

# Supporting People with Dementia and their Caregivers During the COVID-19 Pandemic



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WAI Dementia Care Training  
Day

October 22, 2020



# COVID19 disproportionately affects people with dementia

COVID19 infection is often more severe in older adults (Wang, et al. 2020) and people with chronic medical conditions

Nursing homes have been epicenters for outbreaks (Barnett, et al. 2020)

## Are You at Increased Risk for Severe Illness?



Based on what we know now, those at increased risk for severe illness from COVID-19 are:

- Older adults
- People of any age with the following :
  - Cancer
  - Chronic kidney disease
  - COPD (chronic obstructive pulmonary disease)
  - Immunocompromised state (weakened immune system) from solid organ transplant
  - Obesity (body mass index [BMI] of 30 or higher)

# People with dementia have more social and cognitive barriers

More difficulty accessing, understanding and adhering to public health guidelines

More reliant on caregivers

Older adults more at risk for social isolation (Gerst-Emerson & Jayawardhana, 2015)

## Here Is What You Can Do to Help Protect Yourself



**Limit contact** with other people as much as possible.



**Wash your hands** often.



**Avoid close contact** (6 feet, which is about two arm lengths) with people who are sick.



**Clean and disinfect** frequently touched surfaces.

# Dementia care professionals have unique and valuable perspective on impact of COVID19



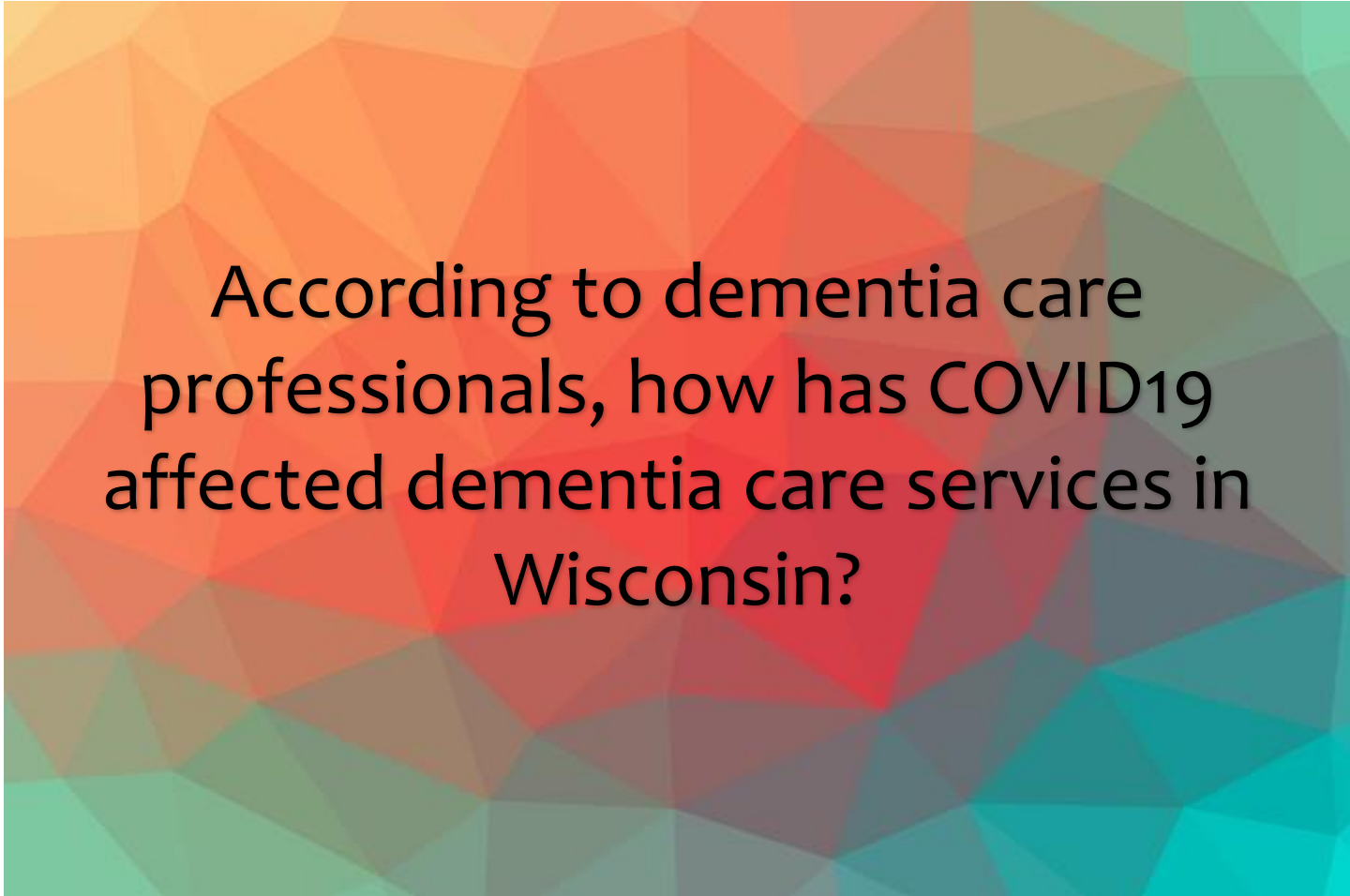
Understand and respond to needs of people with dementia

Direct service provision

Interface with service and health providers



# Our question



According to dementia care professionals, how has COVID19 affected dementia care services in Wisconsin?

# Our talk today

Introduce the “Survey of Dementia Care Professionals on the Impact of the COVID19 Pandemic”

- Goals/purpose
- What was the survey?
- Who took the survey?
- What did the survey ask?
- What did the survey find?

Reflection

Discussion

# The survey team



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Health Leader  
WAI



Jack Hunt, PhD  
MD/PhD Student  
UW SMPH



Molly Schroeder, CSW  
Community Dementia  
Programs Manager  
WAI



Tammy LeCaire,  
MS, PhD  
Associate Scientist  
WAI

# Goals

1. Understand what dementia services have been affected by the COVID19 pandemic
2. Understand what factors have affected service use
3. Understand how COVID19 has affected dementia care professionals

# Purpose

1. Identify potential unmet needs of people with dementia and their caregivers
2. Identify barriers and facilitators for people with dementia
3. Identify common and unique challenges for dementia care professionals
4. *Discuss potential solutions*



