive requested data (attendance logs, taskforce meeting minutes, The Arc of PA progress reports, organization initiative reports, online data usage)	May 1, 2023	The Arc of PA	Data received
Conduct organization scan	May 2023	Research assistants	Organization scan dataset and map
Develop key informant interview guides	May 2023 – June 2023	Project Manager/ Sr. Evaluation Specialist	Key informant interview guides
Review task force meeting minutes	June 2023	Research assistants	Dataset
Conduct key informant interviews	June 2023 – July 2023	Project Manager, Sr. Evaluation Specialist	Recordings, notes
Review The Arc of PA products	June 2023 – July 2023	Research assistants	Dataset
Review The Arc of PA progress reports and Organization Initiative	June 2023 – July 2023	Research assistants	Dataset

reports			
Receive media data	June 2023 – July 2023	The Arc of PA	Data received
Analyze data	July 2023 – Aug 2023	PHMC team	Results summarized
Prepare findings	Aug 2023 – Sept 2023	PHMC team	Report

# Appendix B.

The Arc of PA Interview Guide.

# COVID Health Equity PA The Arc of PA Interview

Thank you again for meeting with me. My name is \_\_\_\_\_\_, and I'm working with The Arc of PA to learn more about the partnerships and organizations involved in the Statewide Task Force and Regional Community Work Groups.

For today, we're hoping to talk about:

- The factors involved in building partnerships
- How your organization engaged in the task force/workgroups
- What outcomes you've seen come out of this partnership

We'll use the answers from these interviews as part of our overall evaluation to assess how effective these novel partnerships were in increasing capacity to improve COVID health outcomes in the disability community.

Here are some important guidelines for our discussion today:

- This interview will last for about 60 minutes.
- There are no right or wrong answers. Keep in mind that we're just as interested in negative comments as positive comments. I encourage you to be direct and honest so we can use your feedback to learn about and improve this program.
- I'm tape recording the session because I don't want to miss any of your comments. People often say very helpful things in these discussions, and I can't write fast enough to get them all down.
- We will be on a first-name basis today, and we won't use any names in our reports. You may be assured of complete confidentiality. The reports will go back to our project team to improve Statewide Task Force and Regional Community Work Group operations.
  - We recognize that there may be discomfort in sharing your thoughts about this project with the group that is collaborating on this evaluation. We assure you that your name or organization will not be shared with The Arc of PA and that your participation or what you share will not impact your involvement in the Taskforce/Work Group.
- If I move us along during the discussion, it isn't because I don't want to hear everything you have to say; it is because I want to be sure to discuss all the questions.

Are there any other questions?

Thank you. Now we will start the recording.

So, let's start with some warm-up questions to get you thinking about these topics.

#### **Organizational Details/Background**

- 1. What is your role in your organization?
  - a) What is your role in building the Statewide Task Force and Regional Community Work Groups?
  - b) Regarding the Statewide Task Force and Regional Community Work Groups, what activities have you enjoyed participating in the most?

Now I'd like us to shift gears a bit and think about the partnerships piece of this project.

#### **Building Partnerships**

- 2. In thinking about the Task Force and Work Groups, how would you define a successful partnership (or Task Force or Work Group)?
  - a) What qualities should a successful partnership have?
  - b) What facilitators are necessary for a successful partnership?
    - Financial (funding, incentives)
    - Non-financial (tech, admin, other)
- 3. How did you know if a particular Work Group was successful?
  - a) Can you describe a successful Work Group and a Work Group that was less successful?
  - b) What factors contributed to their success? What factors limited their success?
- 4. What factors influenced the success of the partnerships at state and regional levels?
  - Barriers and facilitators promoting/inhibiting successful partnerships
  - Contextual factors (local, historical, organizational)
- 5. What worked well for engaging and sustaining new partnerships?
  - a) How did you establish trust?
  - b) Did partners receive a stipend?
  - c) How did you share and communicate information with partners?
- 6. How did these engagement efforts vary based on the partner?
  - a) How, if at all, did partners' needs, limitations, or culture impact engagement efforts?
  - b) In what ways did your relationships with existing partners change throughout this work?
- 7. What difficulties, if any, did you experience in establishing or maintaining relationships with partners?
  - a) What engagement approaches didn't work well?
  - b) How, if at all, was the success of an engagement approach dependent on the partner organization or specific work group?
  - c) Which partners or sectors were you unable to engage in your efforts? What made it difficult to do so?

#### **Depth & Strength of Partnerships**

- 8. How did you support the Statewide Task Force and Regional Community Work Groups?
  - a) In what ways did you:
    - Identify creative ways to solve problems?
    - Minimize barriers to participation in meetings and activities?
    - Evaluate the progress and impact of the partnership?
- 9. What changes (if any) would you make to the structure of processes of the Statewide Task Force/Regional Community Work Groups?

a) What measures are in place to ensure the long-term sustainability of these partnerships?

#### **Evidence of Enhanced Capacity**

- 10. How, if at all, did you modify the products created and methods of working with partners to meet accessibility standards and audience needs?
- 11. What, if any, outcomes have you observed because of this partnership?
  - a) What would you say are the successes of the Task Force/Work Groups?
  - b) What impacts have the work of the Task Force/Work Group had on the community so far?
    - Individual and family-level impacts
    - Population-level impacts on communities
- 12. Thinking about your own organization, what policies, procedures, and processes at your organization have changed because of this collaboration?
  - a) To what extent is your organization better equipped to:
    - Raise awareness of the challenges the disability community faces in receiving healthcare?
    - Reach the disability community with targeted health communications?
    - Connect individuals with disabilities to needed services during health emergencies?
    - Prevent disparities in COVID-19 health outcomes among the disability community?
  - b) What measures are in place to ensure the long-term sustainability of the new efforts that were developed?
- 13. What can other organizations learn about creating systemic change from this effort?
  - a) What do you think are the biggest lessons learned from your role in this work?
  - b) In what ways does this effort impact work beyond the COVID-19 pandemic?

Before we wrap up, is there anything that we didn't cover that you'd like to share, or anything you'd like to emphasize for this interview?

[Wrap-up]

# Appendix C.

Statewide Task Force Interview Guide.

# COVID Health Equity PA <u>Statewide Task Force</u> Interview

Thank you again for meeting with me. My name is \_\_\_\_\_\_, and I'm working with The Arc of PA to learn more about the partnerships and organizations involved in the Statewide Task Force.

For today, we're hoping to talk about:

- The factors involved in building partnerships
- How your organization engaged in the task force
- What outcomes you've seen come out of this partnership

We'll use the answers from these interviews as part of our overall evaluation to assess how effective these novel partnerships were in increasing capacity to improve COVID health outcomes in the disability community.

Here are some important guidelines for our discussion today:

- This interview will last for about 60 minutes.
- There are no right or wrong answers. Keep in mind that we're just as interested in negative
  comments as positive comments. I encourage you to be direct and honest so we can use your
  feedback to learn about and improve this program.
- I'm tape recording the session because I don't want to miss any of your comments. People often say very helpful things in these discussions, and I can't write fast enough to get them all down.
- We will be on a first-name basis today, and we won't use any names in our reports. You may be
  assured of complete confidentiality. The reports will go back to our project team to learn from
  and improve Statewide Task Force operations.
  - We recognize that there may be discomfort in sharing your thoughts about this project with the group that is collaborating on this evaluation. We assure you that your name or organization will not be shared with The Arc of PA and that your participation or what you share will not impact your involvement in the Taskforce.
- If I move us along during the discussion, it isn't because I don't want to hear everything you have to say; it is because I want to be sure to discuss all the questions.

Are there any other questions?

Thank you. Now we will start the recording.

So, let's start with some warm-up questions to get you thinking about these topics.

#### **Organizational Details/Background**

- 1. What is your role in your organization?
- 2. What is your organization's role in the Statewide Task Force?

- a. How did you personally become involved in the work of the Statewide Task Force?
- b. How do your organization's goals align with the overarching mission of the Statewide Task Force?

Now we are going to talk about the partnerships.

#### **Depth & Strength of Partnerships**

- 3. In what ways did your organization engage in / contribute to the Statewide Task Force sessions? (probes: Sharing resources, Initiating collaborative activities, sharing knowledge)
- 4. I'm going to ask a few more direct questions to learn more about the way the SWTF engaged its partners. To what extent:
  - a) Were you involved in discussions and decision-making during SWTF meetings?
  - b) Were your ideas and feedback valued and incorporated in SWTF meetings?
  - c) Were your organization's priorities incorporated into the SWTF activities/approach?
- 5. What experiences, if any, do you have incorporating activities, ideas, or products from Task Force meetings into efforts outside of the SWTF meetings? (disseminating products, cross-posting social media...)
- 6. Think of a time when you felt particularly engaged in the Task Force/Work Group or when you felt the group was particularly successful, engaged, or seemed to be operating really well. What do you think led to that higher level of workflow?
  - a) What was happening in the group regarding activities, communication, timing, etc.?
  - b) How does this experience compare to a time when you felt less engaged in the Task Force or when you felt the group wasn't operating as well? What factors were at play there?
- 7. What other factors influenced the success of the partnerships within the Task Force?
  - Barriers and facilitators promoting/inhibiting successful partnerships
  - Contextual factors (local, historical, organizational)
- 8. What strategies or approaches incorporated community input and/or involvement during meetings?
  - a. How well does the Task Force/Work Group represent and include the populations or groups most impacted by its efforts?
- 9. What changes or improvements would you recommend to the structure or processes of the Statewide Task Force, if other organizations were to develop a similar initiative or if Arc of PA continues the SWTF?

