

# **Parkinson's Employment Study Newsletter**

**Winter 2024**

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**Abilitylab**<sup>®</sup>

# Hello PIECE Study Participants!

## *Parkinson's Disease: Intervening Early Concerning Employment (PIECE)*

We sincerely thank you for your ongoing participation in our study looking at job retention and employment for people with Parkinson's disease (PD).

Our objectives are to track what clinical employment support services are accessed and monitor employment changes over time in people with PD.

Your partnership is crucial to helping us understand the reality of employment barriers for people with PD, and how we can intervene to address these challenges.

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**Miriam Rafferty**  
*Principal Investigator*



**Kurt Johnson**  
*Co-Principal Investigator*



**Paulo Aco**  
*Project Coordinator*



**Jessica Huerta**  
*Voc Rehab Counselor*



**Emily Zivin**  
*Social Worker*



**Pam Capraro**  
*Voc Rehab Counselor*



**Sasha Zivin**  
*Volunteer*



**Linna Jingyu Jin**  
*Postdoctoral Scholar*

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## Research Team Updates

**Linna Jingyu Jin, PhD, CCC-SLP, S-LP(C):** Linna is a recent graduate of the PhD program in Rehabilitation Science at the University of Washington. As a medical speech-language pathologist, she has served adult patients in diverse settings including acute care, neurorehabilitation, and skilled nursing facilities in Canada and the United States. She is currently working as a postdoctoral scholar at the University of Washington.

**Sasha Zivin:** Sasha is a highschool volunteer from Wilmette, IL. She is currently a junior at New Trier High School who aspires to study medicine in college. Sasha spends her time outside the classroom as part of the New Trier rowing team and volunteering in her community.

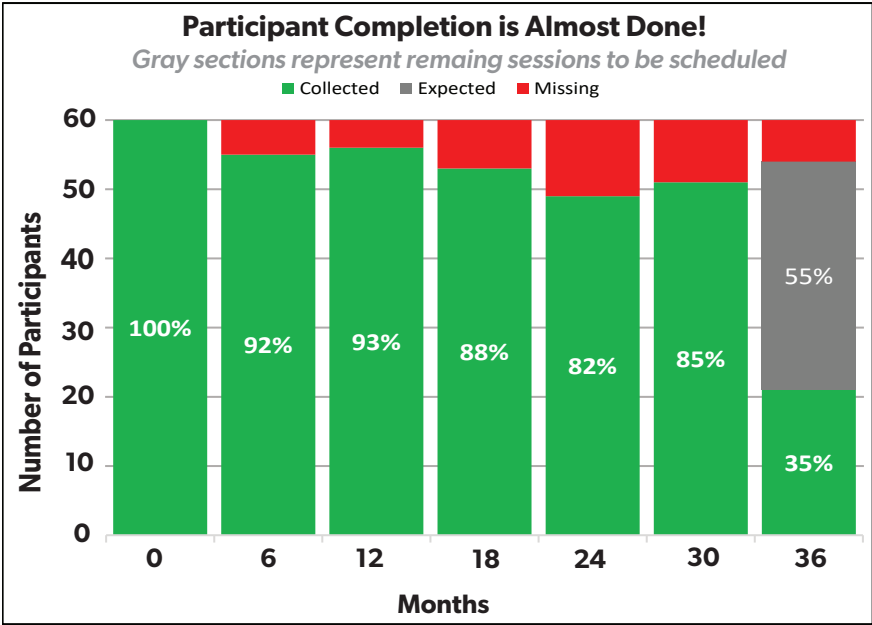
# Data collection is almost complete!

Figure 1

We are excited to report that we have completed data collection from baseline to 30-months. Combining across all timepoints, 89% of you have completed the survey assessments!

We will continue data collection for the next 6 months. Look out for emails from Paulo Aco at [paco@sralab.org](mailto:paco@sralab.org). Thank you for reconnecting with us every six months for three years.

We look forward to continuing to hear about your successes at work and to providing services to assist with employment challenges.