# What was the survey?

Created by team at Wisconsin Alzheimer's Institute

Piloted with 2 anonymous dementia care specialists

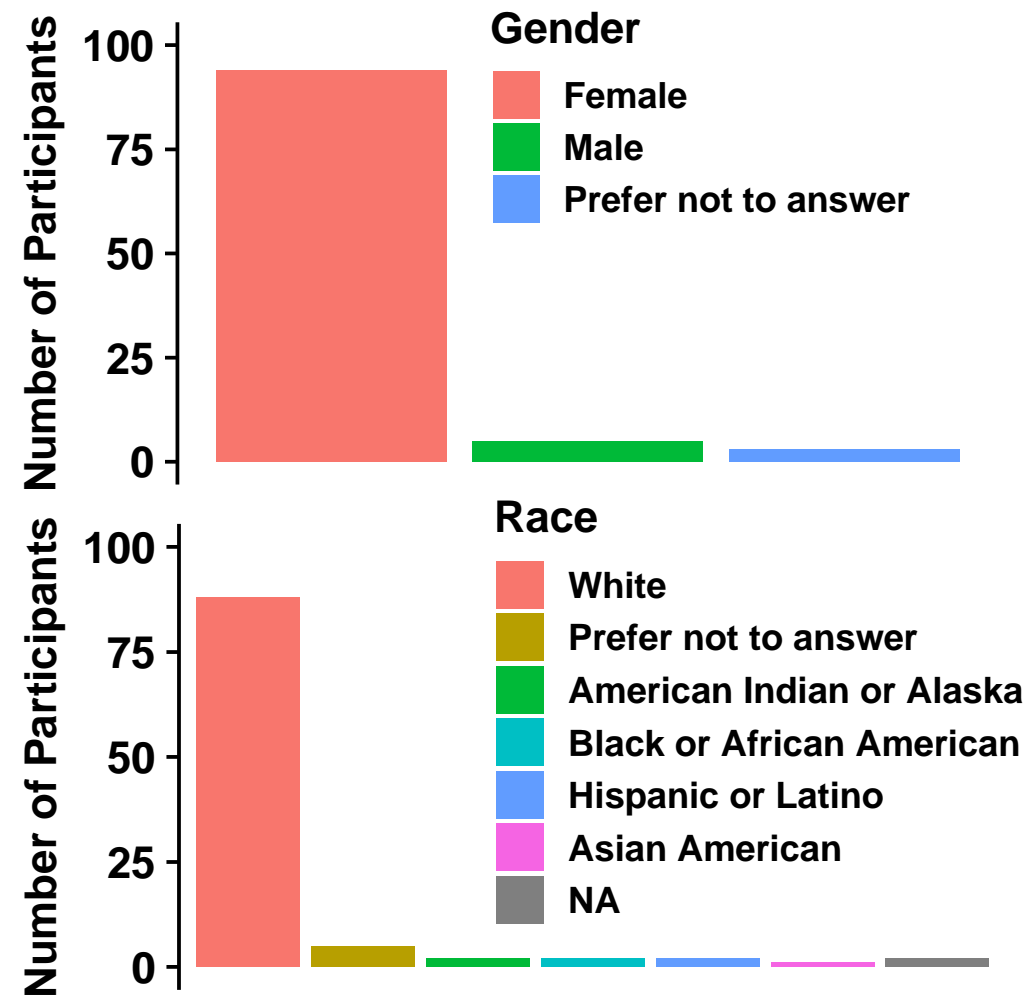
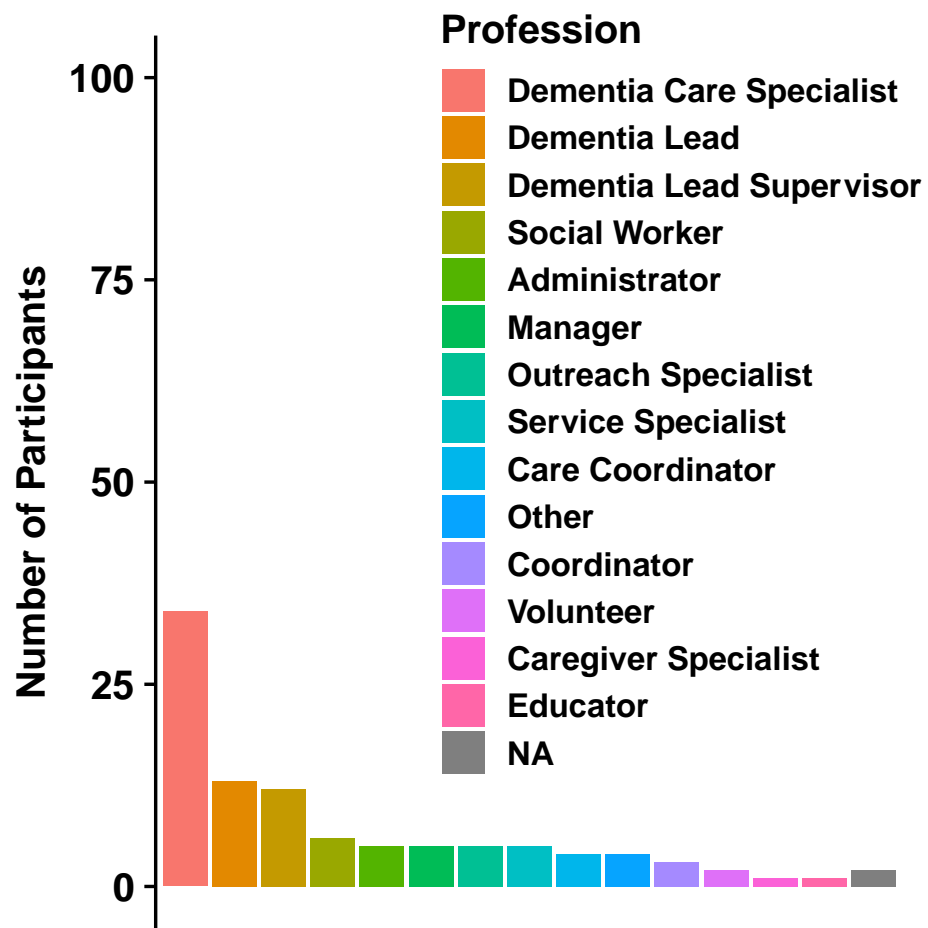
Administered survey 8/28/20 – 10/09/20

