**ADA PARC – Scope of Work and Proposed Activities by Partners**

**Overview**

The new 5 year grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), has provided the resources to take the ADA PARC (the Americans with Disabilities Act Participation Action Research Consortium) project into a new phase. As ADA PARC builds on its existing foundation, a clear delineation on the responsibility of activities based on the technical capacity among CUPPA and other associated partners can help ensure maximum impact and a sustainable framework for future phases.

**Participatory Action Research (PAR) Initiatives**

The project abstract (attached to the email, reproduced in full at the end of this document) outlines seven primary research initiatives that organizations will collaborate on. Based on my own sense of technical capabilities within the Voorhees Center, I color coded these initiatives accordingly:

* Green = areas that match our skill set;
* Yellow = areas where there is overlap, but would require another collaborator with specific expertise to lead;
* Blue = areas where Voorhees Center lacks expertise, could provide likely minimal support
* Additional notes on existing and potential programming languages and platforms included:

1. Examine existing participation disparities using large population level datasets, comparing people with and without disabilities, on 53 indicators of participation (CL, CP, and EE) to document the most current disparities findings, and trends over time;
   1. The data pipeline currently uses R to pull data from the US Census Bureau’s American Community Survey (ACS) API. While other partners will be needed to identify datasets on housing, transportation, and Medicaid/Medicare, and other sources, it is within the Voorhees Center capacity to write code to automate and maintain this download process.
2. Analyze findings specific to people with disabilities from underrepresented communities and intersecting identities by race, ethnicity, age, economic status, gender, sexual orientation, and gender identity, to document disparities of diverse people with disabilities and communities;
   1. Data tabulations and disparities measures are calculated in R based on the clean datasets produced by the download pipeline. These can be adjusted and edited as needed.
3. Analyze findings specific to the immediate and long term impact of COVID on the participation of people with disabilities living in community and institutional settings;
   1. What we can do: We can assist with data download and cleaning if this can be folded into the existing cleaning pipeline in R.
   2. What we can’t do: We do not have the domain knowledge around COVID-specific research, datasets, and the pandemic’s intersection with disability/disability data. More targeted guidance about the desired output would be needed.
4. Validate and share participation equity scorecards that summarize disparities across SDH indicators, and allow stakeholders to compare disparities at state and city levels;
   1. What we can do: We can assist with GIS mapping and output/display of scorecards
   2. What we can’t do: Development of scorecard methodology is beyond our expertise. Adding comparative abilities to the website (e.g. select multiple states or cities, and show information side-by-side) would also require a development of a new website display with enhanced functionality for users to look at states and cities interactively.
   3. Knowledge of: HTML, CSS, R, Adobe InDesign, or other infographic design tools
5. Revise and expand the existing immediate access, interactive ADA PARC website (adaparc.org) to report these findings in multiple, accessible formats for different stakeholders to utilize in actions, and evaluate the KT impact with website users;
   1. Adding significant additional website features and ensuring web accessibility is beyond the Voorhees Center’s expertise, and will require the knowledge of a web developer and/or individuals with extensive experience in Business Intelligence (BI)/Dashboards.
   2. Knowledge of: HTML, CSS, R Shiny, Tableau, Power BI, or other tools
6. Collaboratively design an online, peer mentoring intervention program to create citizen scientists and change agents from diverse disability groups and communities who will learn how to make sense of this disparities research, and use ADA PARC findings to advocate for systems and policy changes at national, state and community levels. This intervention, referred to PEN (Participation Equity Navigators), will be evaluated in a study with 200 diverse participants with disabilities to determine its feasibility, accessibility, outcomes, and KT impact for individual participants and diverse communities they represent; and,
7. Deliver training and KT activities to widely disseminate ADA PARC findings to disability community and key stakeholders involved in ADA implementation and systems change.
   1. What we can do: Depending on our involvement with formal development of equity scorecard output and city/state infographic one pagers, can assist with “How To” documents and teach Navigators the basic components.
   2. What we can’t do: Navigators themselves would be best suited to take research and findings to their communities and link up with stakeholders to leverage this data for pursuing policy changes affecting the disability community.