#### **Evidence of Enhanced Capacity**

- 10. What would you say are the successes of the Task Force?
  - a. What, if any, outcomes have you observed because of this SWTF partnership?

- 11. Thinking about your own organization, what policies, procedures, and processes at your organization have changed because of the SWTF collaboration?
- 12. What can other organizations learn about creating systemic change from this SWTF effort?
  - a) In what ways does this effort impact work beyond the COVID-19 pandemic?
- 13. What do you think are the biggest lessons learned from your role in SWTF?

Before we wrap up, is there anything that we didn't cover that you'd like to share, or anything you'd like to emphasize for this interview?

[Wrap-up]

# Appendix D.

Regional Community Work Group Leader Interview Guide.

# COVID Health Equity PA Regional Community Workgroup Leader Interview

Thank you again for meeting with me. My name is	_, and I'm working with The Arc of PA
to learn more about the partnerships and organizations involved	in the Regional Community
Workgroup.	

For today, we're hoping to talk about:

- The factors involved in building partnerships
- How your organization engaged in the RCWG
- What outcomes you've seen come out of this partnership

We'll use the answers from these interviews as part of our overall evaluation to assess how effective these novel partnerships were in increasing capacity to improve COVID health outcomes in the disability community.

Here are some important guidelines for our discussion today:

- This interview will last for about 60 minutes.
- There are no right or wrong answers. Keep in mind that we're just as interested in negative
  comments as positive comments. I encourage you to be direct and honest so we can use your
  feedback to learn about and improve this program.
- I'm tape recording the session because I don't want to miss any of your comments. People often say very helpful things in these discussions, and I can't write fast enough to get them all down.
- We will be on a first-name basis today, and we won't use any names in our reports. You may be
  assured of complete confidentiality. The reports will go back to our project team to learn from
  and improve RCWG operations.
  - We recognize that there may be discomfort in sharing your thoughts about this project with the group that is collaborating on this evaluation. We assure you that your name or organization will not be shared with The Arc of PA and that your participation or what you share will not impact your involvement in the RCWG.
- If I move us along during the discussion, it isn't because I don't want to hear everything you have to say; it is because I want to be sure to discuss all the questions.

Are there any other questions?

Thank you. Now we will start the recording.

So, let's start with some warm-up questions to get you thinking about these topics.

#### **Organizational Details/Background**

- 1. What is your role in your organization?
  - a. How did you personally become involved in the work of the Regional Community Workgroup?
- 2. What is your organization's role in the RCWG?

a. How do your organization's goals align with the overarching mission of the Regional Community Work Group?

Now we are going to talk about the partnerships.

#### **Depth & Strength of Partnerships**

- 3. What factors influenced the success of the Work Group?
  - Barriers and facilitators promoting/inhibiting successful partnerships
  - Contextual factors (local, historical, organizational)
- 4. How supportive was your organization's leadership of the Work Group?
  - a. What, if any, changes occurred in your leadership during your participation in the Work Group?
- 5. In what ways did your organization engage in/contribute to the Regional Community Work Group sessions? (probes: Sharing resources, Initiating collaborative activities)
- 6. What experiences, if any, do you have incorporating activities, ideas, or products from Work Group meetings into efforts outside of the RCWG meetings? (probes: disseminating products, social media support, etc.)
- 7. How did the Work Group measure progress toward its goals?
- 8. What changes or improvements would you recommend to the structure or processes of the Regional Community Workgroups?
- 9. What do you see as the future of the Group? What do you see as its next steps?
- 10. What strategies or approaches incorporated community input and/or involvement during meetings?
  - a. How well does the Work Group represent and include the populations or groups most impacted by its efforts?

#### **Evidence of Enhanced Capacity**

- 11. What would you say are the successes of the Work Group?
- 12. What impacts have the work of the RCWG had on the community so far?
  - a. Individual and family-level impacts
  - b. Population-level impacts on communities
  - a) Probes:
    - Raise awareness of the challenges the disability community faces in receiving healthcare?
    - Reach the disability community with targeted health communications?
    - Connect individuals with disabilities to needed services during health emergencies?
    - Prevent disparities in COVID-19 health outcomes among the disability community?

- 13. Thinking about your own organization, what policies, procedures, and processes at your organization have changed because of the RCWG collaboration?
- 14. What measures are in place to ensure the long-term sustainability of the new RCWG efforts that were developed?
- 15. What can other organizations learn about creating systemic change from this RCWG effort?
  - a. In what ways does this effort impact work beyond the COVID-19 pandemic?
- 15. What do you think are the biggest lessons learned from your role in RCWG?

Before we wrap up, is there anything that we didn't cover that you'd like to share, or anything you'd like to emphasize for this interview?

[Wrap-up]

# Appendix E.

Regional Community Work Group Member Interview Guide.

# COVID Health Equity PA Regional Community Workgroup Member Interview

Thank you again for meeting with me. My name is \_\_\_\_\_\_, and I'm working with The Arc of PA to learn more about the partnerships and organizations involved in the Regional Community Workgroup.

For today, we're hoping to talk about:

- The factors affecting partnerships
- How your organization engaged in the RCWG
- What outcomes you've seen come out of this partnership

We'll use the answers from these interviews as part of our overall evaluation to assess how effective these novel partnerships were in increasing capacity to improve COVID health outcomes in the disability community.

Here are some important guidelines for our discussion today:

- This interview will last for about 60 minutes.
- There are no right or wrong answers. Keep in mind that we're just as interested in negative
  comments as positive comments. I encourage you to be direct and honest so we can use your
  feedback to learn about and improve this program.
- I'm tape recording the session because I don't want to miss any of your comments. People often say very helpful things in these discussions, and I can't write fast enough to get them all down.
- We will be on a first-name basis today, and we won't use any names in our reports. You may be
  assured of complete confidentiality. The reports will go back to our project team to learn from
  and improve RCWG operations.
  - We recognize that there may be discomfort in sharing your thoughts about this project with the group that is collaborating on this evaluation. We assure you that your name or organization will not be shared with The Arc of PA and that your participation or what you share will not impact your involvement in the RCWG.
- If I move us along during the discussion, it isn't because I don't want to hear everything you have to say; it is because I want to be sure to discuss all the questions.

Are there any other questions?

Thank you. Now we will start the recording.

So, let's begin with some background questions to get us started.

#### **Organizational Details/Background**

- 1. What is your role in your organization?
  - a. How did you personally become involved in the work of the Regional Community Workgroup?
- 2. What is your organization's role in the RCWG?

a. How do your organization's goals align with the overarching mission of the Regional Community Work Group?

Now we are going to talk about the partnerships.

#### **Depth & Strength of Partnerships**

- 3. In what ways did your organization engage in/contribute to the Regional Community Work Group sessions? (probes: Sharing resources, Initiating collaborative activities)
- 4. I'm going to ask a few direct questions to learn more about the way the work groups engaged its partners. To what extent:
  - a. Were you involved in discussions and decision-making during meetings?
  - b. Were your ideas and feedback valued and incorporated?
  - c. Were your organization's priorities incorporated into the partnership?
- 5. How supportive was your organization's leadership of the Work Group?
  - a. What, if any, changes occurred in your leadership during your participation in the Work Group?
- 6. What experiences, if any, do you have incorporating activities, ideas, or products from Work Group meetings into efforts outside of the RCWG meetings? (probes: disseminating products, social media support, etc.)
- 7. Think of a time when you felt particularly engaged in the Work Group or when you felt the group was particularly successful, engaged or seemed to be operating really well. What do you think led to that higher level of engagement?
  - a. What was happening in the group regarding activities, communication, timing, etc.?
  - b. How does this experience compare to a time when you felt less engaged in the Work Group or when you felt the group wasn't operating as well? What factors were at play?
- 8. How well does the work group represent and include the populations or groups most impacted by its efforts?
  - a. What strategies or approaches incorporated community input and/or involvement during meetings?
- 9. What changes or improvements would you recommend to the structure or processes of the Regional Community Workgroups?

#### **Evidence of Enhanced Capacity**

- 10. What would you say are the successes of the Work Group?
  - a. What, if any, outcomes have you observed because of this partnership?
- 11. Thinking about your own organization, what policies, procedures, and processes at your organization have changed because of the RCWG collaboration?

- 12. What can other organizations learn about creating systemic change from this RCWG effort?
  - a. In what ways does this effort impact work beyond the COVID-19 pandemic?
- 13. What do you think are the biggest lessons learned from your role in RCWG?

Before we wrap up, is there anything that we didn't cover that you'd like to share, or anything you'd like to emphasize for this interview?

[Wrap-up]

# Appendix F.

Codebook.

<u>Code</u>	<u>Definition</u>	<u>When to Use</u>	Examples (not exhaustive)
Organizational Details/Background	Basic details, introduction about who's on the call, typically at the beginning of the interview	Do not use the parent node	
<ul> <li>Participant</li> </ul>	Job title, retirement status		
Partner Organization	Characteristics of the organization;		Services, programming, how they

differ from other organizations, location (where they serve), etc.