Emailed to dementia care specialists and Wisconsin Dementia Resource Network

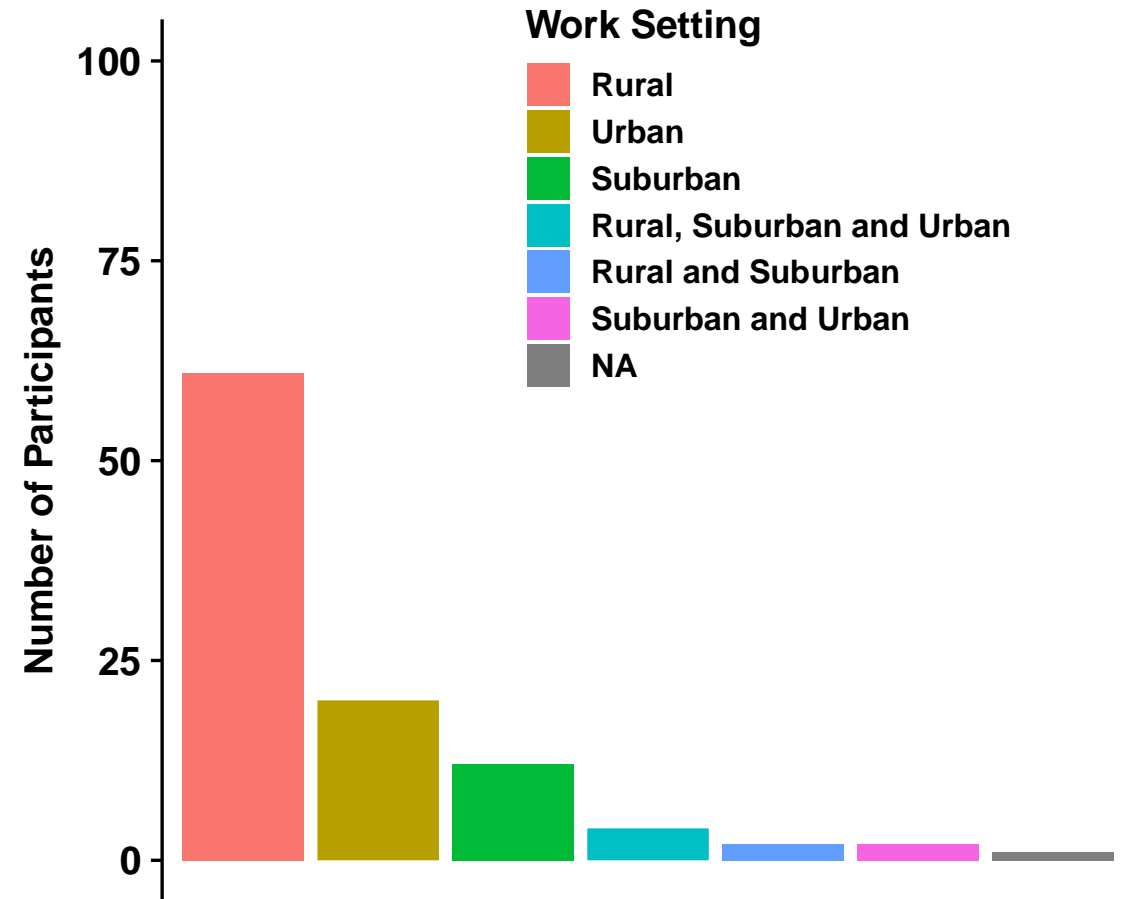
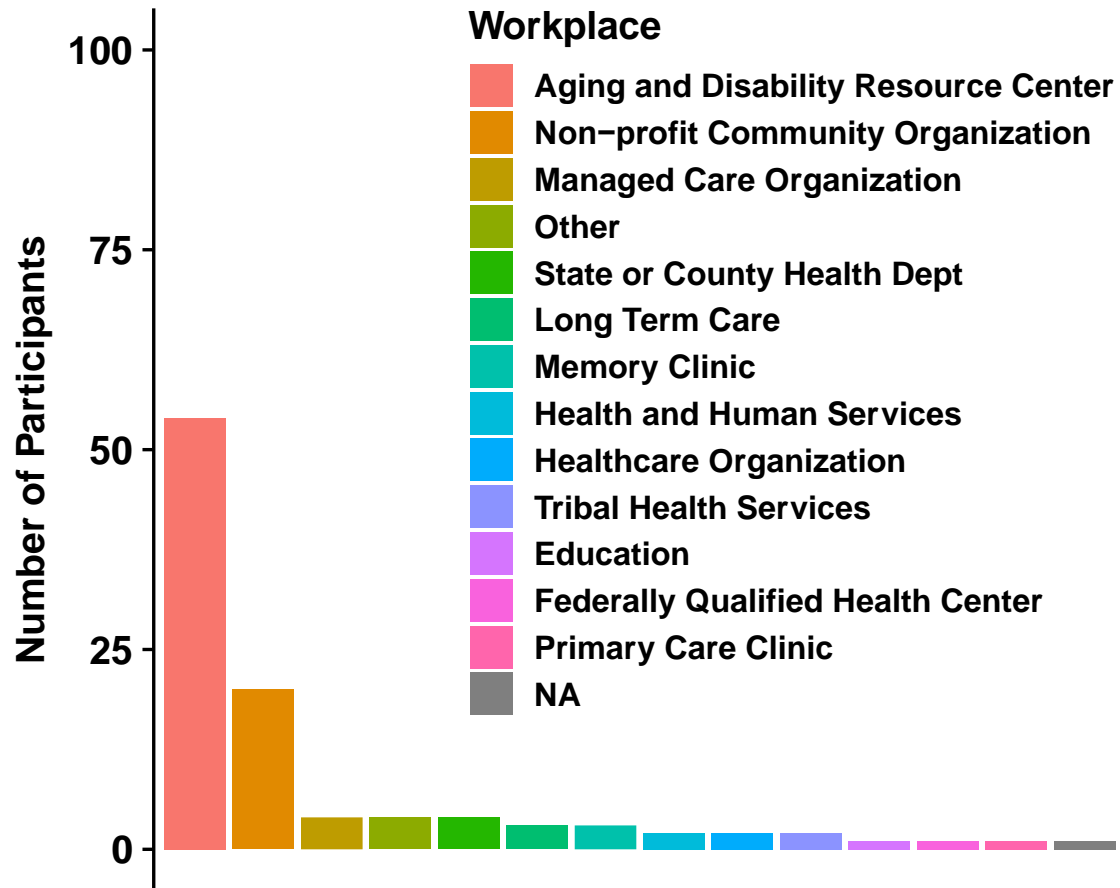
Received 128 responses (102 with complete data)

# Who took the survey?

Dementia care professionals (DCPs)



# Who took the survey?



# What did the survey ask?

\*Dementia care professional

- 1) How has DCP\* service availability been affected by the COVID19 pandemic?
- 2) What factors have affected DCP's ability to perform duties during the COVID19 pandemic?
- 3) How adequate is DCP knowledge base about COVID19-related topics?
- 4) How has client use of healthcare and community-based services changed during the COVID19 pandemic?
- 5) What factors have impacted client use of healthcare and community-based services during COVID19?

# What did the survey ask?

\*Dementia care professional

**1) How has DCP\* service availability been affected by the COVID19 pandemic?**

2) What factors have affected DCP's ability to perform duties during the COVID19 pandemic?

3) How adequate is DCP knowledge base about COVID19-related topics?

4) How has client use of healthcare and community-based services changed during the COVID19 pandemic?






5) What factors have impacted client use of healthcare and community-based services during COVID19?

# How has DCP service availability been affected by the COVID19 pandemic?

## 13 Services Surveyed

- 3 Connection to services
- 3 Facilitating group meetings
- 4 Education and advocacy
- 3 One-on-one services

## Service Availability

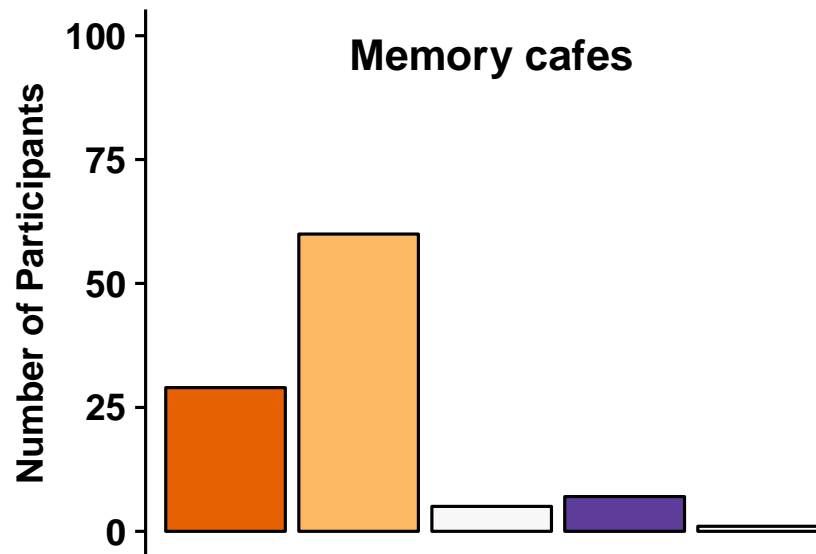
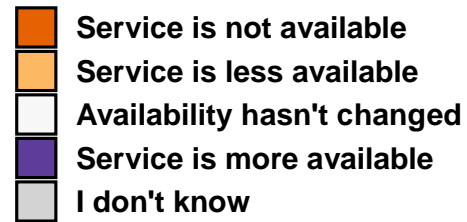
-  Service is not available
-  Service is less available
-  Availability hasn't changed
-  Service is more available
-  I don't know