**Work Plan Activities (Proposed)**

Translating these PAR initiatives to the set work plan, the specific activities are divided like so:

* Green = areas that match our skill set;
* Yellow = areas where there is overlap, but would require another collaborator with specific expertise to lead;
* Blue = areas where Voorhees Center lacks expertise, could provide likely minimal support
* Additional notes on existing and potential programming languages and platforms included:

|  | **Activities (mapped to Voorhees Capacity)** | **Key** |
| --- | --- | --- |
| R1: Participation Disparities Analyses,  Summary Scorecards, and Trends | Update CL, CP, EE disparities data annually & add new data and data sources |  |
| Conduct disparities analyses of people with disabilities from underrepresented groups and intersecting identities |  |
| Conduct trend analyses of disparities to show changes over time and by state since ADA and *Olmstead* |  |
| Conduct trend analysis of disparities since COVID-19 |  |
| Validation of a new Economic Equity (EE) Index and scorecard |  |
| Produce & update GIS community-level maps |  |
| Produce participation scorecards |  |
| R2: PEN intervention | Design Participation Equity Navigator (PEN) education and mentoring program & conduct AI focus groups |  |
| Pilot test PEN program with 5 participants & make revisions as needed |  |
| Implement PEN program feasibility study and evaluate with up to 200 participants |  |
| Knowledge Translation | Monthly call with ADA Centers |  |
| Develop KT strategies, products, and social media campaigns to increase visibility, outreach and uptake of ADA-PARC findings with diverse stakeholder audiences |  |
| Conduct KT evaluations of website and PEN program, and report findings |  |
| Plan and conduct an ADA-PARC State of the Science and evaluate KT Impact |  |
| Dissemination | Update website with findings & resources from R1 & R2 |  |
| Webinars on key disparities topics & promising practice case studies |  |
| Journal article development, review, and submission |  |
| Conference submissions & presentations |  |

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**ABSTRACT: The Americans with Disabilities Act   
Participation Action Research Consortium (ADA PARC)**

Over 31 years since the ADA was passed, people with disabilities continue to experience participation disparities in community living (CL), community participation (CP) and economic equity (EE). These disparities unfold at national, state and city levels, directly affecting participation rights, choice, and control. Stark disparities have been further brought to the forefront with the COVID pandemic. Public health disparities research has applied the Social Determinants of Health (SDH) framework to examine how environmental factors influence health disparities of other underrepresented populations, such as by race, ethnicity, and income. Research that has included disability has studied it as a negative outcome, rather than examining whether people with disabilities as a societal group have equitable access to health and participation opportunities like any other societal group, the level of disparities they experience, and the extent to which environmental factors at the micro (immediate), mesa (neighborhood and community) and macro (policy, systems, economic, and sociocultural) levels affect those disparities or afford opportunities. This type of equity research examines to what extent where you live, and the level of access to opportunities and resources you have, impact your everyday participation, and directly informs policy, systems, and community level actions specific to people with disabilities and to the ADA. ADA PARC will build on many years of participatory action research (PAR) done in collaboration and partnership with a consortium of ten 10 ADA Centers, the ADA Knowledge Translation (KT) Center, and a national network of disability organizations and communities. We propose to strengthen this consortium, and increase its impact on community actions targeted at addressing disparities, over the next 5 years by collaborating on the following PAR initiatives:

