

# A Framework for Investigating Living and Working with Disabilities and Long COVID

**University of New Hampshire  
Institute on Disability**



Hosted by:  
**Center on Knowledge Translation for  
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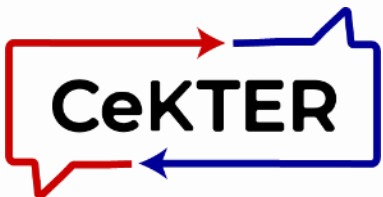
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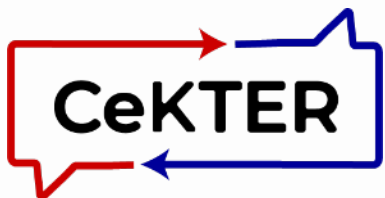
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# Agenda

- Introductory remarks by **Dr. Anjali J. Forber-Pratt, NIDILRR Director**
- Prior research on COVID, Long COVID and disabilities – **Shreya Paul, MPA, University of New Hampshire**
- Overview of planned DRRP projects - **Debra Brucker, PhD, University of New Hampshire**
- Previous employment & job crafting research - **Vidya Sundar, PhD, OTR/L, University of New Hampshire**
- Q&A session



# A framework for investigating living and working with disabilities and Long COVID



# Acknowledgements

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# Prior Research on COVID, Long COVID, and Disabilities

Shreya Paul, MPA





# Research on COVID, Long COVID, and Disabilities

- Prior research (Houtenville et. al, 2021) has highlighted the impact of the COVID-19 pandemic on the employment status of people with and without disabilities.
- From February 2020 to April 2020, the percentage employed dropped from 31.1% to 26.4% for people with disabilities (a relative reduction of 15.1%) and from 74.8% to 63.2% for people without disabilities (a relative reduction of 15.5%) (Houtenville et al., 2021).



# Houtenville et. al (2021):

**Table 1. Estimated monthly percentage distribution across employment statuses, by disability status**

Year	Month	Disability			No disability		
		Employed	Unemployed	Not in labor force	Employed	Unemployed	Not in labor force
2020	Feb.	31.1	3.0	66.0	74.8	2.9	22.3
2020	Mar.	31.7	3.3	65.0	73.4*	3.5*	23.1*
2020	Apr.	26.4*	6.5*	67.1	63.2*	10.5*	26.3*
2020	May	27.8*	6.5*	65.7	65.1*	9.6*	25.3*
2020	Jun.	28.6*	5.9*	65.5	67.8*	8.4*	23.8*
2020	Jul.	28.4*	4.9*	66.7	68.8*	7.9*	23.3*
2020	Aug.	29.1*	4.7*	66.2	69.9*	6.3*	23.8*
2020	Sept.	28.7*	4.4*	66.9	70.2*	5.7*	24.1*
2020	Oct.	29.6	4.0*	66.4	71.5*	4.9*	23.5*
2020	Nov.	29.3	4.5*	66.2	71.3*	4.7*	24.0*
2020	Dec.	29.6	3.7*	66.7	71.1*	4.8*	24.0*
2021	Jan.	28.9*	4.2*	66.9	70.6*	5.1*	24.3*

Asterisk (\*) indicates statistically significance decreases or increase from February 2020 at 0.05 significance level and a one-tailed difference-in-percentages test.



# Reasons for not working during the coronavirus pandemic (April 2021- May 2022) among working-age people with and without disabilities Paul & Brucker (2023)

Compared with persons without disabilities and holding all else constant, **persons with disabilities had significantly higher odds of**

- reporting that they are/were sick with coronavirus symptoms (OR: 1.44,  $P < .05$ ),
- caring for someone sick with coronavirus symptoms (OR: 1.44,  $P < .05$ ),
- they were concerned about getting or spreading the coronavirus (OR: 1.31,  $P < .05$ ),
- they were sick (not coronavirus-related) or disabled (OR: 4.27,  $P < .05$ )
- they were laid off or furloughed due to the coronavirus pandemic (OR: 1.32,  $P < .05$ ),
- their employer went out of business due to the coronavirus pandemic (OR: 1.45,  $P < .05$ ),
- they did not have transportation to work (OR: 1.38,  $P < .05$ ),
- and other reasons for not working (OR: 1.52,  $P < .05$ ).