"this is who we are and what we do"

Specific disability advocacy issues

that interviewees mention

Call to Action

Developing Partnerships [ACTIONS]		Do not use the parent node	
<ul> <li>Engaging existing contacts</li> </ul>	Experiences engaging with familiar	*This is about the initial convening of	
	organizations/individuals to form	the partners, most likely early in the	
	larger partnerships within Task	interview	
	Force/Work Group		
<ul> <li>Developing new relationships</li> </ul>	Experiences connecting with new	*This is about the initial convening of	Connecting with RCWG members,
	organizations/individuals within Task	the partners, most likely early in the	getting other people to join the Work
	Force/Work Group	interview	Group
<ul> <li>Community Involvement</li> </ul>	Instances where community		
	members were involved in		
	partnership activities		
<ul> <li>Buy-In/Motivation</li> </ul>	Experiences with getting/retaining	*This concept may come up	Ex: retaining RCWG member
	individuals/organizations to engage	pertaining to concrete actions to	motivation to attend meetings;
	with the Task Force/Work Group and	secure buy-in during meetings or	getting buy-in from stakeholders not
	activities	holistically/global, about this	previously in disability advocacy
		initiative overall	space to be part of Task Force
<ul> <li>Disability Advocate's or</li> </ul>	Personal and/or organizational		Behaviors, culture/climate,
Organization's skills/qualities	characteristics that		reputation, credibility, expertise,
	facilitated/strengthened/contributed		personality
	to the success of Task Force/Work		
	Group		

<u>Code</u>	<u>Definition</u>	When to Use	Examples (not exhaustive)
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Partnership Operations (SWTF/RCWG)		Do not use the parent node	
<ul> <li>Meetings</li> </ul>	Structure, culture, and processes within meetings		<ul> <li>Using existing platforms &amp; convenings for meetings</li> <li>Sharing agendas</li> <li>Establishing safe space practices</li> </ul>
Accommodations	Practices incorporated to promote accessibility <b>and inclusion</b>	May relate to accommodations in Partnership meetings or outside (e.g., in products)	<ul> <li>Getting Spanish-speaking translators for Listening Tours</li> </ul>
• Activities	Activities conducted during meetings; "what happened in meetings?"		<ul> <li>Discussing</li> <li>barriers/disparities</li> <li>Reflecting on listening tours</li> <li>Prioritizing, editing</li> </ul>
• Roles	Participants' roles during meetings		Member, facilitator, etc.
Engagement depth	Discussion around how (much/often) members participated/contributed to meetings and how they engaged/participated/contributed		<ul> <li>Attendance</li> <li>Participants' discussion</li> <li>around how ideas were</li> <li>incorporated into tasks, etc.</li> </ul>
• Purpose	Purpose of meetings, specific deliverables, long and short-term goals		Differing viewpoints on meetings', deliverables' purpose
Overall partnership workflow	Discussion on how these entities (RCWG, SWTF) feed information to each other and build off one another		

		Code	Definition	When to Use	Examples (not exhaustive)
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Enhanced Capacity [OUTCOMES]		Do not use the parent node	
Partners' awareness	Awareness of challenges the disability community faces in accessing healthcare, and resources available to mitigate	*This is about the partner's awareness of issues	Arc of PA transcript – PA Nurses Association leader, "light bulb" moment regarding training nurses
Communities' awareness	Awareness of challenges the disability community faces in accessing healthcare, and resources available to mitigate	In the larger community, are people more aware?	
Changes in practice	New practices/activities to address disability challenges  Changes in how/where organizations participate		<ul> <li>RCWG members stepping up to join other boards</li> <li>Arc of PA is now more active in the "health space"</li> </ul>
Disseminating information	How partners' shared materials created/collected to report results, share information		<ul><li>Barriers/Solutions report</li><li>Health disparities database</li></ul>
Relationship-building	Connecting to new people, resources, information or connecting differently or connecting more deeply	*Creating partnerships/experiencing changes in relationships, because of the grant	<ul> <li>Disability advocates "putting down their pitch forks"</li> <li>Knowing who to call when an issue comes up</li> <li>"Pockets of work"</li> </ul>
Sustainability of Intervention	Discussion around the sustainability of this initiative/intervention (this Task Force/Work Group entity)	*Thinking ahead to the future	
Improved (public health)	Evidence of improved health outcomes by key indicators	Honestly, this is very unlikely to come up, but just in case	<ul> <li>Personal rating of health</li> <li>Ability to get vaccines</li> <li>Easier access to care</li> </ul>
Lessons/Takeaways from the Experience	Reflections on the experience; includes reflections beyond COVID-19		"What can other organizations learn about creating systemic change from this effort?"  "What are the biggest lessons learned from your role?"

<u>Code</u>	<u>Definition</u>	<u>When to Use</u>	Examples (not exhaustive)
-------------	-------------------	--------------------	---------------------------

	Structu	ral Codes	
Barriers	Challenges/obstacles that impede success, progress; include contextual factors	Co-code with thematic code when relevant	
Facilitators	Things that helped/supported	Co-code with thematic code when	
	successes, progress	relevant	
Improvements	Changes/recommendations in	Co-code with thematic code when	
	response to barriers	relevant	

# Appendix G.

Statewide Task Force Organization Scan.

# **Organizational Scan Memo Arc of PA Statewide Leadership Task Force**

Prepared by the Research & Evaluation Group at Public Health Management Corporation June 2023

### **About this Memo**

The Arc of Pennsylvania, a leading PA disability rights organization, established a Statewide Leadership Task Force in 2021 as part of their CDC-funded Initiative to Address COVID-19 Health Disparities among People with Disabilities.

The R&E Group conducted a scan of participating organizations to investigate the diversity of Statewide Task Force membership regarding: populations served, sector, size, types of **service offered,** and **geography**. The scan also evaluated the potential **reach** of Task Force dissemination efforts.

Data was collected via online search and is therefore limited to publicly available information.

# **Scan Findings**

The Task Force consisted of 31 members representing 23 organizations.

# **Organization Focus Populations**

Organizations served a variety of individuals, with 57% serving one focus population and 43% serving 2–3 focus populations:

78% of organizations served people with disabilities (n=18)

30% of organizations served healthcare workers & professionals (n=7)

17% of organizations served rural residents (n=4)

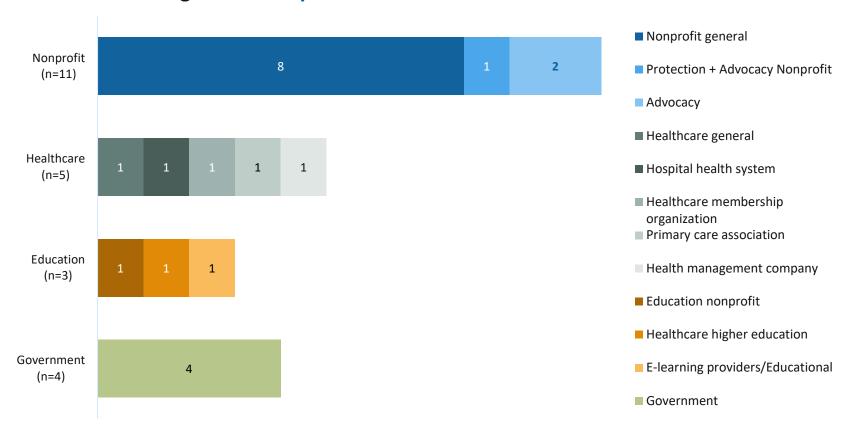
17% of organizations served racial/ethnic minorities (n=4)

4% of organizations served teachers and school employees (n=1)



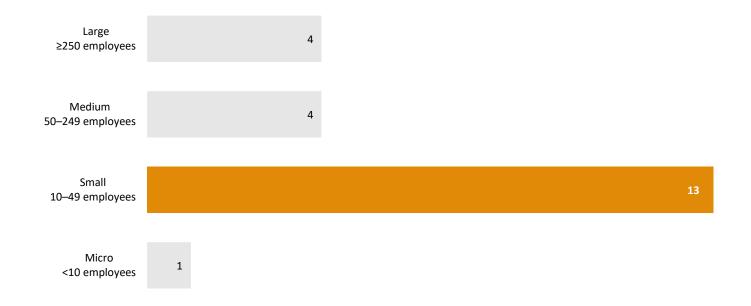
#### Sector

Organizations in the Statewide Task Force were most frequently classified as being in the Nonprofit or Healthcare sectors.



# **Organization Size**

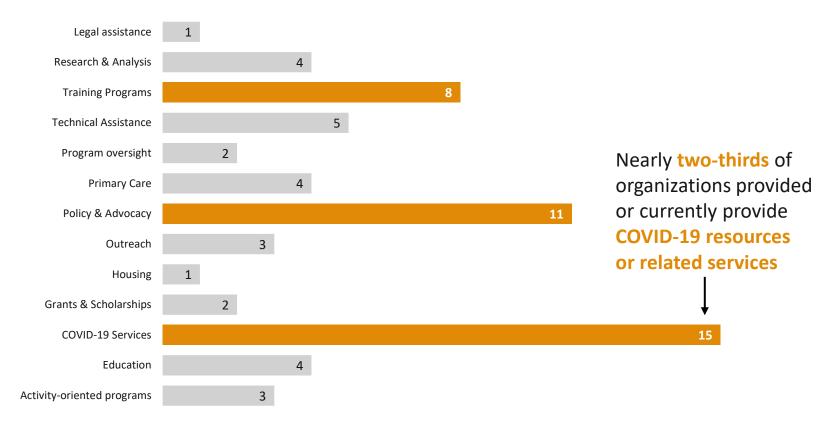
The vast majority of organizations were small, with almost 40% employing fewer than 20 employees.





#### **Services Offered**

The three most prevalent services offered were **COVID-19 services**, **Policy & Advocacy**, and **Training Programs**.



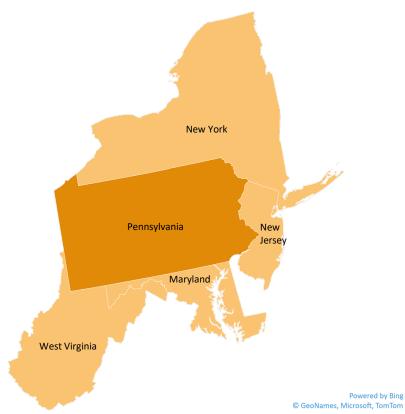
#### **Reach and Service Areas**

14

organizations served all of **Pennsylvania** without a more specific geographic focus.