* Examine existing participation disparities using large population level datasets, comparing people with and without disabilities, on 53 indicators of participation (CL, CP, and EE) to document the most current disparities findings, and trends over time;
* Analyze findings specific to people with disabilities from underrepresented communities and intersecting identities by race, ethnicity, age, economic status, gender, sexual orientation, and gender identity, to document disparities of diverse people with disabilities and communities;
* Analyze findings specific to the immediate and long term impact of COVID on the participation of people with disabilities living in community and institutional settings;
* Validate and share participation equity scorecards that summarize disparities across SDH indicators, and allow stakeholders to compare disparities at state and city levels;
* Revise and expand the existing immediate access, interactive ADA PARC website ([adaparc.org](file:///C:\Users\hammel\Documents\Old%20My%20Documents\My%20Documents\My%20Documents.new\Research\GRANTS\adaparc.2022\grant%20proposal\adaparc.org)) to report these findings in multiple, accessible formats for different stakeholders to utilize in actions, and evaluate the KT impact with website users;
* Collaboratively design an online, peer mentoring intervention program to create citizen scientists and change agents from diverse disability groups and communities who will learn how to make sense of this disparities research, and use ADA PARC findings to advocate for systems and policy changes at national, state and community levels. This intervention, referred to PEN (Participation Equity Navigators), will be evaluated in a study with 200 diverse participants with disabilities to determine its feasibility, accessibility, outcomes, and KT impact for individual participants and diverse communities they represent; and,
* Deliver training and KT activities to widely disseminate ADA PARC findings to disability community and key stakeholders involved in ADA implementation and systems change.

**Table 6: ADA-PARC Workplan**

|  | **Activities** | **Year 1** | | | | **Year 2** | | | | **Year 3** | | | | **Year 4** | | | | **Year 5** | | | |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
| 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 | 1 | 2 | 3 | 4 |
| R1: Participation Disparities Analyses,  Summary Scorecards, and Trends | Update CL, CP, EE disparities data annually & add new data and data sources | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  |
| Conduct disparities analyses of people with disabilities from underrepresented groups and intersecting identities | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  |
| Conduct trend analyses of disparities to show changes over time and by state since ADA and *Olmstead* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |
| Conduct trend analysis of disparities since COVID-19 | \* | \* | \* | \* | \* | \* |  |  | \* |  |  |  | \* |  |  |  |  |  |  |  |
| Validation of a new Economic Equity (EE) Index and scorecard | \* | \* | \* | \* | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  |
| Produce & update GIS community-level maps |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |
| Produce participation scorecards | \* | \* | \* | \* | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  |
| R2: PEN intervention | Design Participation Equity Navigator (PEN) education and mentoring program & conduct AI focus groups | \* | \* | \* | \* |  |  |  | \* |  |  |  | \* |  |  |  | \* |  |  | \* | \* |
| Pilot test PEN program with 5 participants & make revisions as needed |  |  | \* | \* |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |  |
| Implement PEN program feasibility study and evaluate with up to 200 participants |  |  |  | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* |
| Knowledge Translation | Monthly call with ADA Centers | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* |
| Develop KT strategies, products, and social media campaigns to increase visibility, outreach and uptake of ADA-PARC findings with diverse stakeholder audiences | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* | \* |
| Conduct KT evaluations of website and PEN program, and report findings | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* | \* |
| Plan and conduct an ADA-PARC State of the Science and evaluate KT Impact |  |  |  |  |  |  |  |  |  |  |  |  |  | \* | \* |  |  |  |  |  |
| Dissemination | Update website with findings & resources from R1 & R2 | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* | \* |
| Webinars on key disparities topics & promising practice case studies |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |  | \* | \* |  |
| Journal article development, review, and submission | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  |
| Conference submissions & presentations | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  | \* | \* | \* |  |

### R2: Design and Feasibility Testing of the Participation Equity Navigator Intervention

Disparities research can show where people with disabilities are experiencing participation disparities; however, just reporting these findings in publications, or even displaying them on our website, does not mean disability communities or other stakeholders will actually use these findings to inform systems change actions. This involves learning how to effectively translate knowledge to action, thus R2 represents a knowledge translation (KT) focused research project.