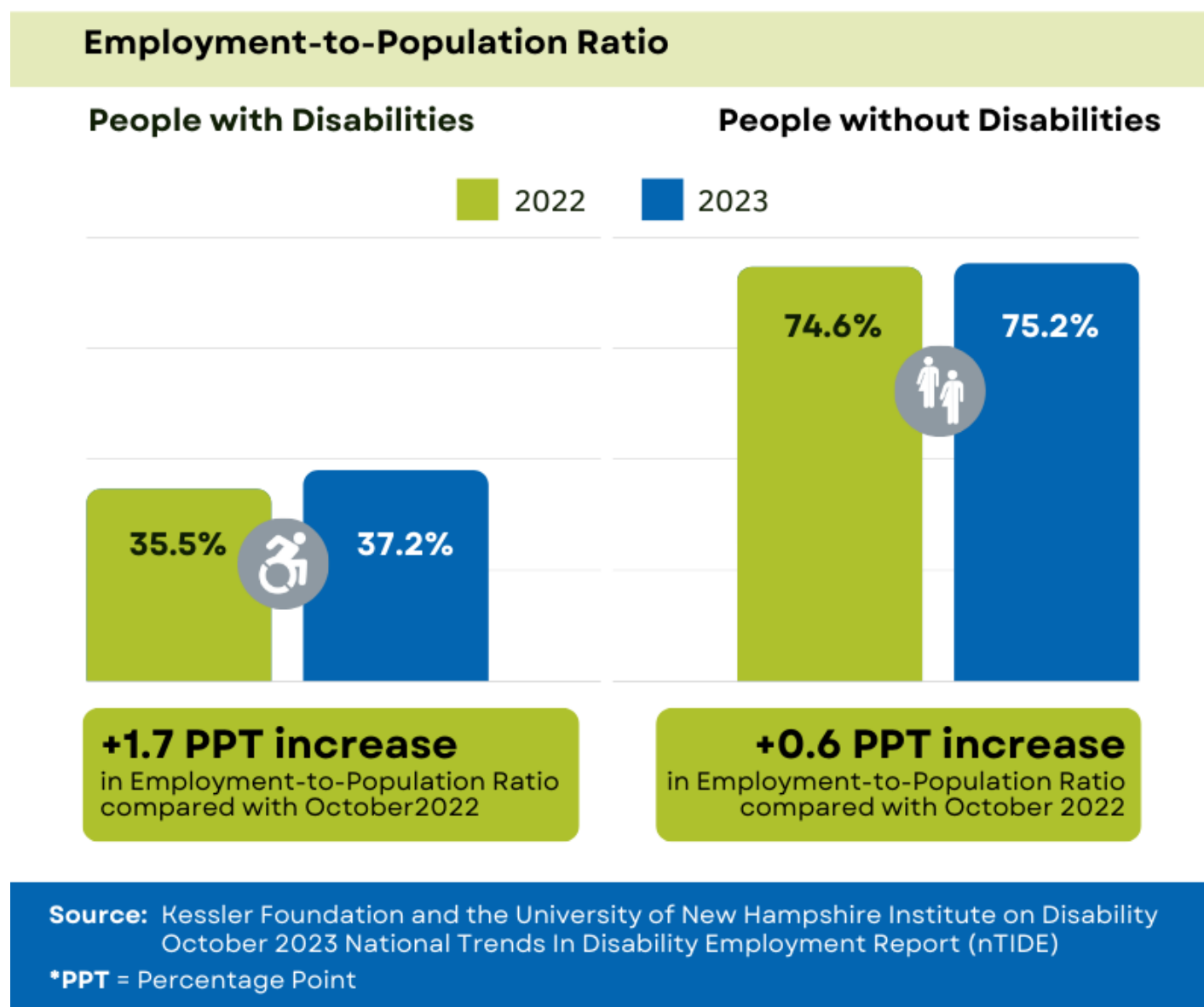
**Persons with disabilities had significantly lower odds of**

- reporting that they did not want to be employed (OR: 0.69,  $P < .05$ )
- and that they were caring for children not in school or daycare (OR: 0.82,  $P < .05$ )

than persons without disabilities



# Employment-to-Population Ratio: Oct 2022 to Oct 2023



# What is Long COVID and what are its symptoms?

People with long COVID have a range of new or ongoing symptoms that can last weeks or months after they are infected with the virus that causes COVID-19 and that can worsen with physical or mental activity (CDC, 2023).

- Examples of common symptoms of Long COVID include:
- Tiredness or fatigue
- Difficulty thinking or concentrating
- Shortness of breath or difficulty breathing
- Headache
- Dizziness on standing
- Fast beating or pounding heart
- Chest pain
- Cough
- Joint or muscle pain
- Depression or anxiety
- Fever
- Loss of taste or smell



# Prevalence of Long COVID (KFF, 2023)

- As of January 16, 2023, 15% of all adults in the US reported having had long COVID symptoms at some point and 6% reported current symptoms.
- Although a smaller percentage of people with COVID reported having long COVID, 5% of the adult population is struggling with activity limitations from long COVID.

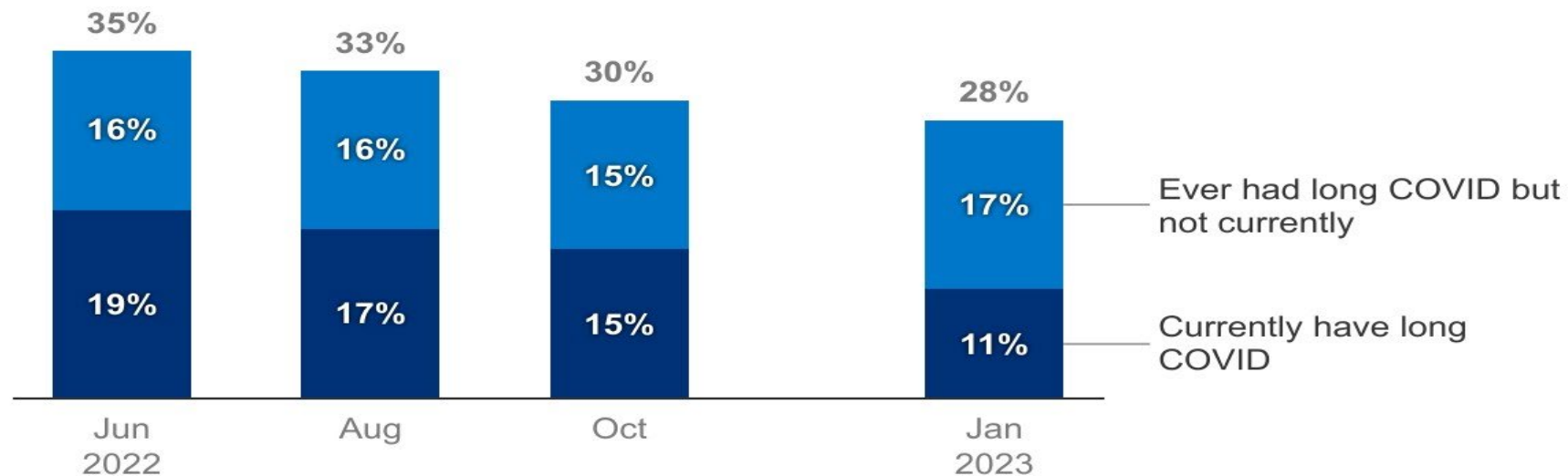


# Long COVID: What Do the Latest Data Show? (KFF, 2023)

Figure 1

## Among People Who Have Had COVID, the Percentage who Currently Have Long COVID is Declining

*Percentage of people reporting that they currently have or ever had long COVID among those who have had COVID as of January 16, 2023*



NOTE: The Pulse Survey, an experimental survey conducted by the Census Bureau and National Center for Health Statistics, asked respondents whether they had any symptoms of COVID that had lasted longer than 3 months. This figure reports the findings as of 6/13/2022, 8/8/2022, 10/17/2022, and 1/16/2023.