# Unavailable services

## Service Availability

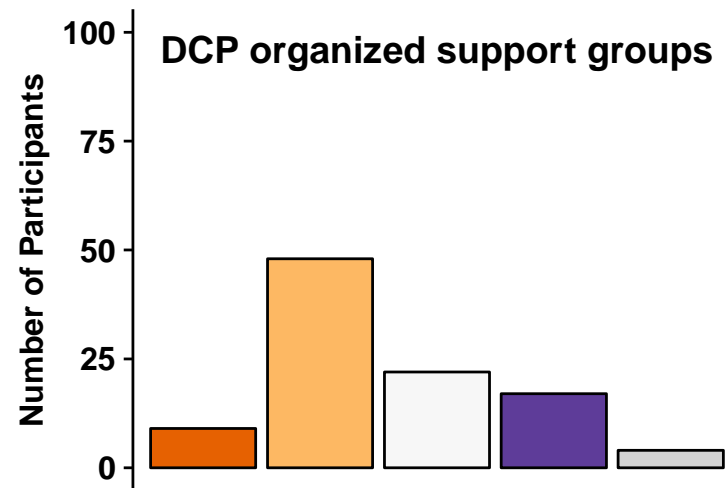
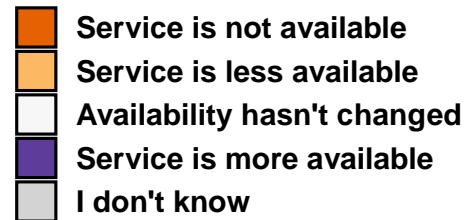


## Other similarly unavailable services

- Care planning assistance
- Public presentations and meetings
- Training dementia-friendly businesses
- In-home visits

# Limited services

## Service Availability

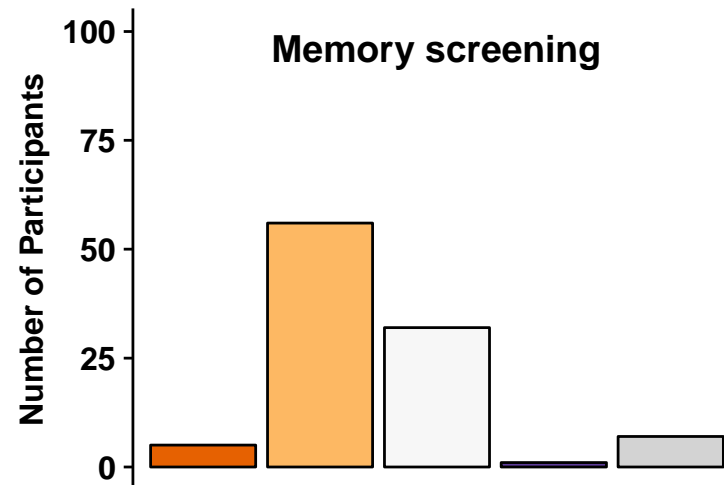
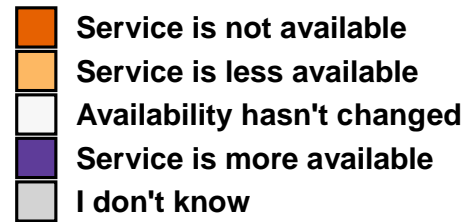


## Other similarly limited services

- Other support groups
- Connection to enrichment opportunities
- Connection to respite services
- Connection to research opportunities

# Less affected services

## Service Availability



## Other less affected services

- Training dementia capable agencies
- Community dementia coalitions

# What did the survey ask?

\*Dementia care professional

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- 4) How has client use of healthcare and community-based services changed during the COVID19 pandemic?
- 5) What factors have impacted client use of healthcare and community-based services during COVID19?

# What factors have affected DCP's ability to perform duties during the COVID19 pandemic?




## 10 Factors Surveyed

2 Changes in health

3 Changes in personal life

5 Changes in job-related changes




## Effect on job performance

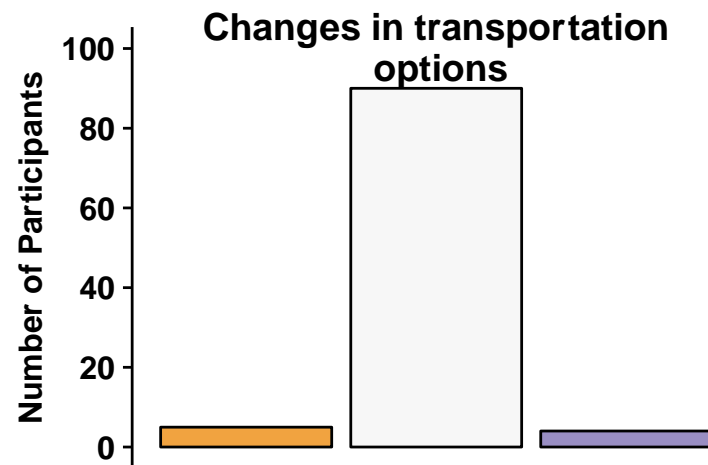
-  Negatively affected job performance
-  Hasn't affected job performance
-  Positively affected job performance



# Factors with minimal effect on DCP performance

## Effect on job performance

-  Negatively affected job performance
-  Hasn't affected job performance
-  Positively affected job performance



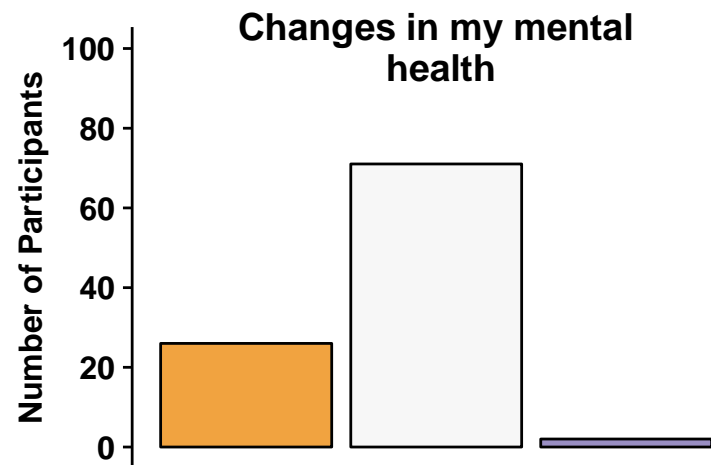
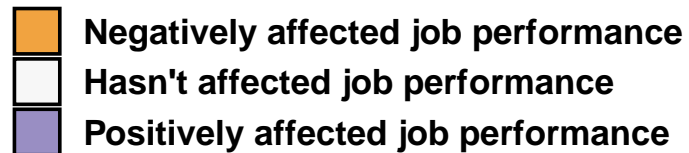
## Other factors with minimal effect

- Changes in language service availability
- Changes in physical health
- Changes in financial situation



# Factors with moderate negative effect on DCP performance

## Effect on job performance






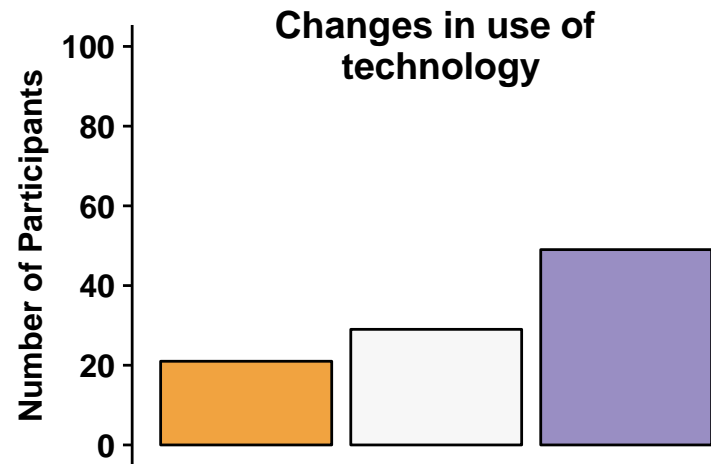
## Other factors with moderate negative effect

- Changes in physical health
- Changes in job duties
- Changes in familial obligations
- Changes in organization priorities

