World Parkinson Coalition Leadership Forum 2021
Presentation summary from June 2021

Global Equity, Access & Inclusion Working Group Members
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Working Group Background
The Global Equity, Access & Inclusion Working Group was formed to address how best to reach underserved portions of the Parkinson’s community. It quickly determined that it wanted to address health equity — the principle that all people have a right to health — and the health disparities and inequities that exist within marginalized communities.

Some common causes for health inequities include:
- Socioeconomic status
- Race/ethnicity
- Sexual orientation
- Gender
- Disability status
- Geographic location

Health inequities often result in less access to health care services, healthy food, a lower sense of safety and stability, discrimination based on their health status, and health education disparities.

Health Equity, Access & Inclusion Checklists
Through discussion and research into the best practices of organizations approaching health equity, the Working Group determined a need for checklists to help organizations ensure everyone has the opportunity to reach their full health potential. They will be developed to advise and guide all other WPC Working Groups to ensure equity, access, and inclusion are top of mind as they plan and complete their initiatives.

Five checklists are in development to address different issues and groups within the Parkinson’s community. They are meant to offer a series of questions and prompts to help organizations engage communities that aren’t currently appearing and participating in programs, meetings, clinics, and conferences. Their intention is to guide organizations on how to embed the values of equity, inclusion, and accessibility into every component of their work and to support processes that ensure the
inclusive values and goals of the global Parkinson's community are reflected in the questions we ask, the partners we recruit, the connections we make, and the projects we develop. They will help identify gaps in knowledge and practice and establish actions required for Parkinson’s health equity programming, and communication. They will be open-ended so they can be adjusted to different locations, types of organizations, and programs.

Proposed Checklists

First, the checklists will be used and reviewed by the Leadership Forum Working Groups. Then, based on feedback, they will be expanded and made available to anyone within the global Parkinson’s community to use and adapt as they see fit. The five lists and the issues each will address include:

Organizational Capacity Checklist — to address an organization’s commitment to advancing health equity
● What funding decisions do you need to make to ensure the organization is equitable?
● Do you have a commitment to advanced health equity?
● Do you have a skilled and diverse workforce?
● What are product and service offerings to ensure you are an equitable organization?

Community Engagement Checklist — to address how to effectively engage the full Parkinson’s community
● What barriers exist to community engagement?
● How can we engage both community and clinical expertise in our outreach efforts?

Partnerships Checklist — to address how to build diverse and inclusive partnerships
● How do we engage with partners in a meaningful way to the benefit of our community?
● What challenges exist to building such relationships?

Health Inequities Checklist — to address how to identify health inequities
● What information can we use to identify health inequities?
● What tools and resources do we need to do this?
● How can we engage with our community members in analyzing data?

Developing Equitable Strategies Checklist — to address how to incorporate health equity, access, and inclusion concerns into the strategic development and program design processes
● What tools and resources do we need to do this?
● How do we address health equity during the implementation stage?

Breakout Rooms
Breakout rooms discussed three questions:
1) What value do you see in the checklists?
2) What gaps do you identify?
3) What are the barriers to implementation within your organization?
Key takeaways from breakout room discussions:

- The concept and intention of the checklists is appreciated, and it was generally recognized that there is much work to do regarding health equity.
- It is critical for the Working Group and other organizations to listen to marginalized communities and take the time to build relationships within it before moving forward with initiatives.
- It is easy for people and organizations doing business from desks and in meetings to become disconnected from the realities being lived out in the world. It’s important to be present and engaged in the community — i.e., attend meetings, listen, be present and available, build relationships, build trust.
- There are many meaningful opportunities for larger organizations incorporating health equity into their work to support smaller organizations with information, expertise, and resources.
- It may be helpful to partner with humanitarian organizations already doing health equity work. They can support our work and we can educate them about Parkinson’s.
- Precise and careful language is important, and it’s valuable for everyone to see themselves represented in the language used in the checklists.
- Ensure checklists are simple, easy to use, and adaptable — no “one size fits all.”
- Perhaps using broader language to describe the lists — i.e., guiding principles — may be helpful until the lists are fleshed out with more details.
- It’s important not to simply follow checklists and have the appearance of inclusion, but to consider how the principles proposed in these guidelines can be embedded into the culture of an organization and become an effortless part of every day and every initiative.
- Resources exist within marginalized parts of the Parkinson’s community, and it’s critical to understand and respect their work — e.g., build partnerships, support who is already engaged in the community and addressing these issues.
- Consider how to tell and share stories from the Parkinson’s community, ensuring inclusion of the full breadth of stories and images.
- Materials should be available in different languages, but also consider whether the content is culturally specific.
- Invite diverse voices to be part of the strategic design process — e.g., new websites, new programs, etc.

Membership
The members of the Global Equity, Access & Inclusion Working Group have now spread out to work across the other working groups. If you are interested in getting involved in this work, you are welcome to contact us to learn more.

Questions for the Global Equity, Access, and Inclusion Working Group?
Contact David Leventhal at david@danceforpd.org

Questions for the WPC?
Contact Elizabeth Pollard at eli@worldpdcoalition.org

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