SOURCE: National Center for Health Statistics. Post-COVID Conditions. Data accessed Jan 26, 2023. Available from: <https://data.cdc.gov/d/gsea-w83j>.

**KFF**



# Long COVID: What Do the Latest Data Show? (cont..)

## (KFF, 2023)

Figure 2

### Many People with Long COVID Have Activity Limitations but Most are Not Significant

*Percentage of people reporting that they have activity limitations from long COVID as of January 16, 2023*



NOTE: The Pulse Survey, an experimental survey conducted by the Census Bureau and National Center for Health Statistics, asked respondents who currently reported symptoms of long COVID whether those symptoms reduced their ability to carry out day-to-day activities.

SOURCE: National Center for Health Statistics. Post-COVID Conditions. Data accessed Jan 26, 2023.  
Available from: <https://data.cdc.gov/d/gsea-w83j>.

**KFF**



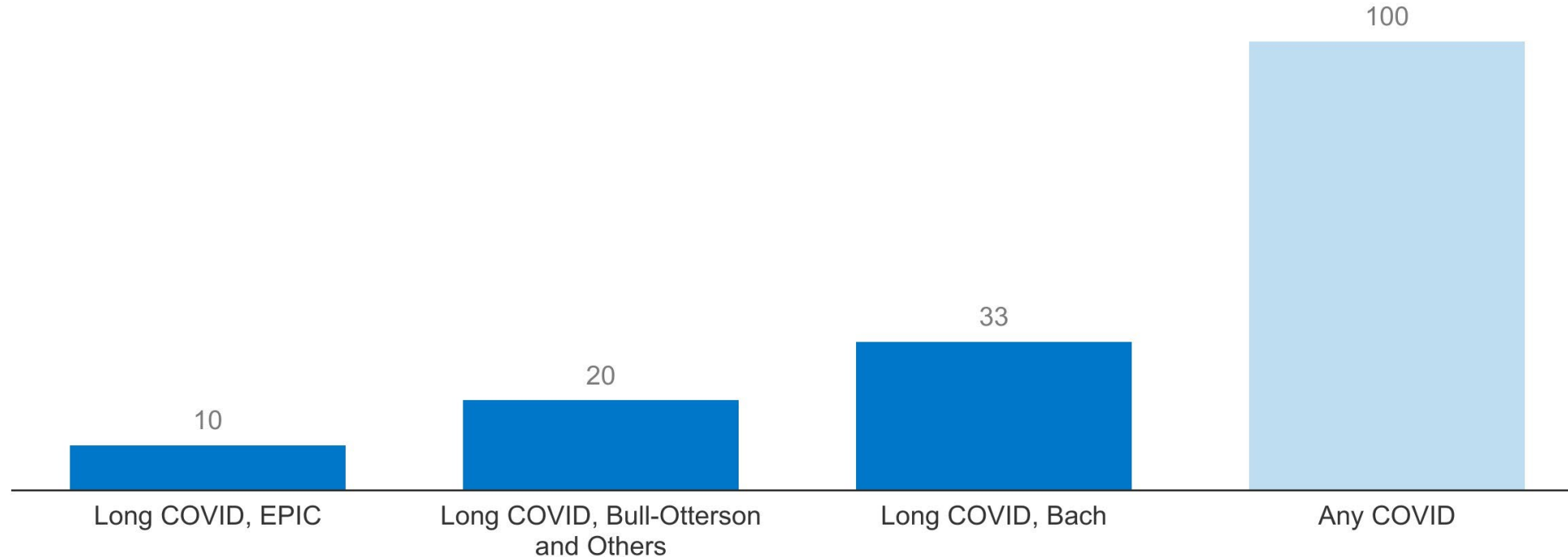


# What are the Implications of Long COVID for Employment and Health Coverage? (KFF, 2022)

Figure 1

## Prevalence is Highly Uncertain but an Estimated 10 to 35 Million Working-Age Adults May Have Long COVID

Long COVID cases (millions) among adults ages 18-64, assuming 100 million cases of COVID infection



SOURCE: KFF estimates based on KFF estimates based on Katie Bach, "Is 'Long COVID' Worsening the Labor Shortage," Brookings Institute; Lara Bull-Otterson and others, "Post-COVID Conditions Among Adult COVID-19 Survivors Aged 18-64 and  $\geq$  65 Years," CDC Morbidity and Mortality Weekly Report May 24, 2022; CDC COVID Data Tracker; and EPIC Dual Team Study, "Nearly 1 in 10 COVID Patients Seek Treatment for Long-Term Symptoms," EPIC Research.