# Factors with positive effect on DCP performance

## Effect on job performance

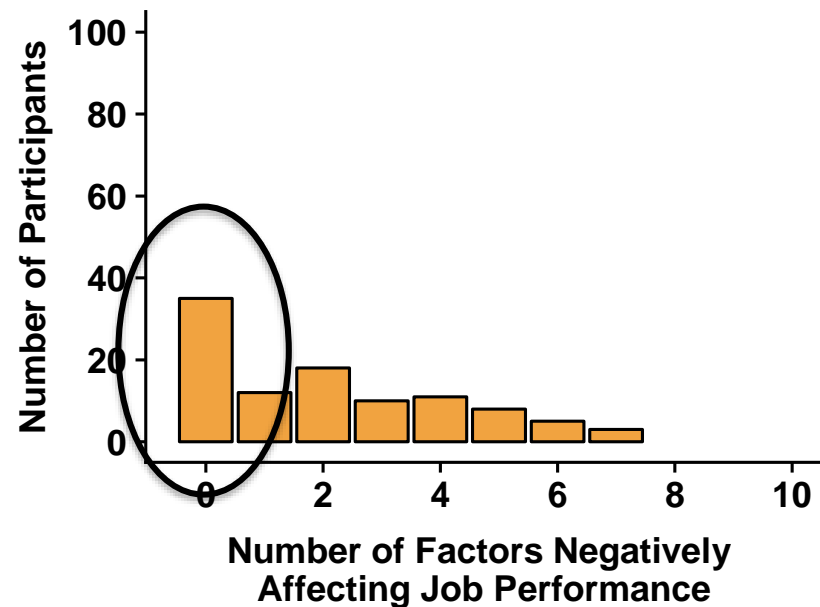
-  Negatively affected job performance
-  Hasn't affected job performance
-  Positively affected job performance



# Not everyone reported negative factors

## Effect on job performance

- Negatively affected job performance
- Hasn't affected job performance
- Positively affected job performance



# What did the survey ask?

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- 4) How has client use of healthcare and community-based services changed during the COVID19 pandemic?
- 5) What factors have impacted client use of healthcare and community-based services during COVID19?

# How adequate is DCP knowledge base about COVID19-related topics?

## 9 Knowledge Areas Surveyed

- 2 COVID19 risks and guidelines
- 3 Effects of social isolation
- 4 Available resources

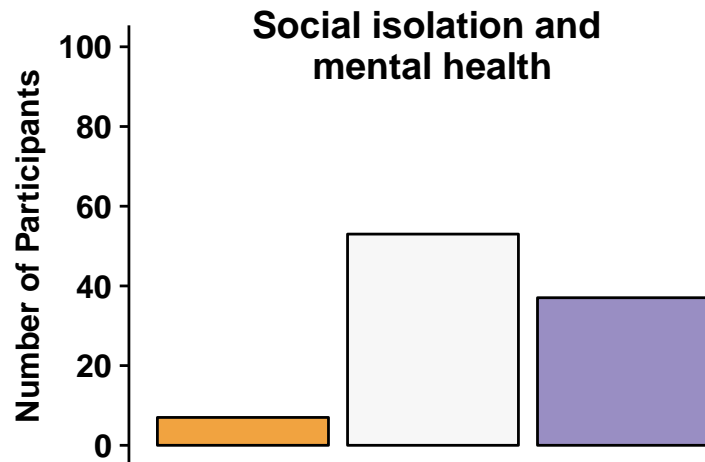
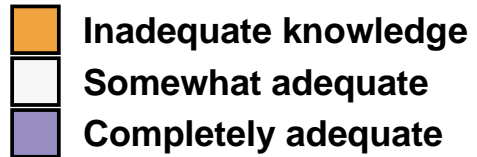
### Adequacy of knowledge

-  Inadequate knowledge
-  Somewhat adequate
-  Completely adequate



# Well understood topics

## Adequacy of knowledge



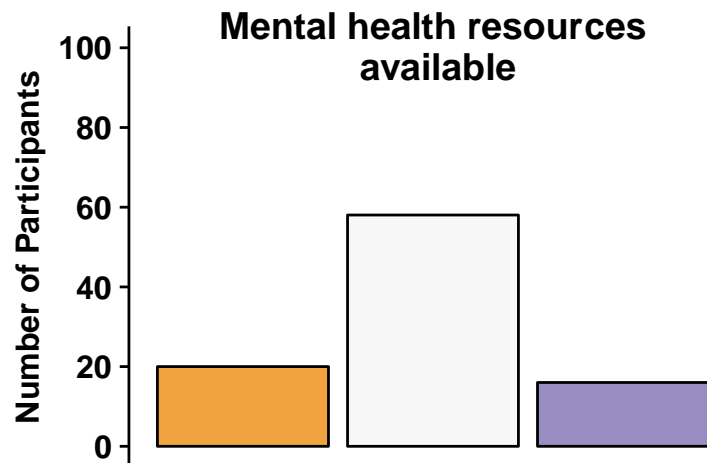
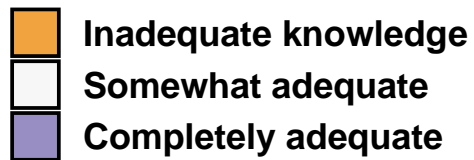
## Other well understood topics

- Social isolation and domestic/elder abuse
- Social isolation and physical health
- Local public health COVID19 guidelines
- Physical risks of SARS-CoV2 for clients



# Areas where more knowledge may be useful

## Adequacy of knowledge



## Other areas where more knowledge could be useful

- Financial resources available
- Respite care resources available
- Medical care resources available

# What did the survey ask?

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- 5) What factors have impacted client use of healthcare and community-based services during COVID19?

# How has client use of healthcare and community-based services changed during the COVID19 pandemic?






## 14 Services Surveyed

4 Healthcare services

3 Caregiver services

7 Community-based services

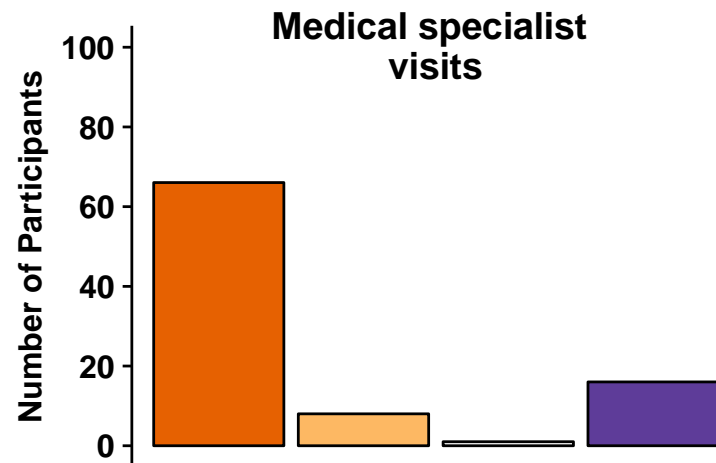
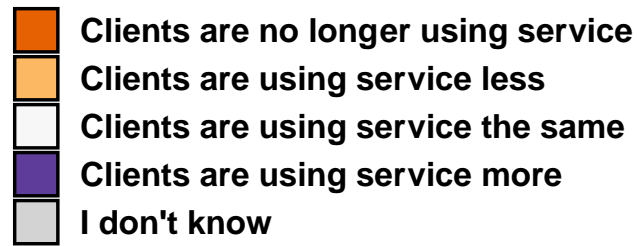
## Changes in Service Use

-  Clients are no longer using service
-  Clients are using service less
-  Clients are using service the same
-  Clients are using service more
-  I don't know