1

organization provided services **nationwide** with no regional focus.

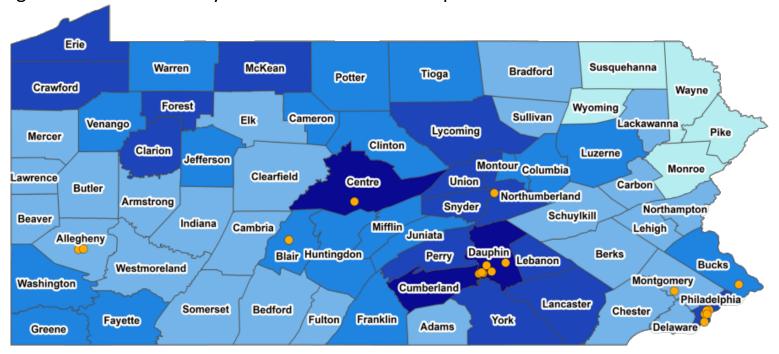


Task Force organizations also served communities in New Jersey, New York, Maryland, and West Virginia.



#### **Reach and Service Areas Continued**

Centre, Cumberland, and Dauphin counties were served by SWTF organizations the most at 18 organizations. The Pennsylvania health districts are presented below for reference.





During the initial research, some organizations specified which counties they served while others simply stated that they served the entire state. There were 14 organizations whose target geography was the entirety of Pennsylvania, which is why 14 is the lowest number in the map legend.



# Appendix H.

Regional Community Work Group Organization Scan.

# Organizational Scan Memo Arc of PA Regional Community Work Group

Prepared by the **Research & Evaluation Group** at Public Health Management Corporation

September 2023

#### **About this Memo**

The Arc of Pennsylvania, a leading PA disability rights organization, established Regional Community Work Groups in 2021 as part of their CDC-funded Initiative to Address COVID-19 Health Disparities among People with Disabilities.

The R&E Group conducted a scan of Regional Community Work Group participating organizations to investigate the diversity of membership regarding: **membership composition**, **populations served**, **sector**, **types of COVID-19 service offered**, **geography**, **and** the potential **reach** of Task Force dissemination efforts.

Data was collected via online search and is limited to publicly available information.

# **RCWG Scan Findings**

The Regional Community Work Groups (RCWGs) consisted of **224 individuals** across **155 entities which includes organizations, self advocates, and retirees**.

All 224 RCWG members were asked to report their **Participant Type** (Advocate for those with Disabilities, Person who Identifies as having a Disability, Professional, Parent/Family Member/Care Provider).

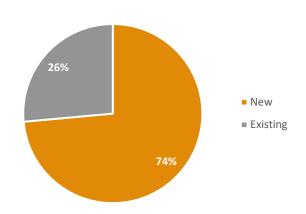
Additional data indicated significant overlap between Participant Type categories, illuminating the nuanced, intersectional nature of participant identities:

- 75% selected Professional (n=169)
- 10% selected Person who identifies as having a disability (n=22); 7 of whom also selected the Professional title
- 10% selected Advocate for those with disabilities (n=22)
- 5% selected Parent/Family member/Care provider (n=11)
- 7% reported their participant type as *something other than* **Advocate for those with disabilities** but held professional titles indicating their involvement in disability advocacy work (n=16).

# **New and Existing Partnerships**

There were 114 new organizations, self-advocates, and retirees\* (74%) in the Regional Community Work Groups. A total of 41 (26%) organizations, advocates, and retirees were pre-existing partnerships.

<sup>\*</sup>The Arc of Pennsylvania indicated in their data whether or not an organization, self-advocate, retiree was a partnership that was new to Arc or was an existing partnership.





### **Target Population Composition**

IDD, ASD, Dual Diagnosis*  46.8%  Other & Multiple  Physical  14.5%  13.9%
--

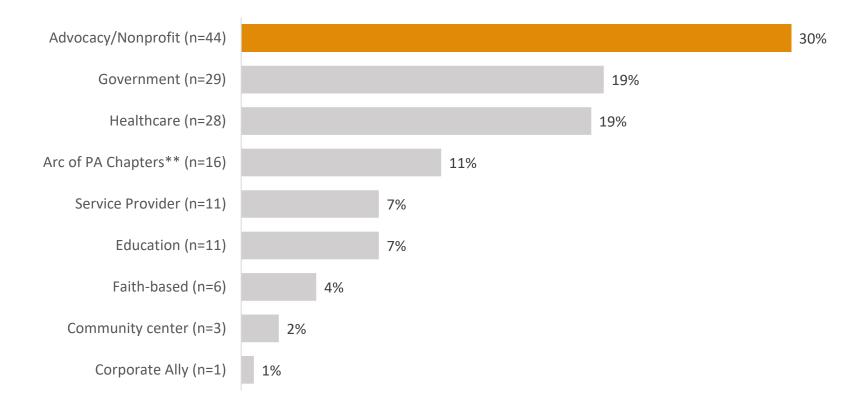
Each RCWG coordinator was asked whether any members of their group (1) identified as having a disability; (2) represented agencies serving the disability community; and/or (3) were family members of or caregivers for people with a disability, and if so, what type(s) of disability. The workgroups reported 163 members who fit the criteria above.

	*Disability Type Abbreviations
IDD	Intellectual/Developmental Disability
ASD	Autism Spectrum Disorder
DHH	Deaf/Hard of Hearing
BVI	Blind/Visually Impaired
DB	Deaf-Blind

**Disability Types** represented across individuals and agencies in the RCWGs reflected the Arc of PA's priority population, with Intellectual/Developmental Disabilities, Autism Spectrum Disorder, Dual Diagnosis composing nearly half (46.8%, n=81) of the 173 reported.

#### **Sectors**

A majority (n=44) of Regional Community Work Group organizations were from the **Advocacy/Nonprofit** sector\*. Government (n=29) and Healthcare (n=28) organizations also took up a large share of all organizations.



<sup>\*</sup> **Sector** in this instance refers to each organization's primary business or operational focus.

<sup>\*\*</sup> There is a specific category for Arc of Pennsylvania chapters that were a part of the RCWG initiative. While Arc organizations can be categorized as Advocacy/Nonprofit or other sectors, we have decided to keep them a separate category to show the prevalence of RCWG organizations that were not directly affiliated with the Arc.

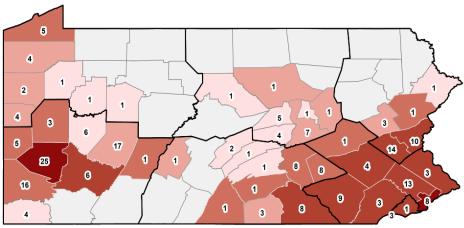


#### **Reach and Service Areas**

Each RCWG organization listed the counties that they serve. R&E leveraged this data to total the number of organizations working in each county while cross-referencing such data with total COVID-19 cases for each area.

The maps below are divided by Pennsylvania's health districts, the map for which is presented on the side for reference. All COVID-19 data was taken from Open Data Pennsylvania.





**COVID-19 Cases by RCWG-Covered Counties** 

5813 - 18593 18594 - 35550 35551 - 73534 73535 - 202195 202196 - 397762

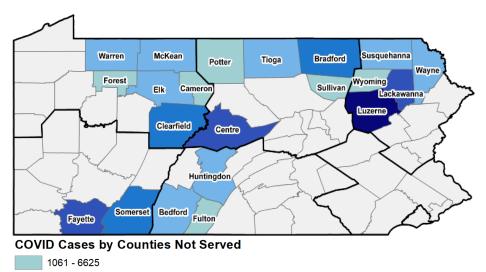
6626 - 14010

14011 - 24793 24794 - 59785

59786 - 95778

This heat map shows the prevalence of **COVID-19 by cases** for each county that was served by a RCWG organization. The numbers above each county shows how many RCWG organizations served those areas.

Some counties, such as **Allegheny** was served by a proportional number of organizations relative to the number of COVID cases. Counties such as **Delaware and Bucks** had a disproportionately low number of organizations relative to the number of COVID cases.



This map shows the prevalence of COVID-19 cases in the 21 counties not served by any RCWG organization during the initiative.

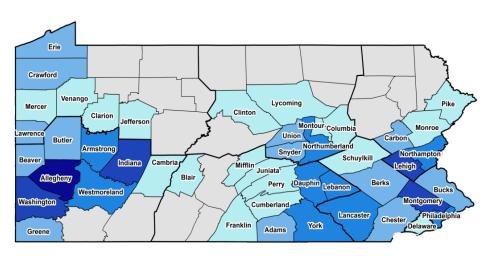
The maximum number of cases in unserved counties (n=95,778) was lower than the maximum number of cases in RCWG-served regions (n=397,762).

These unserved counties present opportunities to expand the RCWG's overall reach and geographical diversity. It also displays potential to reach more target demographics in Pennsylvania.

<sup>\*</sup>These maps show aggregate COVID data from March 1, 2020 to June 15, 2023, which is when Open Data Pennsylvania stopped tracking COVID-19 case data. Also note that data for the counties covered by the RCWGs as shown in these maps are based solely off of materials provided by the Arc of Pennsylvania. COVID-19 services and other related work may have occurred in counties shown in the second map. The maps do not account for this possibility and are merely reflecting the information provided by the Arc of Pennsylvania materials.