**KFF**

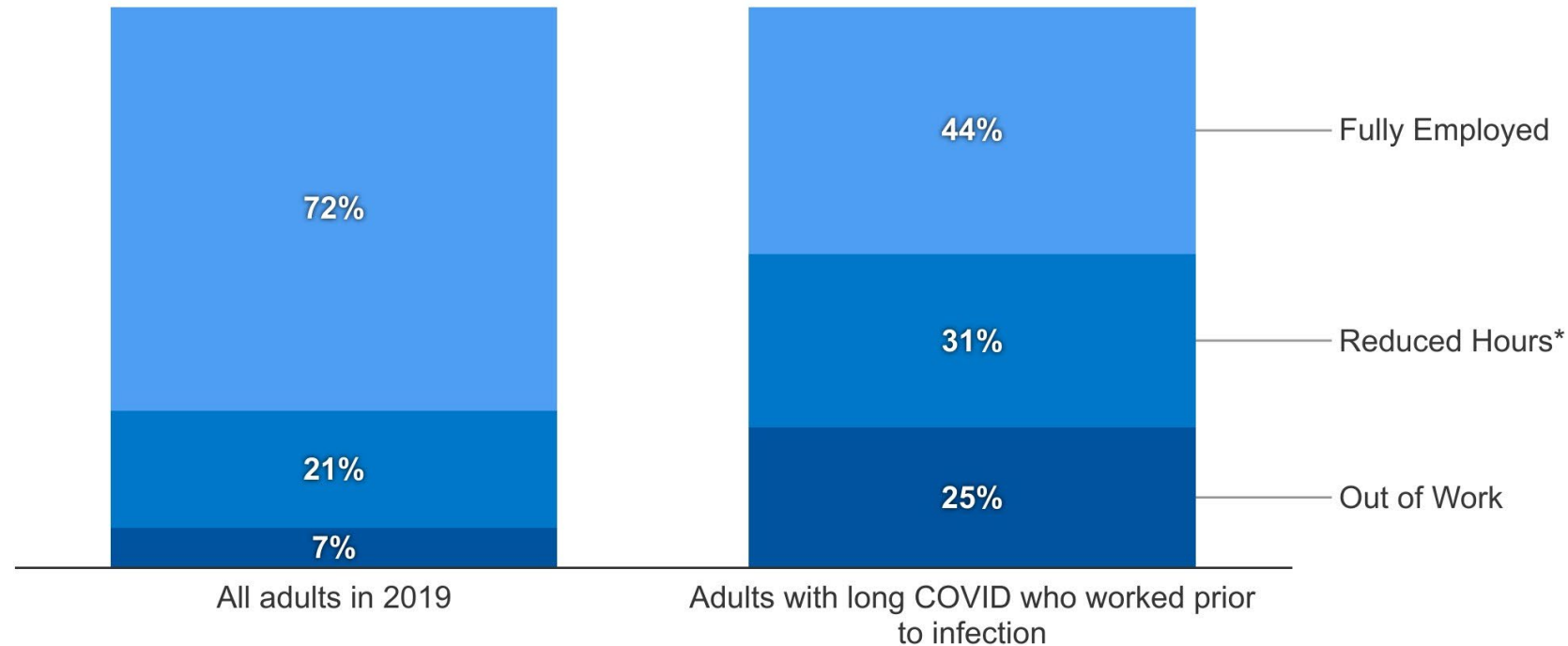


# What are the Implications of Long COVID for Employment and Health Coverage? (KFF, 2022) cont.

Figure 2

## Fewer than Half of Working Age Adults with Long COVID Who Worked Prior to Infection Work Full-Time After Infection

Employment status of working age adults (percent of population) for all adults in 2019 (Current Population Survey) and for survey respondents who worked prior to COVID infection (average of two surveys)



NOTE: KFF Analysis of: Katie Bach, "Is 'Long COVID' Worsening the Labor Shortage?" Brookings (Jan 1, 2022); Hannah E. Davis and others, "Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact, The Lancet, v. 38 (August 1, 2021); Workers' Experiences of Long COVID: A TUC Report (June 2021); and US BLS Labor Force Statistics from the Current Population Survey (2019).

# Employment and Long COVID

- A qualitative study (Stelson et. al) explored the return-to-work experiences of people living with Long COVID.
  - Participants described how fluctuating symptoms, exacerbated by work-related tasks, made returning to work challenging.
  - Participants' ability to work was often predicated on job accommodations and support.
  - Non-work factors were also essential, especially receiving a Long Covid medical diagnosis (key to accessing leave and accommodations) and help at home to manage non-work activities.
  - Many participants described barriers to accessing these supports, illuminating stigma and disbelief in Long Covid as a medical condition.



# Overview of Planned DRRP Projects

Debra Brucker, PhD



# Overview of planned DRRP Projects

5-year grant designed to increase our understanding of how people with disabilities who have Long COVID are navigating living and working

## Research Team

\*Active Advisory Group that includes persons with disabilities who have Long COVID and other stakeholders

## University of New Hampshire (UNH)

Vidya Sundar, PhD, OTR/L, Associate Professor of Occupational Therapy (PI)

Debra Brucker, PhD, Research Associate Professor, Institute on Disability (Co-PI)

Other key UNH faculty/staff:

Shreya Paul, Master of Public Administration, Project Director, Institute on Disability

Eugenia Opuda, MLS, Med, Associate Professor, Health and Human Services Librarian

Institute for Health Policy and Practice

(Amy Costello, MPH; Erica Plante, MS; Bethany Swanson, MSW; Chris White, E

Partners:

Kessler Foundation (West Orange, NJ)



# Overview of planned DRRP Projects:

## 1) Participatory Action Research

Conduct 3 focus groups:

Current employees with disabilities who have Long COVID

Former employees with disabilities who have Long COVID

Stakeholders that support employment for persons with disabilities

## 2) Risk of Long COVID

Analyze nationally representative household survey data to examine individual characteristics associated with a risk for Long COVID among persons with disabilities

## 3) Patterns of Care

Analyze Massachusetts health care insurance claims data to examine health care treatment patterns for persons with disabilities who have Long COVID



# Overview of planned DRRP Projects :

## 4) Job crafting intervention

Enroll a diverse group of 50 employees (25 employees with disabilities and Long COVID who receive an 8-week intervention and 25 healthy employees without disabilities or Long COVID who do not receive an intervention) to examine changes in work engagement, work performance, etc.

## 5) Systematic review

Search for and synthesize existing research on Long COVID and disability.