# Services that many clients are no longer using

## Changes in Service Use

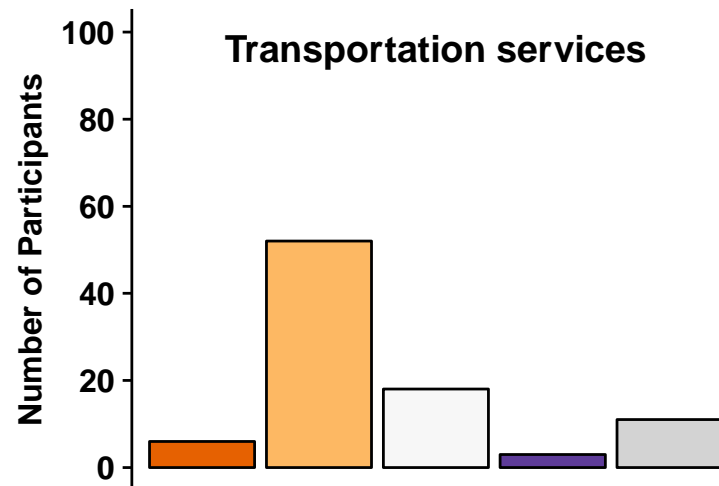
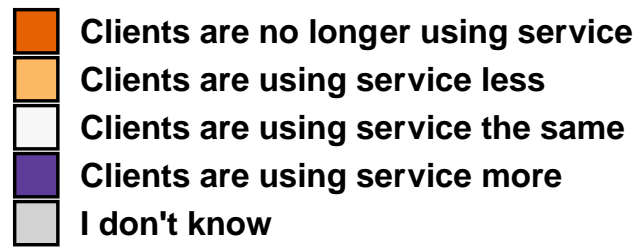


## Other services many are no longer using

- Senior center programs
- Adult day programs
- Companion/friendly visitor services

# Services most clients are using less

## Changes in Service Use

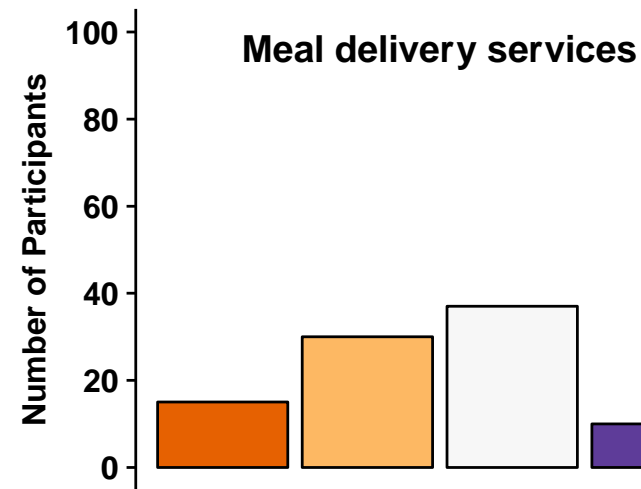
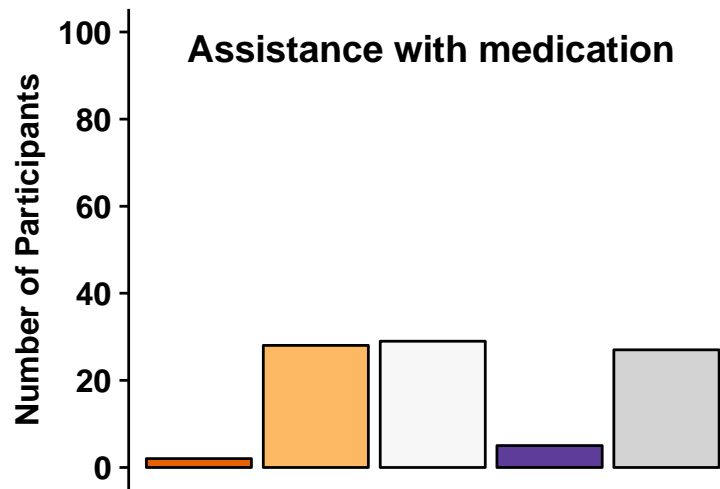
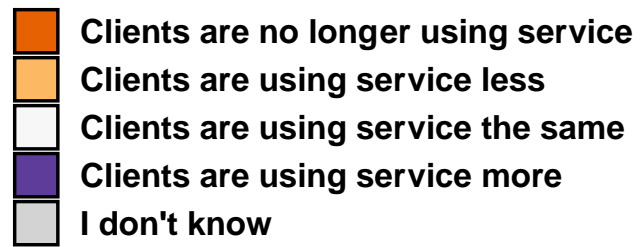


## Other services many are using less

- Caregiver support/respice services
- Caregiver counseling services
- Caregiver education classes
- Physical therapy visits
- Primary care visits
- Counseling/behavioral health visits
- Homecare services

# Services many clients are still using

## Changes in Service Use



# What did the survey ask?

\*Dementia care professional





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- 4) How has client use of healthcare and community-based services changed during the COVID19 pandemic?
- 5) What factors have impacted client use of healthcare and community-based services during COVID19?**

# What factors have impacted client use of healthcare and community-based services during COVID19?

## 15 Factors Surveyed

- 2 Technology
- 5 Support systems
- 2 Financial
- 4 Healthcare engagement
- 2 Personal health

## Effect on Service Use

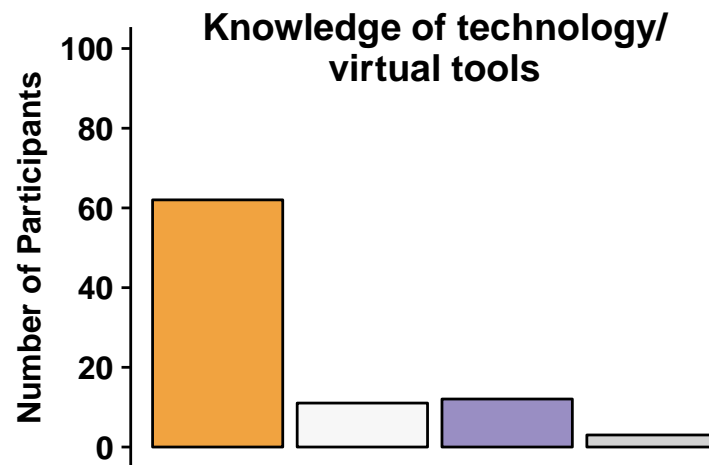
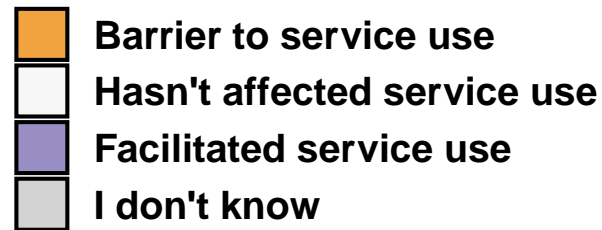
-  Barrier to service use
-  Hasn't affected service use
-  Facilitated service use
-  I don't know





# Barriers for clients identified by most DCPs

## Effect on Service Use

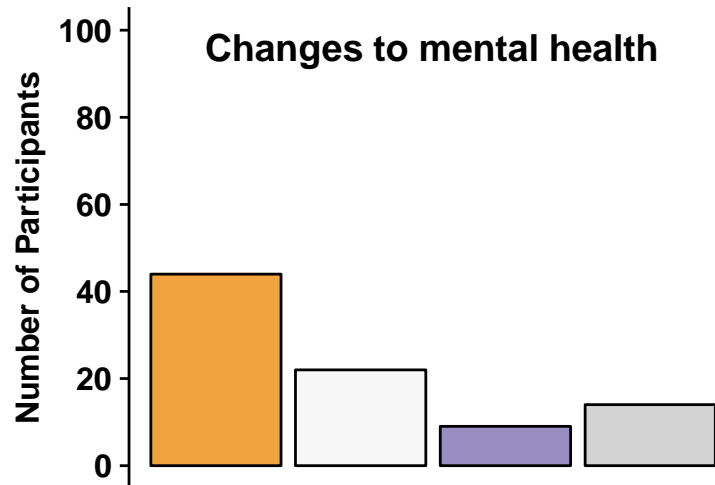
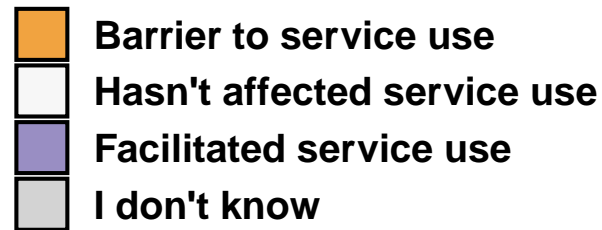