In R2, the primary aim is to design and evaluate the Participation Equity Navigator (PEN) intervention program. The goal of PEN is to create citizen scientists and change agents who can effectively use participation disparities findings in direct community actions. To do this, community members need to learn how to: access and make sense of disparities findings; create community reports that show disparities in their specific communities; effectively communicate these disparities to key stakeholders, such as policymakers, federal and state organizations, politicians, media, and the public; and effectively advocate for change at different levels (legislative, policy and systems, programming, and services, etc.). The PEN program will be designed as an online intervention program in which ADA-PARC researchers, ADA Center staff, and disability rights mentors come together to teach these skills, and upon completion, develop a community of participation equity navigators and change agents for community action.

In year 1, we will design the PEN program with our community collaborators and pilot it with our first group of five participants in Chicago, IL. Based on their feedback, we will revise the program and then conduct a pre-post feasibility test of it with 200 participants (20 per ADA Center region x 10 ADA regions across years 2-5). Each navigator will receive an honorarium and reasonable accommodations to participate. Approximately 50 navigators will be trained each year, and they will be invited to continue in future years as mentors to new participants.

***R2 Stage of Research*:** This R2 project is focused on the intervention development stage of research in that we will be designing and testing an intervention that has the potential to address and act upon participation disparities experienced by people with disabilities. This state involves determining active components and content, testing measures to illustrate outcomes, conducting pilot field tests, and assessing feasibility of delivering the online program to participants with diverse disabilities. This type of intervention, focused on creating citizen scientists and change agents, has not been previously tested, so the development stage is appropriate and can inform the design of future intervention efficacy and scale-up evaluations.

***R2 Research Hypothesis*:** Participants who complete the PEN program will demonstrate improved community enfranchisement, self-efficacy, and satisfaction with accessing participation disparities findings and using them in direct systems and policy change actions to improve participation opportunities for diverse disability communities.

***R2 Sample:*** In years 2-4, each of the 10 ADA Centers will recruit five new people with disabilities from their region to participate in the PEN intervention, for a total of 200. ADA Centers will work closely with collaborating disability communities to identify people who represent diverse constituencies, including people with different types of disabilities (e.g., physical, vision, hearing, developmental, cognitive, psychiatric, chronic health, and multiple sensitivities), and people with disabilities from underrepresented communities, such as people who identify as BIPOC and LGBTQ+, and from diverse ages and socioeconomic status. We will track this information so each year ADA Centers can recruit new participants that represent diverse communities. Participation will be open to people who: self-identify as having a disability (as defined within the ADA); are able to participate in an online mentoring program with reasonable accommodations and supports as needed; are able to give informed consent or assent/consent with a guardian or caregiver; and want to work on participation equity issues and advocacy. If participants would prefer to have supports from a personal attendant or significant other during the program, they can choose to do so. Learning materials will be developed in English, and then translated to Spanish in Year 2, and into other languages in Years 3-5 upon request. By using an online format, we can design alternative, accessible formats (text, pictures, captioned, audio descriptions, etc.), and accessibility will be checked by the ADA Centers.

Since COVID, many communities are now providing increased access to technology (phone, laptop, tablet, etc.) and internet services, especially to under resourced communities, and many disability communities have been hosting meetings and advocacy sessions online. We will work with participants to ensure digital access, individually or within community settings, and will provide support on how to access materials and use Zoom to participate.

***R2 Methods*:** R2 will take place in 2 phases: 1: Participatory Design & Pilot Test, and 2: PEN Feasibility Intervention Study. In Year 1, we will design the PEN program using a PAR strategy called Appreciative Inquiry (AI) [193]. AI involves a series of three online focus groups to 1) explore the existing ADA-PARC participation disparities website and resources; 2) discuss specific disparities people with disabilities are currently experiencing in their communities and priorities for action they want to feature in the PEN program; and 3) action plan the specific content and delivery of the PEN program and how to make it accessible to people with diverse disabilities from underrepresented communities. These qualitative focus groups will be co-facilitated by a PAR researcher and the ADA Centers. Participants will include 14 diverse people with disabilities from collaborating organizations and groups who are actively involved in current disability rights advocacy and policy/systems change and can inform the design of the new PEN program. We will hold two rounds of online focus groups, each round involving seven participants. We will obtain informed consent from the participants, and they will receive a stipend for participating. ASL and other requested accommodations will be provided. Focus groups will be captioned, which also produces a transcript for qualitative analyses.