# Job Crafting among Workers with Disabilities

Vidya Sundar, PhD, OTR/L

(NIDILRR FIR 90IFRE0008)





# Deconstructing Work

## Deconstructing work

Our day-to-day work can be deconstructed into

- What we do (task component)
- Who we do it with (relational component)
- What we think about it (cognitive/appraisal component)

## Relevant outcomes

- **Engagement in work** → Helps build identity, self-fulfillment, self-development, social involvement, financial stability
- **Flourishing and thriving** at work → deriving purpose and meaning from work tasks, and workplace interactions
- Impact on job retention and long-term job tenure



# Job Crafting

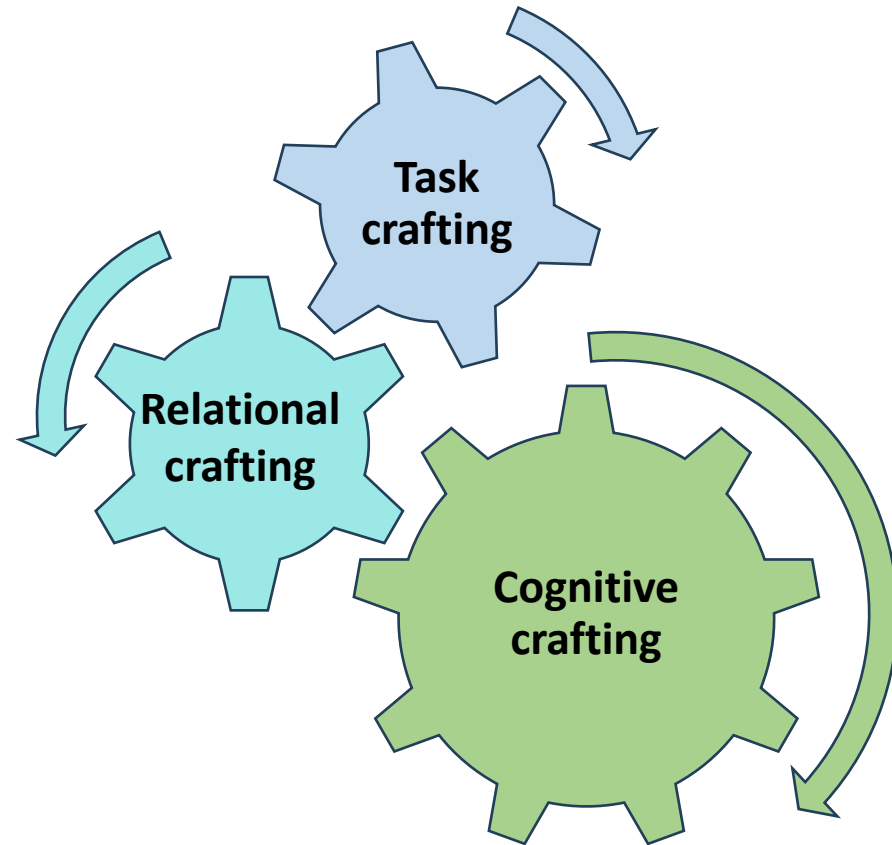
Job crafting can occur through

**Task crafting** e.g., using assistive technology devices

**Relational crafting** e.g., seeking mentorship relationships

**Cognitive crafting** e.g., reframing meaning behind (mundane) job tasks

Wrzesniewski, A., & Dutton, J. E. (2001).



# Job Crafting among workers with disabilities

**Job Crafting** or redesigning and reimagining one's job can be a bottom-up, idiosyncratic process

Job crafting may be an innate or acquired skill

Strong evidence supporting job crafting as an intervention to improve work engagement, work performance etc., among workers without disabilities

In general, workers with disabilities may

- Craft less than their peers without disabilities
- Use prevention-oriented crafting rather than promotion-oriented crafting



## Field Initiated Research - Goals

- **Overarching goal:** To test the efficacy of a 5-week coaching-based intervention. Specifically,
  1. What is the impact of the job crafting intervention on self-efficacy, work performance, and work engagement for workers with disabilities?
  2. How do people with disabilities craft their jobs? In other words, which types of job crafting are employed?
- **Operational definition of disability:** Any work limitation resulting from a chronic/health condition that impacts a person's ability to work