## Other barriers identified by most DCPs

- Access to technology/virtual tools
- Changes to caregiver support/respite services
- Compassion fatigue/caregiver burnout
- Changes in familial obligations
- Changes in access to other natural supports

# Barriers for clients identified many DCPs

## Effect on Service Use

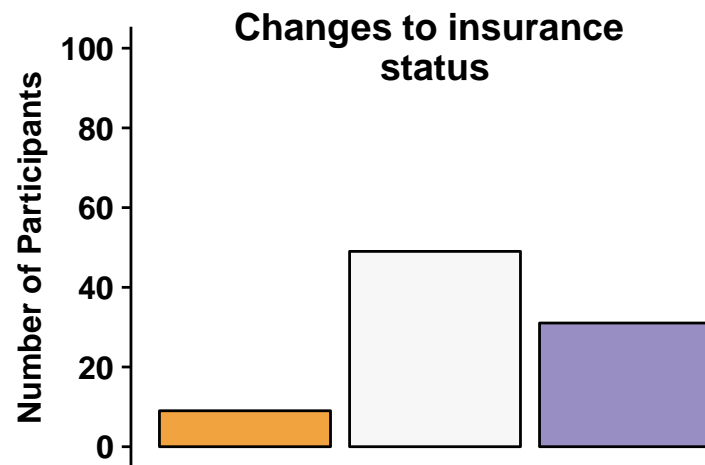
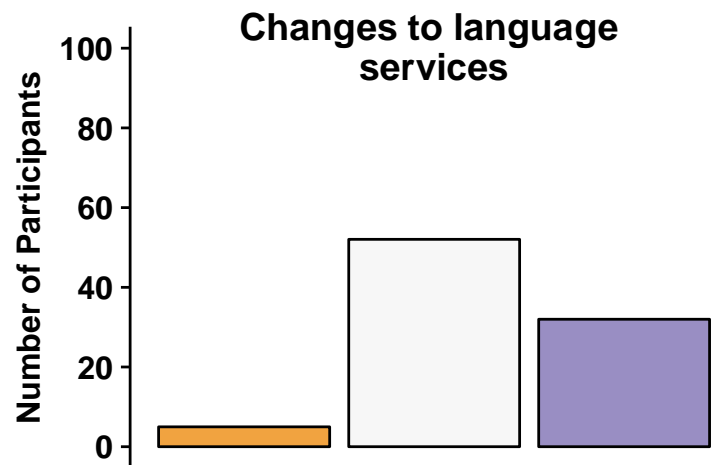
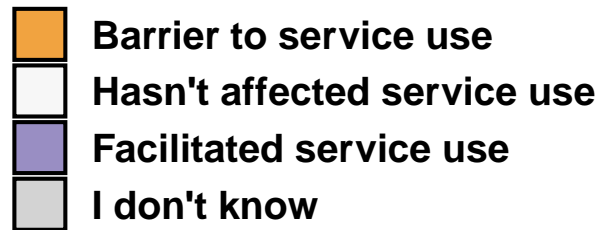


## Other barriers identified by many DCPs

- Changes in access to primary caregiver
- Changes in physical health
- Changes in appointment availability
- Changes in transportation
- Changes in financial resources
- Changes to employment status

# Facilitating factors identified by DCPs

## Effect on Service Use



# Summary and reflection

Mostly white, female, dementia care specialists, dementia leads and dementia lead supervisors working in ADRCs or non-profits serving rural areas

All DCP services are decreased, particularly in-person

Most DCPs reported at least one barrier to performing job

Technology was a barrier for some DCPs, facilitator for others

Overall, DCPs felt they had the knowledge they needed to serve clients

Clients using all healthcare and community-based services less

Multiple barriers for clients (technology, support systems, respite)

Improved language services and insurance access are facilitators

# Summary and reflection

*Whose voices are missing?*

*Are there unique challenges in urban/rural settings, specific cultural contexts?*