We will use Dedoose software for organization and analysis of qualitative data. Descriptive coding and a constant comparative approach will be used to generate themes and detailed examples related to PEN content and its accessible delivery [194]. Two PAR researchers will independently code the same transcripts, then review preliminary codes to generate an initial codebook before proceeding. We will conduct member checks with participants to confirm accurate interpretation and representation of the themes, ideas, and recommendations. The information will then be shared with our ADA Center collaborators for another round of member checking. Using the results from this phase, we will design the PEN intervention program.

***Feasibility Study in Years 2-5:*** The primary outcome of this phase of R2 is to test intervention feasibility. Feasibility will be assessed by measuring recruitment (benchmark: 5-7 participants per group, recruited within 1 month) and retention rates (benchmark: 80% of participants completing the intervention), adherence to study assessments (benchmark: 80% completion of assessment battery), and participant satisfaction using the Client Satisfaction Questionnaire-8 (benchmark: item average of 3 or greater, indicating that participants are mostly satisfied). Descriptive statistics will be compared with defined benchmarks. In addition to feasibility data, interviews with participants and facilitators will guide future refinement of the PEN intervention. Changes to the protocol will be documented and disseminated with study results.

Within-group change on the *primary outcome*, community enfranchisement, will be explored as a secondary outcome of this study. Participation will be measured using the Enfranchisement Scale from the Community Participation Indicators (CPI) [195-197]. This scale measures the extent to which people endorse that they are members of communities of choice, have a voice in community decisions, have rights and opportunities in society and in their communities, are respected and treated equitably, and can meaningfully make changes in their communities. Enfranchisement is directly related to PEN goals and content. Members of our research team were involved in the development and psychometric evaluation of this scale [196, 197], and it is a reliable and valid outcome measure with established cut points and sensitivity to change.

We will also use the Concerns Report Method (CRM) to measure the participation equity issues they worked on, action goals set by participants to address these issues, and outcomes of and satisfaction with those goals. The CRM was developed and validated in PAR with disability and underserved communities, including people who identify as BIPOC [198]. It uses a Goal Attainment Scaling methodology to document individual and community goals and actions.

Additionally, we will use the Community Empowerment and Perceived Control assessment developed in PAR by Israel and Zimmerman [199], and the Knowledge Translation and Impact assessments developed by the ADA KT Center and by researchers at Cornell University/ADA Center to analyze whether participants felt they were actively involved in this PAR research, whether they used knowledge and skills gained in actions in their communities and examples of how they did this, and whether this then resulted in outcomes for people with disabilities and at what levels. We will also gather qualitative data on actions and impact from navigators.

We will calculate effects on our outcome measures to assess trajectories of change from pre-intervention to post-intervention, computing effect sizes to show relative size of changes [200], and to inform the revision of the PEN program and the design of future efficacy and scale-up evaluation studies. Based on previous research of a community-based intervention that used the CPI Enfranchisement Scale, short-term effect sizes ranged from .34 to .74 on subscales, with a median effect size of d = .51 [201]. Given prior research, an attrition rate of 20% is anticipated. By retaining 160 participants (out of 200 enrolled), assuming an effect size of .50, and a one-tailed alpha of .05, a power of .92 is obtained and should be sufficient to obtain statistical power for this intervention development study.

***R2 Knowledge Translation:*** Upon completion of the PEN feasibility study, we will share the PEN program with disability communities and organizations that are interested in replicating it and offering it to their constituencies. Our goal is for such a program to be of value and feasible to integrate into community-based independent living organizations and programming. By incorporating the ADA-PARC findings and website into the PEN program, we also create another mechanism for widely disseminating disparities research and enhancing the potential for its use in actions to increase participation opportunities for people with disabilities.