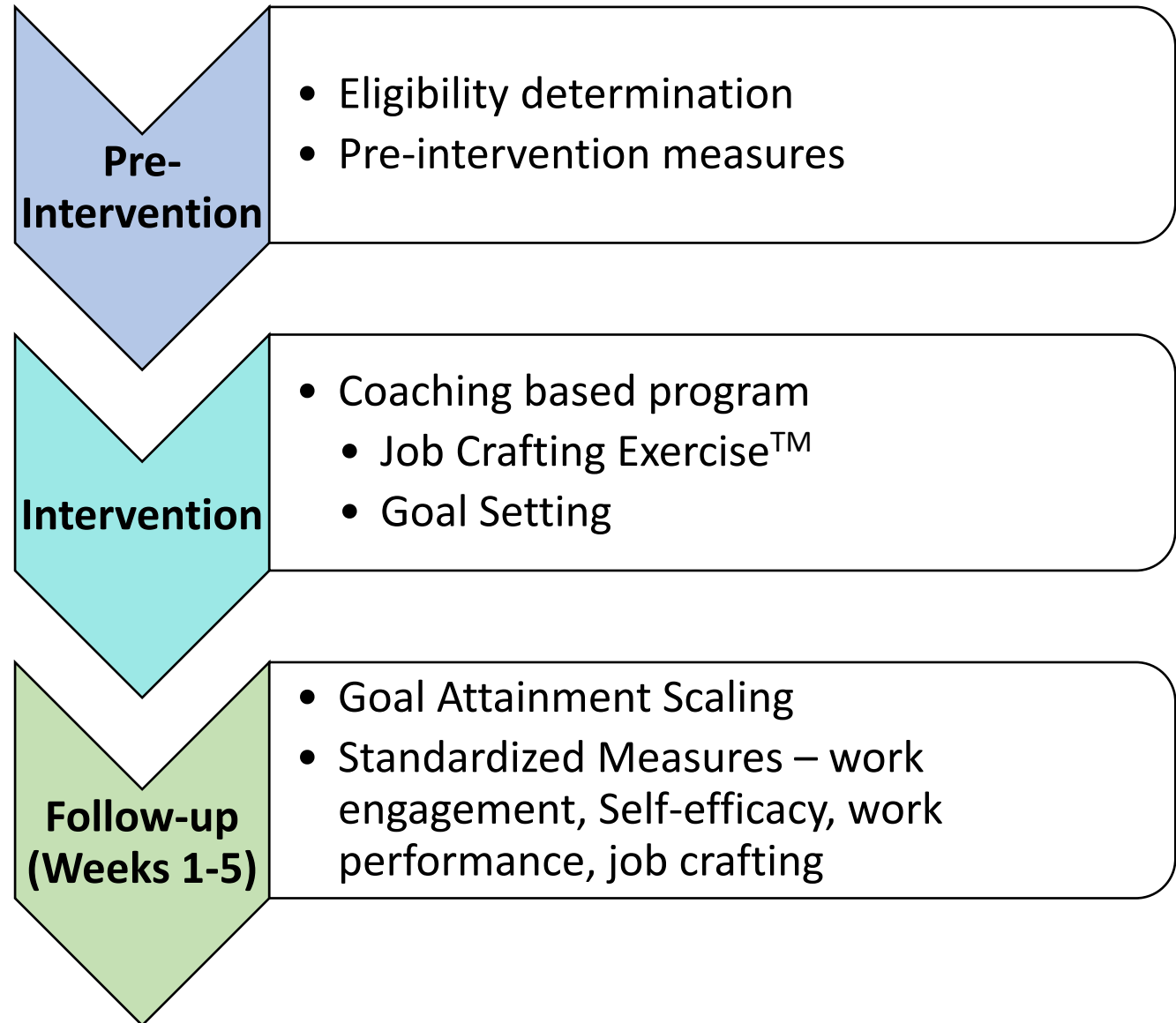


# Study Design

- **Study Design:** Mixed-method concurrent design
- **Sampling:** Convenience sample, recruited by word of mouth, clinical research recruitment companies
- **Eligibility:** 18-64 years of age; able to comprehend/speak English; Physical or mild mental/psychological disability; worked at least 10 hours a week but were not self-employed;
- **Exclusion Criteria:** A primary diagnosis of cognitive or psychiatric disorders; cognitive limitations that prevented providing informed consent



# Data Collection Timeline



# Participant demographics

Demographic Characteristics	Freq (N=75)
Age	
18-24	8
25-34	29
35-54	25
55 to 64	11
Gender	
Male	21
Female	52
Other	2
Education	
Less than Bachelor's degree	24
Bachelor's degree or higher	47

Demographic Characteristics	Freq (N=75)
Hours of Work	
5-20 hours	16
20-40 hours	34
Over 40 hours	23
Work Experience	
1 year or less	9
2-10 years	23
11-20 years	31



# Examples of Goals

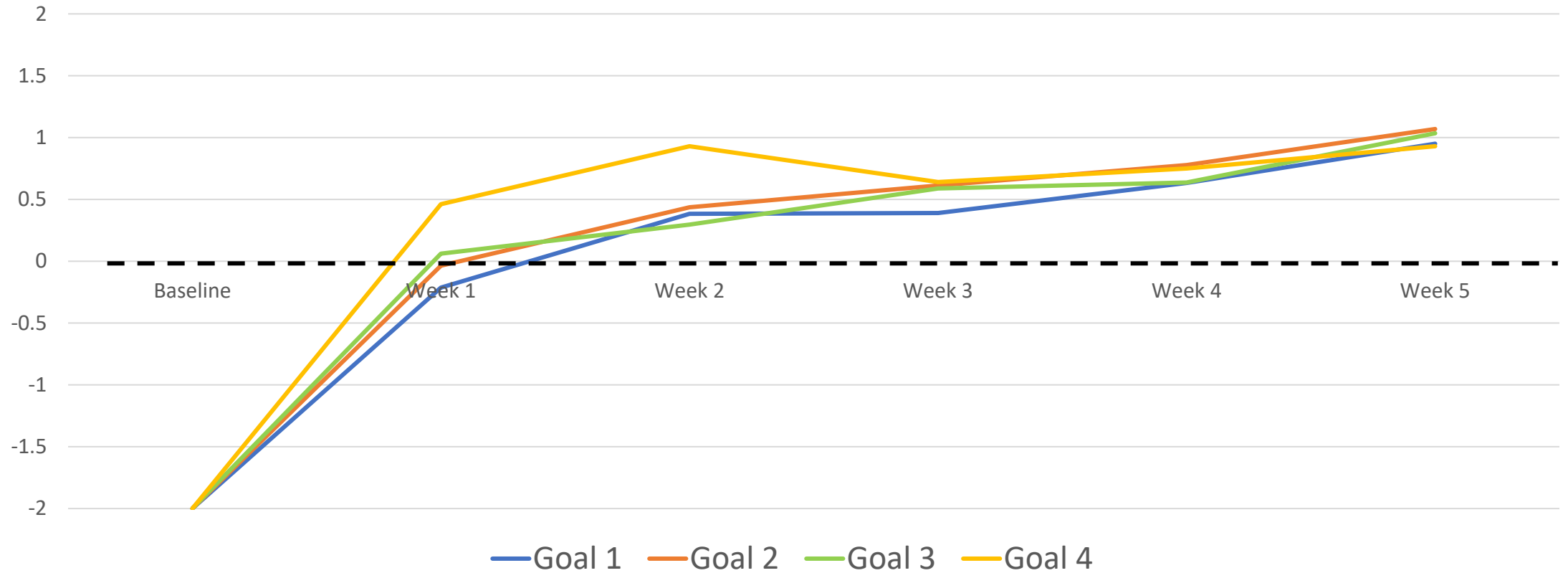
Goal	Type of Goal
Create more engaging and innovative lesson plans.	Task crafting
Increase visitor engagement by developing orchid and/or mushroom education program	Task crafting
Seek creative project opportunities in addition Increase social interactions with investment community	Task, relational crafting
Find a more effective way of communicating with management to secure desired schedule.	Relational, task crafting
I will delegate tasks to other members of the team to reduce my workload	Relational crafting
I will become a leader in the workplace by connecting with people	Cognitive crafting
Reduce self-doubt around cognitive challenges OR Increase comfort talking about cognitive challenges/concussion	Cognitive crafting