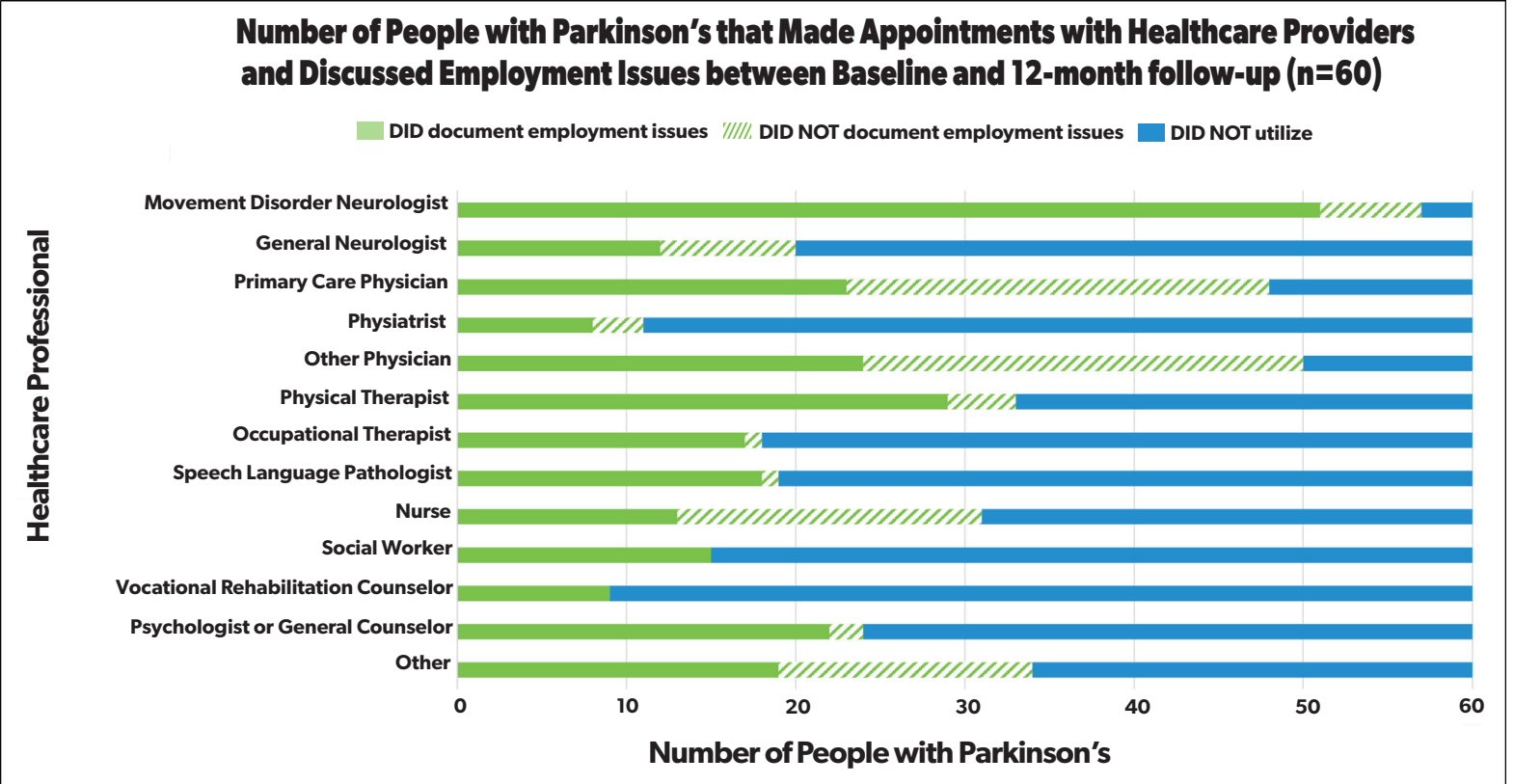
## Preliminary Data Analysis

Our phone assessments track which healthcare providers are seen by study participants during the first-year of study participation and whether employment-related challenges were discussed. Figure 2 below shows the number of study participants that had appointments with various healthcare providers and if healthcare providers documented employment-related issues.

- Solid green = participant reported visiting that provider and the provider DID document employment-related challenges
- Striped green = participant reported visiting that provider but the provider DID NOT document employment-related challenges
- Blue = participant did not visit that healthcare provider

Movement Disorder Neurologists and other physicians were the most accessed healthcare providers (the longest sections that are solid and striped green). Rehabilitation was used less often. Providers documented employment challenges related to the following topics: (1) adjustment to disability, (2) challenges at work, (3) problem-solving, (4) referrals to specialists, (5) community resources, and (6) supportive counseling. Final analyses will examine changes and employment challenges across all three years.

Figure 2



# Resources for Working with Parkinson's Disease

Some people with Parkinson's disease (PD) experience changes that impact their job performance related to their Parkinson's or other work demands. You may benefit from seeking help from a professional to help you address these challenges.

How could a neurologist help?

A Movement Disorders Neurologist is the best person to treat PD-specific problems.

**Treat:** Help manage PD symptoms such as tremor, anxiety, or mood

**Refer:** Provide referrals to see other specialists who could help with job-related issues

How could rehabilitation help?

**Physical therapist (PT):** Help with walking, balance, endurance, pain or stiffness

**Occupational therapist (OT):** Provide strategies for hand coordination for computer use, handwriting, energy conservation for fatigue, ergonomic advice for office setup  
**Speech Language Pathologist (SLP):** Provide strategies to improve voice control for phone calls, public speaking, and concentration at work

**Assistive Technology:** Could work with an OT or SLP to learn about technology that can help with productivity in the workplace, including working from home

How could a social worker help?

Social workers have knowledge about supportive resources for people with PD.

**Support:** Help find community resources, discuss changes in the workplace, provide strategies for stress management

**Educate:** Share information about employment-related policies, problem-solve and make referrals regarding difficulties at work

**Guide:** Provide guidance on issues related to disclosing your diagnosis, Medicare, insurance, Social Security and Disability, and the Americans with Disabilities Act

How could vocational rehabilitation (VR) help?

A vocational rehabilitation (VR) counselor is different from an occupational therapist. A VR counselor has expertise in topics such as disclosing PD to an employer, helping to request the right accommodations, and discussing how to interview for new jobs.

**Navigate:** Help work through the decision to disclose PD status to an employer or colleagues, guide through job search, changing job roles, or returning to work, facilitate benefits or FMLA with employer

**Accommodate:** Recommend strategies to assist with organization and concentration, physical accessibility at work, transportation, or travel

If you have additional questions or concerns about employment:

**For vocational rehabilitation:** contact Paulo Aco at [paco@sralab.org](mailto:paco@sralab.org) or (312) 238-7275

**For social work:** contact your neurologist's office for assistance

For more information on the PIECE study and additional resources, visit the PIECE study website by scanning the QR code



Interested in participating in other Parkinson's Disease research studies? Learn more at the Shirley Ryan AbilityLab Clinical Research Registry using the following link: <https://www.sralab.org/clinical-trials/clinical-research-registry>