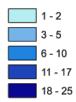
# **Reach and Service Areas Continued**



This map shows how many RCWG organizations served which Pennsylvania counties.

Allegheny county had the highest number of RCWG organizations serving their area at 25 organizations.

## **Count of RCWG Organizations per County**



# **Regional Community Work Group Sampling Method**

## **Reasons for Stratifying**

The original plan for the RCWG organization scan was identify each of the 149 organizations' target populations, COVID-19 services, sectors, geography, and other key figures.

However, the Research and Evaluation team decided that doing so for 149 organizations would not be feasible given the time and resources allocated to this analysis. After discussing with NNPHI, the team opted to conduct a truncated analysis using a **proportional stratified random sample**.

Initially, R&E planned to stratify by geography and organizational sector. However, the sample of 149 organizations was not statistically significant to properly stratify by both categories. As such, sector became the primary category.

#### **Stratification Methods**

R&E Group identified a proportional stratified random sample based on sector to conduct an analysis of target populations and COVID-19 services. Sectors included Advocacy/Nonprofit, Arc Affiliate, Community Center, Education, Faith-Based, Government, Healthcare, Service Provider.

A total of 48 organizations were chosen from the full sample, representative of sector proportions. The number 48 was selected to represent about one-third of the total number of organizations. To find the appropriate number to include for each subgroup, R&E used this equation:

For example, there were 44 Advocacy/Nonprofit organizations. When inserted into the equation we find this:

Based on this equation, we find that 14 Advocacy/Nonprofit organizations will be randomly selected for the 48 organization sample. This equation was applied to each of the 8 categories, after which random samples were selected using SPSS. The proportional stratified random sample of RCWG organizations used for this analysis are the following:

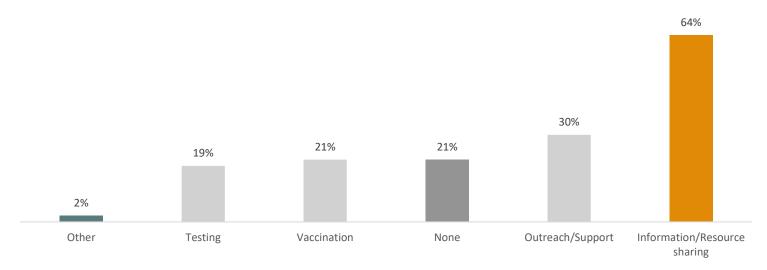
Advocacy/Nonprofit	Healthcare	Government	Corporate Ally
Academy for Adolescent Health	Cornerstone Care	Bucks County Department of Health	IndiGo
American Red Cross	Excela Health	Chester County Department of Human	Arc Chapters
Community Hero Action Group	Good Shepherd Rehabilitation	Services	ARIN IU 28
Disability Options Network	Network	City of Philadelphia	CMU
Easterseals Eastern PA	IRMC	HCQU	Duquesne University
Grapevine Center	Jefferson Center for Autism and	Indiana County Sheriff's Office	Penn State College of Medicine
Greater Pittsburgh Digital Inclusion	Neurodiversity	Local Emergency Planning Committee	Service Provider
Alliance	Primary Health Network	Montgomery County Office of Mental	BCRC
Growth Horizons	The Advocacy Alliance/South Central	Health	Person Directed Supports, Inc
GSV United Way	Health Care Quality Unit (SC-HCQU)	OVR	Threshold Rehabilitation Services Inc.
Mental Health America Lancaster	Union Community Care	Philadelphia Department of Public	
County	Washington Health System	Health	Arc Chapters
,		<u> </u>	The Arc Indiana County
PAHrtners Deaf Services	Faith-Based	Community Center	The Arc Alliance
Susquehanna Service Dogs	Friendship Community	Hispanic Center Lehigh Valley/St.	The Arc Lancaster Lebanon
Susquehanna Valley Mediation	New Castle UMC	Luke's University Health Network	The Arc of Pennsylvania
Vibrant Strategies			The Arc of York County



# **Stratified Regional Community Work Group Findings**

## **COVID-19 Services**

Most organizations offered multiple COVID-19 services (43%, n=20), although 21% did not offer any (n=10). Information/Resource Sharing was the most common COVID-19 service by far (64%, n=30). One organization offered COVID Long Haulers Treatment (categorized as Other), a specialized service for patients suffering from long COVID. This unique service along with the number of organizations rolling back or not offering any services speak to evolving priorities in the ongoing COVID-19 pandemic.

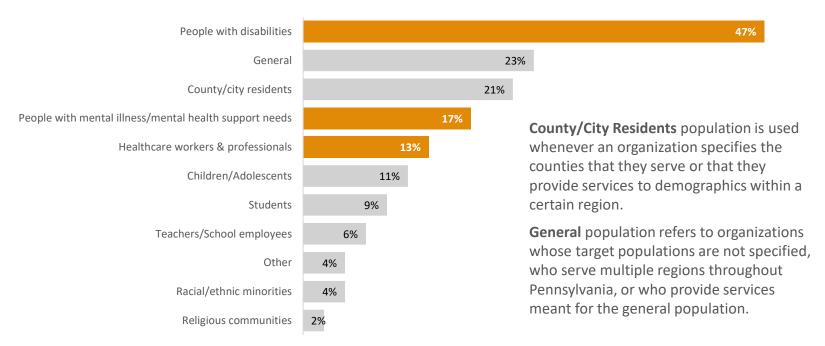


**Information/Resource Sharing** refers to any activity that provided COVID-19 guidance or other relevant information and resources to an organization's constituency.

**Outreach/Support** refers to activities such as connecting individuals to COVID services, modifying daily activities to accommodate for COVID protocols, and other initiatives that goes beyond simply sharing information or resources.

# **Populations Served**

Organizations served a variety of individuals, with **57% serving one focus population** (n=27) and **43% serving multiple focus populations** (n=20). Most (77%, n=36) served at least one population related to health and/or disability: **People with disabilities** (47%, n=22), **People with mental illness/mental health support needs** (17%, n=8), and **Healthcare workers and professionals** (13%, n=6). The diversity of the populations served by the RCWG composition indicates increased capacity to address health disparities and advance health equity among a wide range of demographics including high-risk populations.



<sup>\*</sup>Note: n=47 for both COVID-19 Services and Populations Served. One of the 48 organizations was excluded from calculations, as it did not have any information about services offered or populations served available online.



# Appendix I.

Attendance Analysis.

# **Attendance Analysis Memo: Regional Community Work Groups**

Prepared by the **Research & Evaluation Group** at Public Health Management Corporation for The Arc of Pennsylvania

August 2023

#### **About this Memo**

The **Regional Community Work Group** aimed to increase awareness of the COVID-19 barriers the disability communities face at the **local level** while identifying and improving awareness of potential solutions and best practices for future emergencies.

The R&E Group conducted an **analysis of attendance logs** to investigate an aspect of **overall engagement** of each regional community work group within the initiative. The data in this memo is based on attendance logs and figures provided by the Arc of Pennsylvania.

To answer, in part, the question: "To what extent were partner organizations engaged in the initiative?", this analysis looks at each RCWG's attendance for 6 RCWG sessions (session 2-7).

#### **Regional Community Work Group Background**

There were 13 Regional Community Work Groups (RCWG) managed by 10 The Arc of Pennsylvania Chapters.

Arc Chapters	RCWGs (one group per cell)			
	Allegheny			
Achieva	Beaver, Butler, Lawrence			
	Erie, Crawford			
	Westmoreland			
Alliance	Berks, Bucks, Chester, Montgomery			
Indiana	Armstrong, Indiana			
Lancaster/Lebanon	Lancaster, Lebanon, Dauphin			
Lehigh Northampton	Lehigh, Northampton, Schuylkill			
NEPA	Carbon, Lackawanna, Luzerne, Monroe, Pike,			
	Susquehanna, Wayne			
Philadelphia/City of Inclusion	Philadelphia			
Susquehanna Valley	Northumberland, Snyder, Union, Columbia, Montour			
Washington	Greene, Washington			
York	York & Adams			

The Arc of Pennsylvania initiated 7 RCWG sessions from November 2021 to April 2023. For each session, the Arc of Pennsylvania facilitated multiple, 2-hour virtual meetings over 4-5 days, from which members of the work groups could attend based on their availability. The **Arc chapter coordinators** received the meeting links and registered groups based on their availability. The Arc members took notes on behalf of their RCWGs or, on occasion, facilitated parts of the meeting.

#### **Considerations**

While attendance was limited for certain work groups when compared with another, this does not necessarily indicate a lack of engagement from RCWG organizations. Attending meetings was a part of each RCWG's tasks. Work groups routinely provided valuable input by creating and holding presentations, disseminating resources, conducting advocacy work, and other initiatives throughout the course of the meeting sessions. As such, a work group with low attendance should not immediately be labeled as being disengaged.



#### **Regional Community Work Group Attendance**

The table below shows attendance across RCWG meeting series #2-7. The Arc chapter members were excluded to focus on the participation of non-Arc organizational members. Each meeting was held virtually. The Arc of Pennsylvania collected attendance data from each meeting's Zoom data. The attendance data from session 1 is excluded from this analysis as The Arc did not have the necessary Zoom account access for the first meeting.

High attendance, defined as over 10 members, is displayed as colored + bolded text.

- Members of all work groups attended at least one RCWG session.
- Attendance was highest at Session #2 and decreased over the course of the sessions.
- Members of 7 of the 13 RCWGs attended every work group session.
- The Allegheny/Erie and Lancaster work groups consistently had the highest number of attendees across sessions 2 through 7.