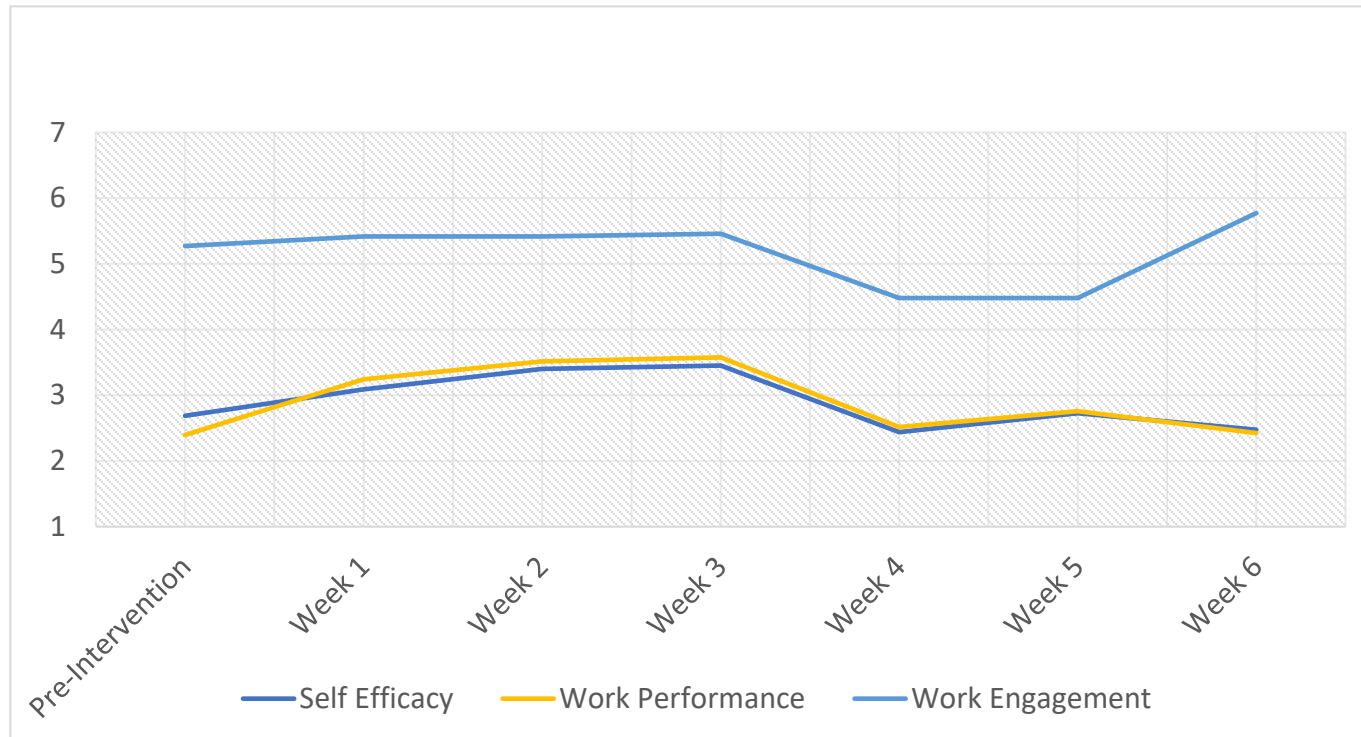


# Findings - Goal Attainment Scale

Average Goal Attainment Progress



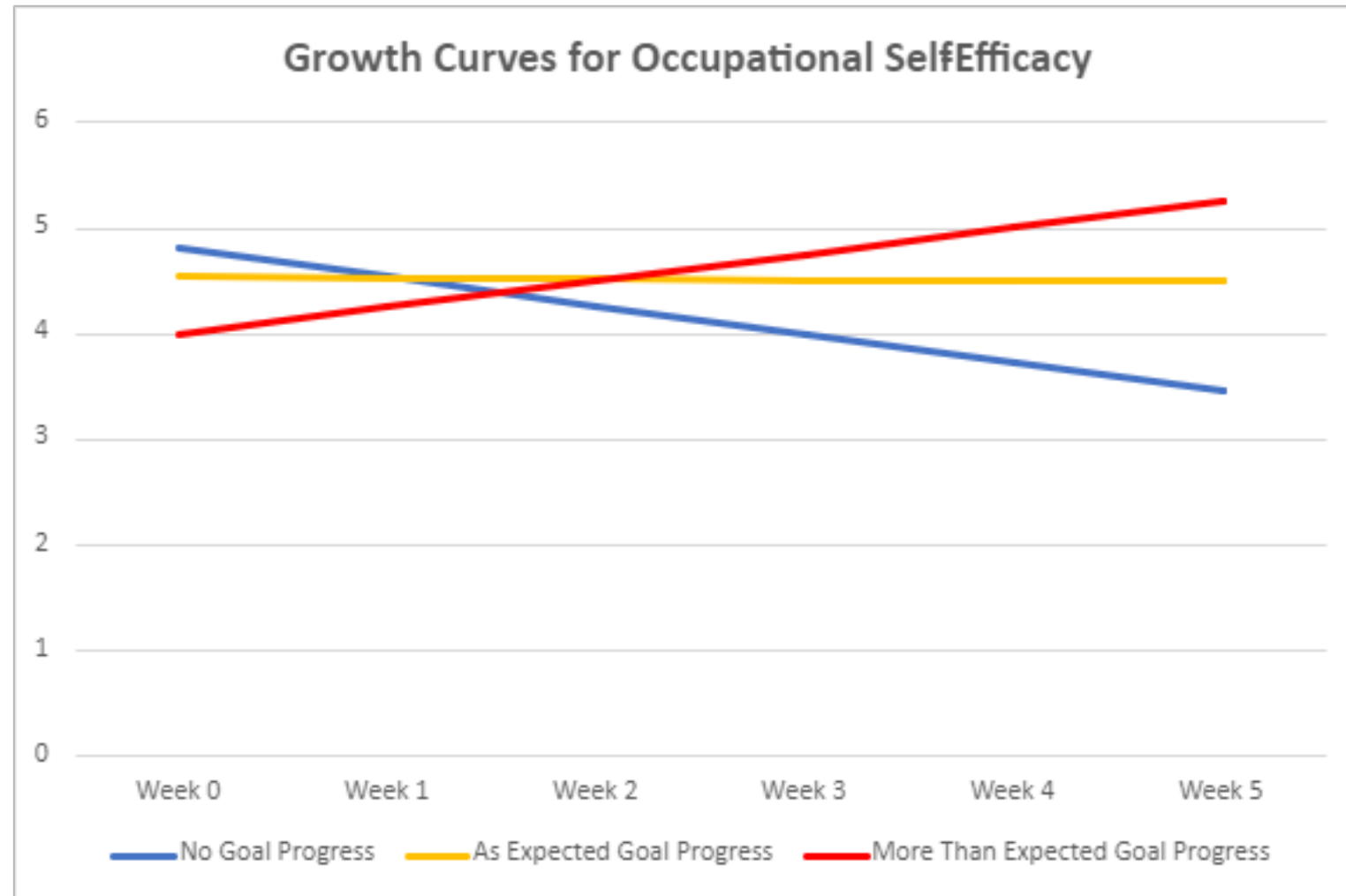
# Findings – Change over time



## Repeated Measures ANOVA

	F-value, Sig
Work Engagement	8.046, $p < .001$
Self-efficacy	3.204, $p = 0.005$
Work performance	3.974, $p < .001$

# Longitudinal Growth Modelling – Preliminary results



## Discussion & Implications

- Job crafting has the potential to help participants feel **re-invigorated by reimagining and redrawing boundaries** of their job tasks.
- In general, participants used both promotion and prevention types of crafting
- Goals were disability and non-disability related – importance for **holistic approach**

## Limitations

Small sample size; short duration of intervention

## Conclusion

These results are promising as **job crafting is a low-cost, employee-directed** intervention that, to date, had not been studied thoroughly for employees with disabilities





# Questions & Comments?

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# Houtenville et. al (2021) cont..

**Table 2. Estimated monthly percentage distribution across unemployment statuses, by disability status**

Year	Month	Disability		No disability	
		Temporary layoff	Looking for work	Temporary layoff	Looking for work
2020	Feb.	9.1	90.9	17.1	82.9
2020	Mar.	21.8*	78.2*	30.0*	70.0*
2020	Apr.	72.9*	27.1*	79.0*	21.0*
2020	May	68.9*	31.1*	72.5*	27.5*
2020	Jun.	49.7*	50.3*	57.8*	42.2*
2020	Jul.	46.5*	53.5*	55.7*	44.3*
2020	Aug.	33.0*	67.0*	44.6*	55.4*
2020	Sept.	24.0*	76.0*	34.3*	65.7*
2020	Oct.	20.8*	79.2*	26.9*	73.1*
2020	Nov.	23.1*	76.9*	24.4*	75.6*
2020	Dec.	19.6*	80.4*	30.0*	70.0*
2021	Jan.	20.9*	79.1*	29.4*	70.6*

Asterisk (\*) indicates statistically significance decrease or increase from February 2020 at 0.05 significance level and a one-tailed difference-in- percentages test.



# Paul & Brucker (2023):

Table 2: Percentage of working-age people with and without disabilities by reasons for not working between April 14,