Number of members who attended Sessions, by Work Group

	Session #2	Session #3	Session #4	Session #5	Session #6	Session #7	<b>Grand Total</b>
Allegheny/Erie	13	14	14	12	9	14	76
Butler	3	5	3	7	4	1	23
Westmoreland	3	7	2	4	0	3	19
Crawford	0	1	1	0	0	0	2
Alliance	5	2	4	1	3	1	16
Indiana	16	7	6	6	11	8	54
Lancaster	20	16	10	4	11	6	67
LHNH	4	3	0	0	0	0	7
NEPA	14	2	4	0	0	0	20
Susquehanna	2	3	1	1	0	0	7
Wash/Greene	11	4	6	4	2	7	34
York	3	3	3	6	3	3	21
Uncategorized*	2	8	2	0	0	0	12
Philadelphia**	1	0	0	0	0	0	1
Total (per session)	97	75	56	45	43	43	493

<sup>\*</sup> Refers to individuals who were not assigned to a specific group, according to the Arc of Pennsylvania.

<sup>\*\*</sup> The Philadelphia Arc Chapter coordinator was involved in a regional health disparities initiative with an organization called Cities of Inclusion, a group of non-profit organizations and local health organizations in Philadelphia. The Arc Chapter coordinator attended the RCWG sessions and would share information discussed during RCWG meetings with Cities of Inclusion, rather than have those members attend the RCWG sessions as well. Therefore, there is only one recorded participant for the Philadelphia work group, as members were not asked to attend any meetings after the second session.

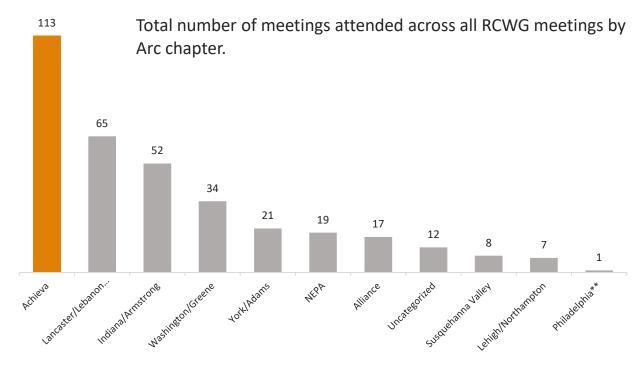




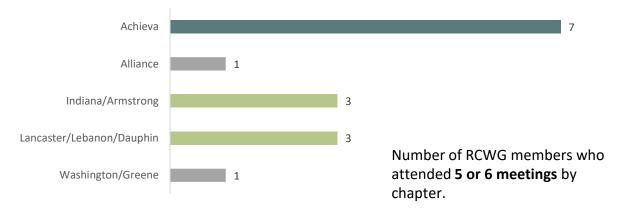
# **Regional Community Work Group Attendance By Chapter**

Regional community work group members attended 349 total meetings between sessions 2 through 7. This total excludes any RCWG members who were also The Arc of PA staff.

After accounting for all unique RCWG participants across the 6 RCWG sessions, the Achieva chapter, which coordinated 4 RCWGs, attended meetings most frequently at 113. This accounted for nearly one-third of all meeting attendances.



Chapters had specific members who attended meetings more frequently than others. The **Achieva chapter** had 7 different non-Arc RCWG members attend 5 or 6 meetings\*, with the **Indiana/Armstrong** and **Lancaster/Lebanon/Dauphin** chapters each having 3 such members.



<sup>\*</sup>The Lehigh/Northampton, NEPA, Philadelphia, Susquehanna Valley, and York/Adams did not have members who attended 5 or 6 meetings.



#### **Methods**

The Arc of Pennsylvania provided a spreadsheet showing total attendance across Regional Community Work Group meetings #2 through #7. They also provided a total unique participant count from every work group for each The Arc chapter. Total attendance counts were grouped into The Arc chapters.

The R&E team collaborated with the Arc of Pennsylvania team through emails and virtual meetings to clarify how the meetings were held, how attendance was logged, and certain discrepancies in the total counts.

Attendance totals were counted for all unique participants and divided by both work groups and by Arc chapters.

#### **Limitations**

There was no official process for keeping count of the attendees for each group. Zoom links for the RCWG meetings were provided to The Arc chapter coordinators who would then disseminate the links to work group participants.

Zoom only provided the names of each participant and did not delineate their organizations or work groups.

The Arc of Pennsylvania worked with a health organization in Philadelphia county that was conducting similar work to the RCWGs. They utilized a liaison who attended both The Arc RCWG meetings and meetings from the independent Philadelphia organization. Both The Arc and the Philadelphia organization exchanged information and notes throughout the course of the meetings. As such, the attendance for the Philadelphia chapter remained low to non-existent throughout the initiative due to a lack of a participating work group.



# **Regional Community Work Group Composition & Data Collection**

**Work groups** typically represented a single county or region. **Chapter coordinators**, who were designated by The Arc chapters, recruited RCWG members within the counties that they managed.

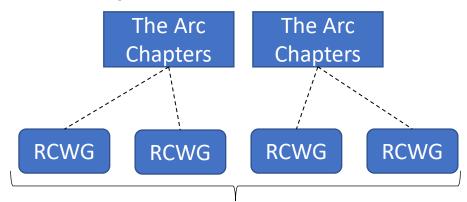
**Chapter coordinators** created and managed the RCWGs, as the Arc of Pennsylvania hoped that this would facilitate strong relationships between The Arc chapters and their regional partners. The Arc chapters sent the work group registration links to listservs and to individual recruits.

Most work groups maintained a membership list using the online registration link, but some chapters such as Achieva maintained their membership information themselves.

Originally, **chapter coordinators** planned to hold separate work group meetings by county, but eventually created work groups that represented multiple counties such as the "Lancaster, Lebanon, Dauphin" group. This allowed for wider regional coverage.

Throughout the course of the meeting sessions, The Arc chapters with one county or work group shifted from a county-oriented mindset to a region-oriented one.

Some chapters would also expand the number of counties that they covered. The Achieva chapter originally started with Allegheny, Erie, Beaver, Lawrence, and Westmoreland work groups, and eventually added Butler during the series.



Created and managed by Arc chapters

Certain groups **would merge with others** due to scheduling conflicts or a lack of resources to carry out project initiatives.

The Washington and Greene work groups merged due to Greene lacking the proper resources and capacity to keep up with project initiatives. Allegheny and Erie also combined during the meeting sessions.

Groups That Merged During Meetings + Merged Group Name							
Allegheny + Erie	Allegheny/Erie						
Washington + Greene	Washington/Greene						

# **Attendance Analysis: Statewide Taskforce**

Prepared by the **Research & Evaluation Group** at Public Health Management Corporation for The Arc of Pennsylvania

August 2023

### **About this Report**

As part of their CDC-funded **Initiative to Address COVID-19 Health Disparities among People with Disabilities, The Arc of Pennsylvania**, a leading PA disability rights organization, established a **Statewide Task Force** in 2021.

The R&E Group conducted an **attendance log analysis** to investigate the **overall engagement** of the statewide task force during the initiative. The data in this memo is based on attendance logs and figures provided by The Arc of Pennsylvania.

#### **Considerations**

While attendance was limited for certain task force organizations, this does not necessarily indicate a lack of engagement from task force organizations. Attending meetings was a key task. Each task force organization provided valuable input in discussing pertinent topics, disseminating resources, gathering member input, and other initiatives throughout the course of the meeting sessions. As such, a task force with low attendance should not immediately be labeled as being disengaged.

### Statewide Leadership Task Force (November 2021 – May 2023)

The Statewide Leadership Task Force meetings were attended by **33 members** from the following organizations:

The Arc of Susquehanna	Rehabilitation & Community Providers Association
Department of Human Services (DHS)	Temple University Institute on Disabilities
Penn State Health	Hispanos Unidos para Niños Excepcionales (HUNE)
Vision for Equality	Department of Education   Bureau of Special Education
Office of Developmental Programs	Pennsylvania Association of Community Health Centers
The Hospital and Health System Association of Pennsylvania	Jefferson Continuing Care Program
The Arc of Pennsylvania	Pennsylvania State Nurses Association (PSNA)
Pennsylvania Developmental Disabilities Council	Dignity Health Global Education
The Arc of Blair County	UPMC
Department of Human Services - Office of Mental Health & Substance Abuse Services	PerformCare
Harrisburg University of Science and Technology	Pennsylvania State Nurses Association (PSNA) & Harrisburg University of Science and Technology
Special Olympics Pennsylvania	Physician General for the Commonwealth of Pennsylvania
Pennsylvania Statewide Independent Living Council	Woods Services
Pennsylvania Counsel for Independent Living	Ceisler Media
Disability Rights Pennsylvania	Pennsylvania Office of Rural Health

# **Statewide Leadership Task Force (November 2021 – May 2023)** continued

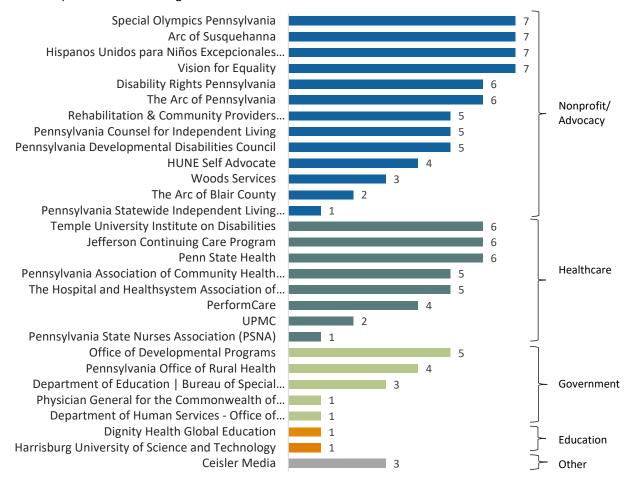
#### Statewide Leadership Task Force Attendance by Meeting

	Meeting							
	#1	#2	#3	#4	#5	#6	#7	
# of Attendees	16	16	21	17	17	18	19	

Members consistently attended the Statewide Leadership Task Force meetings. **Meeting #3** (May 13, 2022) saw the highest number of attendees at 21.

Out of the 30 organizations who attended at least one Statewide Taskforce Leadership meeting, 4 attended every meeting. Each of these 4 organizations with a perfect attendance were from the Nonprofit/Advocacy sectors.

Organizations from the **Healthcare sector** also showed consistent attendance throughout the Statewide Leadership Task Force meetings.



#### Methods

The Arc of Pennsylvania provided a spreadsheet with attendance records for all seven Statewide Leadership Task Force meetings from November 2021 to May 2023. The spreadsheet also provided which representatives were present and which organizations were excused from attending.

The R&E team totaled the number of times each organization attended a Statewide Leadership Task Force meeting.

#### **Limitations**

The attendance logs provided by The Arc of Pennsylvania noted whether certain participants were late or did not attend the entire meeting. Due to limited information on when each meeting was held, these details were not fully reflected in the bar chart in page 7.

The attendance logs also noted whether certain participants were alternates from those who initially signed on to attend each meeting. The data for the chart in page 7 does not specify whether certain organizations sent an alternate, and simply counts these instances as regular attendance.



# Appendix J.

Impressions & Clicks Analysis.

# **Impression and Click Analysis Report**

Prepared by the **Research & Evaluation Group** at Public Health Management Corporation for The Arc of Pennsylvania

October 2023

### **About this Report**

As part of their initiative to address COVID-19 health disparities among people with disabilities, The Arc of Pennsylvania disseminated various media campaign products promoting COVID-19 services and resources through digital and radio advertisements.

The Arc of Pennsylvania sourced iHeartMedia to track total impressions and clicks generated by the media campaign products. The Research & Evaluation Group analyzed 12 impression and click reports to understand the extent to which there was a potential increase in awareness of disparities among individuals living with disabilities in Pennsylvania and of resources related to COVID-19. This document presents findings and takeaways from this analysis.

### **Media Campaign Products**

The Arc of Pennsylvania worked with a subcontractor to develop COVID-19 educational and outreach materials through online pop-up advertisements, audio advertisements, and other static ads disseminated through social media. These materials targeted the disability community as well as home and community-based service providers in Pennsylvania.

These materials targeted individuals with disabilities in racially and ethnically diverse communities as well as rural regions. They focused heavily on dispelling COVID-19 myths, building trust, and communicating in languages understood by the disability community. Examples of the static ads used in this campaign are below:







The Arc of Pennsylvania also shared audio advertisements and live radio broadcasts to disseminate COVID-19 educational and outreach materials during the campaign. Metrics from these resources are also included in this analysis.



### **Evaluation Findings (June 2022 - May 2023)**

#### **Data Collection and Definitions**

The Arc of Pennsylvania worked with iHeart Media to track the visibility of the different media campaign products, mainly focusing on "impressions" and "clicks" generated by the various audio and static ads used in this campaign.

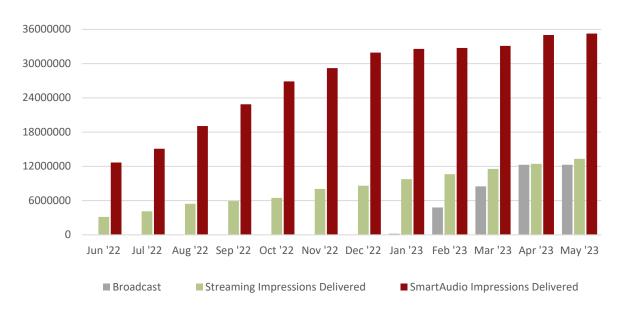
An **impression** is measured based on the number of times an ad was seen or heard. This applies to both the static digital ads as well as audio ads and radio broadcasts used for this campaign. A **click** is measured by the number of times the static ad is clicked on for more information.

#### SmartAudio, Streaming, and Broadcasts: Impressions

The Arc of Pennsylvania produced radio advertisements to promote COVID-19 information and resources. These advertisements were disseminated through both terrestrial radio and through iHeartRadio, a digital streaming platform.

The terrestrial radio advertisements were tracked through Smart Audio, while advertisements played through iHeartRadio were tracked on its own. There were also live radio advertisements that were broadcast between February to May of 2023 that was tracked separately.

SmartAudio advertisements gained substantially more impressions than the streaming advertisements and the live broadcasts. All three types gradually gained more impressions over time, with streaming and SmartAudio impressions leveling out in the last two



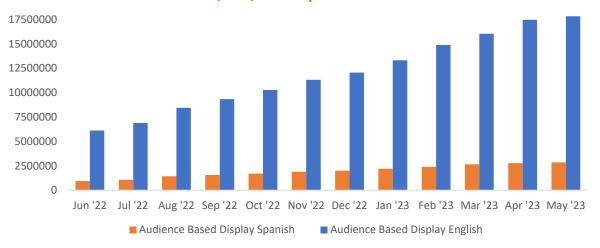


## **Evaluation Findings (June 2022 - May 2023)**

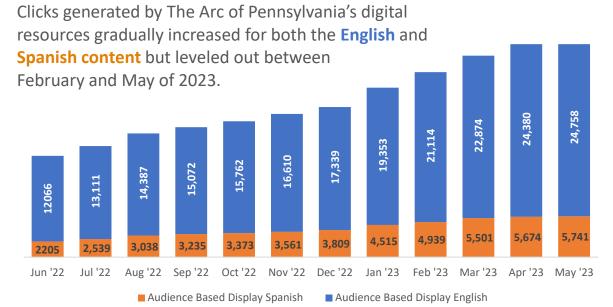
#### **Display Ads: Impressions and Clicks**

The Arc of Pennsylvania disseminated online pop-up advertisements and other digital media. iHeartRadio tracked both the total impressions and clicks generated from all resources. All digital materials were translated to Spanish, the impressions and clicks for which were tracked separately.

The total number of impressions for the English audio advertisements was **17,834,143**. The Spanish audio advertisements **received 2,865,145** impressions.



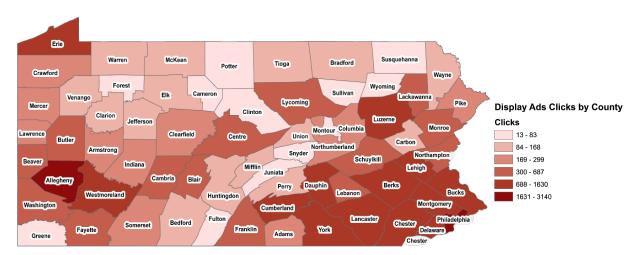
As more digital resources were disseminated between June 2022 and May 2023, total impressions gradually increased for both English and Spanish content. Clicks generated by the resources generally followed the same trend.



# **Evaluation Findings (June 2022 – May 2023)**

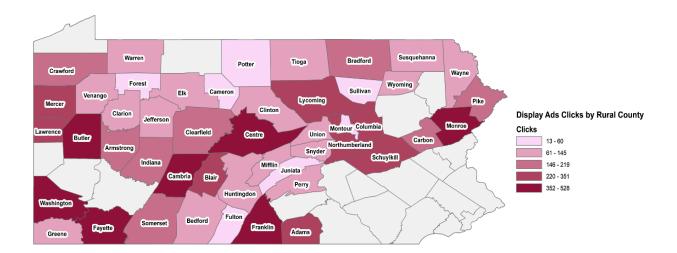
#### **Geographic Reach**

iHeartMedia provided The Arc of Pennsylvania with geographic information on where those impressions and clicks were coming from. The Arc of Pennsylvania then organized the data by Pennsylvania counties, with a specific focus on noting whether rural counties were viewing and clicking on the resources.



Counties from the **Southeast region** consistently had a high volume of clicks compared to counties in other regions. **Allegheny** and **Philadelphia counties** had the highest click volume compared to all other counties.

**Seven of the 48 counties** that the Arc of Pennsylvania identified as "rural" clicked on the digital resources at a higher rate than the other counties.





# Appendix K.

Product Review: Accessibility Assessment.

# **Product Review Memo**

# Accessibility Assessment of NEPS Products made by Arc of PA

Prepared by the Research & Evaluation Group at Public Health Management Corporation January 2024

#### **About this Memo**

**The Arc of Pennsylvania**, a leading PA disability rights organization, created several products in collaboration with their Statewide Leadership Task Force as part of their CDC-funded **Initiative to Address COVID-19 Health Disparities among People with Disabilities**.