2021 to May 9, 2022

Reason	Disability			No Disability		
	Total	Male	Female	Total	Male	Female
Did not want to be employed at this time	4.2	4.4	4.0 *	9.0	9.7	8.5 *
I am/was sick with coronavirus symptoms or caring for someone who was sick with coronavirus symptoms	5.1	4.6	5.5 *	5.3	5.3	5.3
I am/was caring for children not in school or daycare	6.2	1.9	8.8 *	10.2	3.3	15.4 *
I am/was caring for an elderly person	2.8	2.3	3.1 *	2.6	2.1	2.9 *
I was concerned about getting or spreading the coronavirus	4.0	4.7	3.7 *	4.2	4.8	3.7 *
I am/was sick (not coronavirus related) or disabled	24.9	22.6	26.3 *	7.3	7.2	7.4
I am retired	10.0	13.3	8.0 *	11.8	12.9	11.0 *
I am/was laid off or furloughed due to coronavirus pandemic	6.8	7.7	6.2 *	7.4	8.9	6.2 *
My employer closed temporarily due to the coronavirus pandemic	2.6	3.0	2.3 *	3.1	3.9	2.6 *
My employer went out of business due to the coronavirus pandemic	2.6	3.4	2.1 *	2.4	3.0	1.9 *
I do/did not have transportation to work	2.0	2.6	1.6 *	1.9	2.3	1.5
Other reason, please specify	27.4	28.3	26.8 *	26.4	26.9	26.1 *
Did not report	1.4	1.2	1.6	8.4	9.7	7.5

\*Indicates statistical significance at 0.05 significance level between males and females by disability status using 2 tailed difference-in-proportion test  
(Unweighted N = 876, 865)





# Guidance on Long COVID (HHS, 2021)

- The Office for Civil Rights of the Department of Health and Human Services and the Civil Rights Division of the Department of Justice have joined together to provide guidance about Long COVID.
- This guidance explains that Long COVID can be considered a disability under:
  - Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA);
  - Section 504 of the Rehabilitation Act of 1973 (Section 504); and,
  - Section 1557 of the Patient Protection and Affordable Care Act (Section 1557).
- Each of these federal laws protects people with disabilities from discrimination.





# QUESTIONS?

Please post your questions in the Q&A button below.