The R&E Group conducted this review of **modifications around language**, **accessibility**, **and medium** based on audience need that The Arc of PA made to the following **five products** released during the Initiative:

"What We Know Now"

product 1: Infographic

2021

Research Existing Before Initiative

"Recommendations for Addressing COVID-19 Health Disparities Among the Disability Community"

product 4: Recommendations Report
product 5: Recommendations Fact Sheet

2023
Recommendations from Initiative

# 2022 Initiative Research Findings

"COVID-19 Health Care Barriers Among People with Disabilities" product 2: Barriers Report product 3: Barriers Fact Sheet

# **Product Modifications Reviewed**

Language	Medium	Accessibility				
<ul> <li>Number of languages         offered: English, Spanish,         Mandarin</li> </ul>	Number of mediums used     Written	<ul> <li>Meet minimum accessibility standards (WCAG 2.0 AA) requiring content to be:</li> </ul>				
<ul> <li>Plain language used or offered in addition to technical language</li> <li>Braille available by request</li> </ul>	<ul><li>Pictures</li><li>Graphics/Data</li><li>Visualization</li></ul>	<ol> <li>Perceivable</li> <li>Operable</li> <li>Understandable</li> </ol>				
• Inclusive language: used person-first language*	<ul><li>Video</li><li>Audio</li></ul>	4. Robust				



## Methodology

Language and medium modifications were assessed manually by the R&E Group team.

Product accessibility was checked using Web Content Accessibility Guidelines (WCAG) 2.0 Level AA, which are the standards currently required by Section 508. Section 508 of the Rehabilitation Act requires accessibility in all information and communication technology developed, procured, maintained, or used by federal agencies.

Three tools facilitated the accessibility assessment:

- 1. Adobe Acrobat PDF's comprehensive Accessibility Report automatically checked 30 items total, and then flagged failures were manually verified
- 2. Reading order was manually checked using Adobe Acrobat's PDF Reading Order Tool
- Color contrast ratios were manually checked using the WebAIM Color Contrast Checker

### **Review Findings: Language & Medium Modifications**

- Modifications increased and accessibility improved over time.
  - Languages offered progressed from one in 2021 (English), to two in 2022 (English + Spanish), to three in 2023 (English + Spanish + Mandarin).
  - Video was implemented as an additional medium for the Recommendations report in 2023.
- The main products for public distribution (i.e., Barriers and Recommendations reports) had the most modifications, reflecting prioritization in resource allotment.
- All products used inclusive language.
- Audio was the only medium not used.

	Product #					% of Products
Language and Medium Modifications		Two	Three	Four	Five	with Modification
Plain language	yes	yes	no	yes	yes	80%
Braille	no	yes	yes	yes	yes	80%
# of Languages (including English)	1	2	2	3	3	n/a
Inclusive Language	yes	yes	yes	yes	yes	100%
Total # of Mediums	2	3	2	4	1	n/a
written	yes	yes	yes	yes	yes	100%
pictures	no	yes	no	yes	no	40%
graphics/data visualization	yes	yes	yes	yes	no	80%
video	no	no	no	yes	no	20%
audio	no	no	no	no	no	0%



<sup>\*</sup>Note on person-first language: Whether to use person-first language (e.g., person with a disability) or identity-first language (e.g., disabled person) is an ongoing discussion within the disability community. The Arc of PA currently uses person-first language, unless an individual expresses a different preference for how they would like to be described.

### **Review Findings: Accessibility Modifications**

Conformance with Web Content Accessibility Guidelines 2.0 AA is assessed via 38 specific, testable success criteria that are organized around four principles:

- Perceivable (14 success criteria): users can perceive content by means of the senses (i.e.., sight, sound, touch).
- Operable (12 success criteria): users can successfully operate controls, buttons, navigation, and other 2. interactive elements. This includes using assistive technology like screen readers to access content.
- Understandable (10 success criteria): users can comprehend content, as well as learn and remember 3. how to operate the user interface to access content.
- 4. Robust (2 success criteria): content is robust enough that a wide variety of users can reliably interpret it and access it using the technology they choose.
- All products met Understandable (principle 3) and Robust (principle 4) success criteria, which aligns with The Arc of PA's expertise in Intellectual and Developmental Disabilities.
- Products inconsistently met 7 of the 26 total WCAG success criteria for Perceivable (principle 1) and Operable (principle 2) content. The table below presents the PDF accessibility checks not passed by all products. Of note:
  - The color contrast ratio standard was not met by any products, most notably with the orange/white used extensively throughout the Barriers and Recommendations reports
  - Three products did not meet logical reading order standards, which is necessary to successfully operate screen readers

WCAG 2.	0 Standard		Pı	Pass					
Principle	Applicable Success Criteria	PDF Check	1	2	3	4	5	Rate	
	1.1.1	Alternate text	yes	no*	no*	no*	no*	20%	
1. Perceivable	1.3.1 1.4.1 1.4.3	Color contrast	no	no	no	no	no	0%	
	2.4.1 2.4.5	Bookmarks	n/a	no	n/a	no	n/a	0%	
2. Operable	2.4.2	Title	yes	no	no	no	no	20%	
2. Operable	2.4.3	Logical Reading Order	no	no	yes	no	yes	40%	
	2.1.1 2.4.3	Tab order	yes	no	yes	no	yes	60%	

\*Note: Alternate text included for most but not all non-text elements

- Although some accessibility requirements were not met, products often went above and beyond standards:
  - Two versions of reports (plain language and technical language) offered
  - QR codes with use instructions included for additional, easy information access
  - Braille copies of reports made available by request
  - Recommendations report available online as a flipbook with page-turning animations



#### Recommendations

- Focus on incorporating Perceivable & Operable accessibility principles
  - > Color contrast ratios should be ≥4.5:1 for normal text and ≥3:1 for large text (18 pt or bold 14 pt)
  - > Include titles and metadata in PDF document information
  - > Employ bypass blocks, especially in documents 21 pages or longer (e.g., bookmarks in PDFs, linked table of contents in Word documents)
  - Improve product compatibility with screen readers and other assistive technology via alternate text, accurate tagging with logical reading order, and setting the correct tab order
- Utilize audio as an additional medium
  - Example: offer audio recordings of written reports
- Create plain language overview of the Barriers report to expand reach
  - > Distributing overviews of the Barriers report in both plain and technical language would maximize reach and improve accessibility.
- Maintain ongoing discussions about best practices for accessibility, prioritize feedback from self-advocates, and change practices when needed
  - Example: using person-first vs. identity-first language



#### Sources & Resources

#### Arc of PA Products

- Healthcare Initiatives: Background
- Healthcare Initiatives: Findings

#### Accessibility

- WCAG (Web Content Accessibility Guidelines) 2.0 by WAI (Web Accessibility Initiative)
  - W3C Accessibility Standards Overview
  - How to Meet WCAG (Quick Reference)
  - CUNY: WCAG Accessibility Principles
  - Understanding WCAG 2 Contrast and Color Requirements
  - PDF Techniques for WCAG 2.0
- U.S. Access Board Revised 508 Standards and 255 Guidelines
  - Section 508: Compliance or Conformance?
  - Section 508 and WCAG: What's the Difference?
- Acrobat User Guide Create and verify PDF accessibility
- WebAIM Color Contrast Checker tool
- plainlanguage.gov: Checklist for Plain Language
- "The Accessibility Guy" on YouTube
  - PDF Accessibility playlist
  - Reading Order Tool in Adobe Acrobat DC video
  - How to test for Color Contrast | TPGI & WebAIM | WCAG video

#### Person-first Language vs. Identity-first Language

- ASAN (Autistic Self Advocacy Network) on <u>Identity-First Language</u>
- NCDJ (National Center on Disability and Journalism) <u>Disability Language Style Guide</u>, see "A note about person-first language"
- Unmasking Autism: Discovering the New Faces of Neurodiversity by Devon Price, 2022



# **Complete Results of PDF Accessibility Check**

		Product							
Category	Adobe Acrobat Accessibility Tool Check	1	<b>2</b> (plain language)	2 (technical language)	3	<b>4</b> (plain language)	4 (technical language)	5	Notes
	Accessibility permission flag	1	1	1	1	1	1	1	
	Image-only PDF	1	1	1	1	1	1	1	
	Tagged PDF	1	1	1	1	1	1	1	
_	Logical Reading Order*	0	0	0	1	0	0	1	*Manually checked
Document	Primary language	1	1	1	1	1	1	1	
	Title	1	0	0	0	0	0	0	
	Bookmarks	n/a	0	0	n/a	0	0	n/a	Only applies if ≥21 pages
	Color contrast*	0	0	0	0	0	0	0	*Manually checked
	Tagged content	1	1	1	1	1	1	1	
	Tagged annotations	1	1	1	1	1	1	1	
	Tab order	1	0	0	1	0	0	1	
	Character encoding	1	1	1	1	1	1	0	Not addressed by WCAG
Page Content	Tagged multimedia	1	1	1	1	1	1	1	
	Screen flicker	1	1	1	1	1	1	1	
	Scripts	1	1	1	1	1	1	1	
	Timed responses	1	1	1	1	1	1	1	
	Navigation links	1	1	1	1	1	1	1	
_	Tagged form fields	1	1	1	1	1	1	1	
Forms	Field descriptions	1	1	1	1	1	1	1	
	Figures alternate text	1	0.5	0.5	0	0	0	0	
	Nested alternate text	1	1	1	1	1	1	1	
Alternate Text	Associated with content	1	1	1	1	1	1	1	
	Hides annotation	1	1	1	1	1	1	1	
	Other elements alternate text	1	1	1	0	1	1	1	
	Rows	1	1	1	1	1	1	1	
	TH and TD	1	1	1	1	1	1	1	
Tables	Headers	1	0	0	1	1	1	1	
	Regularity	1	1	1	1	1	1	1	
	Summary	1	0	0	1	1	1	1	Recommended but not required
Lists	List items	1	1	1	1	1	1	1	
	Lbl and LBody	1	1	1	1	1	1	1	
Headings	Appropriate Nesting	1	1	1	1	1	1	1	
Passed checks total	•	29	24.5	24.5	27	26	26	27	•
		90.6%	76.6%	76.6%	84.4%	81.3%	81.3%	84.4%	