*Are there suitable and safe alternatives to in-person services?*

*Why do some DCPs report no barriers and others many?*

*Why is technology a barrier for some DPCs and a facilitator for others?*

# Discussion

**How can we put this information into action?  
What is a concrete next step?  
How can WAI help?**

# Thank you!

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@JackFVHunt

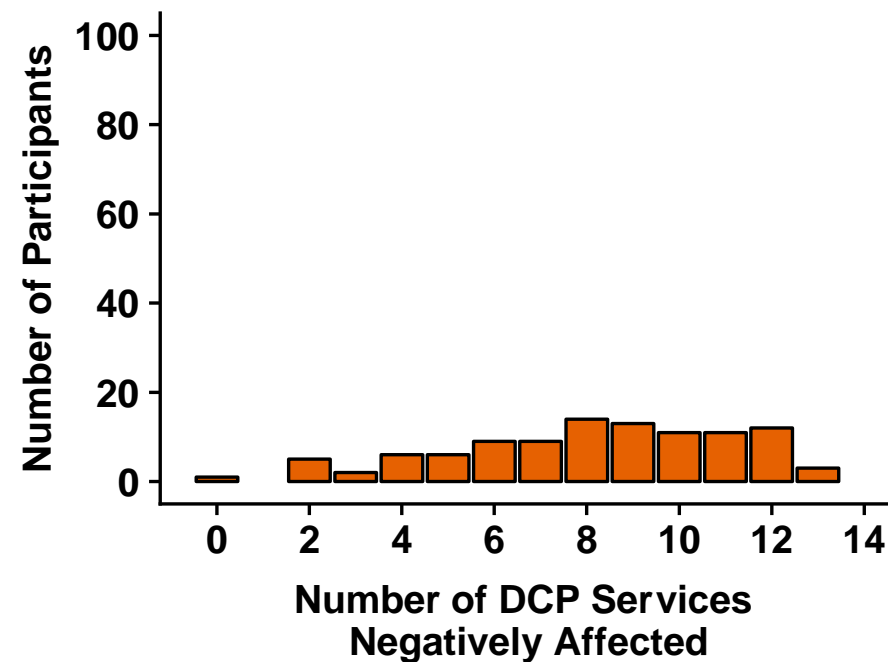


**Wisconsin Alzheimer's Institute**  
UNIVERSITY OF WISCONSIN  
SCHOOL OF MEDICINE AND PUBLIC HEALTH

# Extra Slides



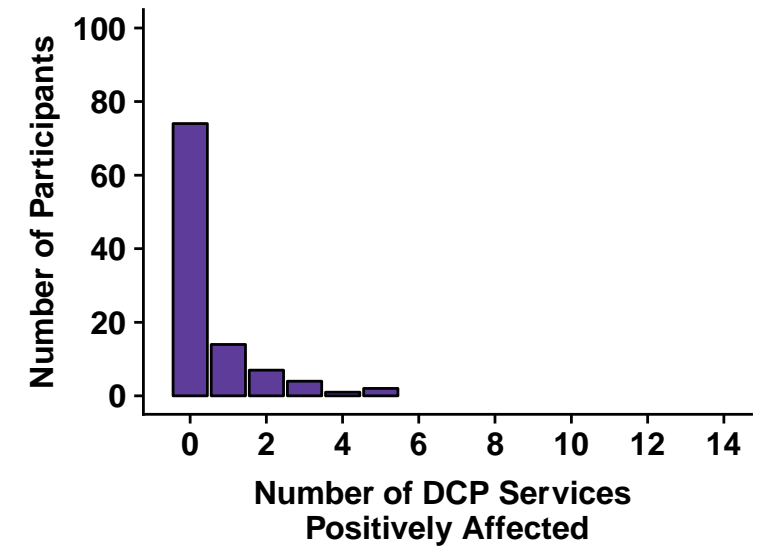
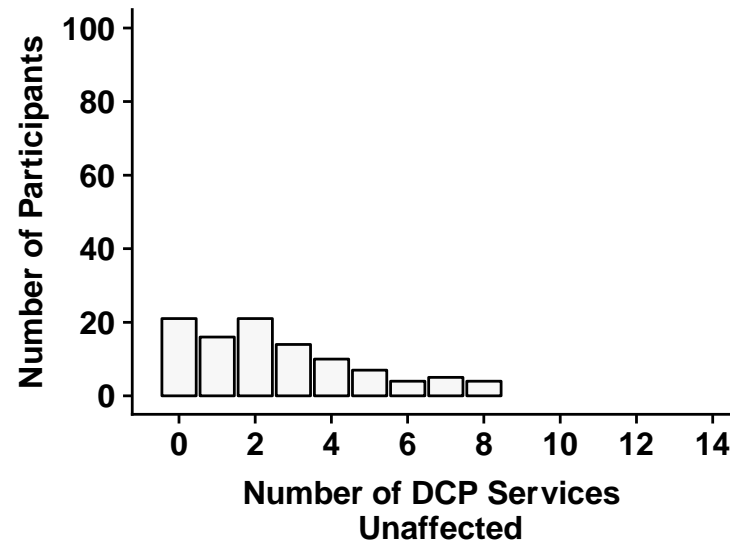
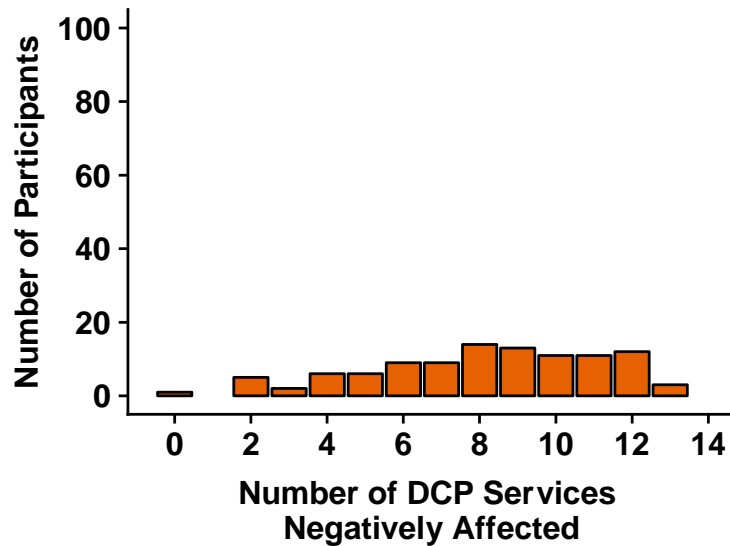
Participants reported 8.1 out of 13 DCP services negatively affected on average



# Are many DCP services are affected?

## Service Availability

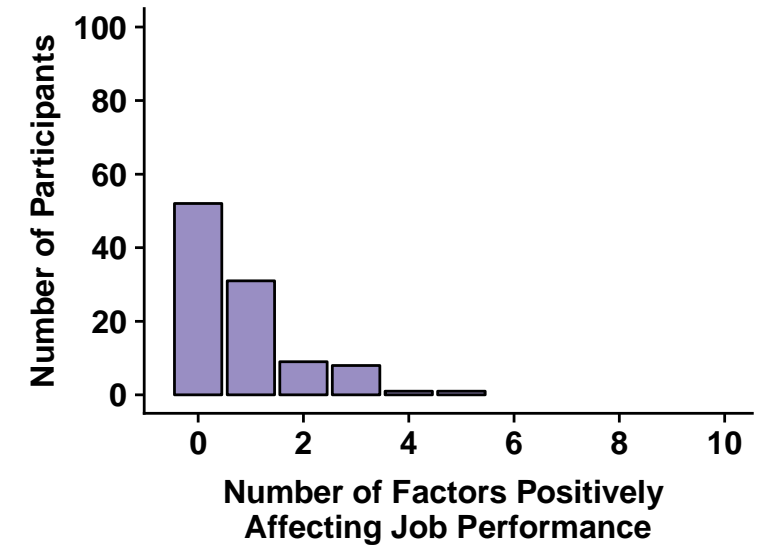
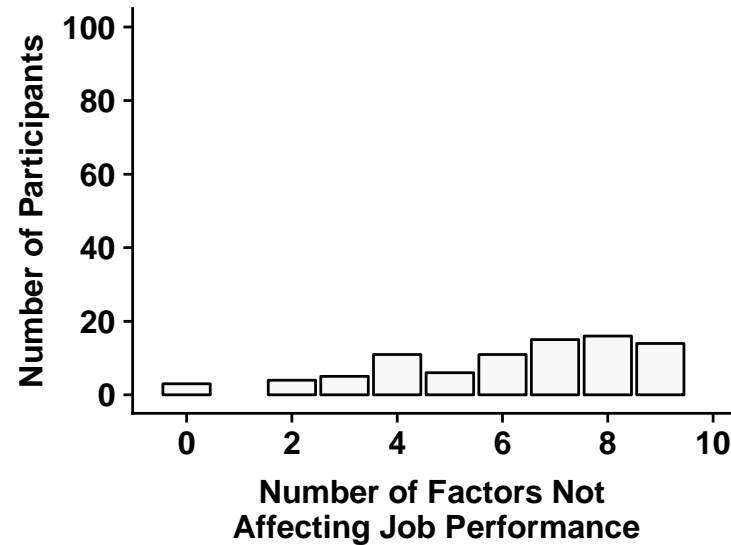
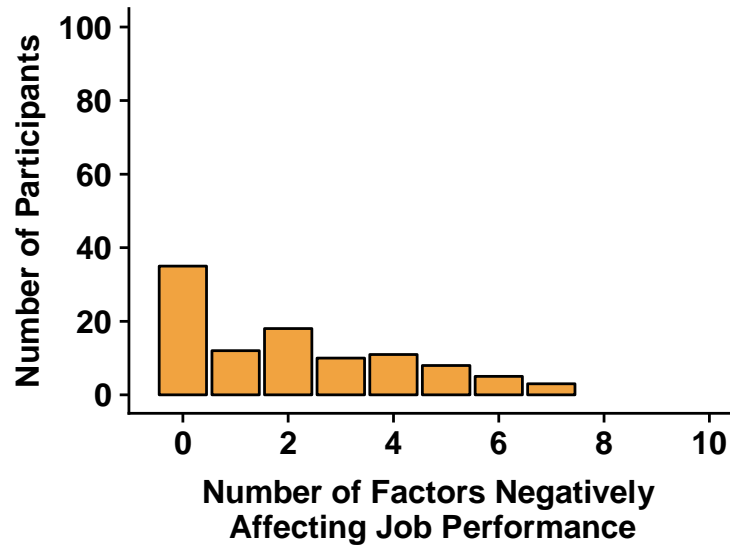
- Service is not available
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- I don't know



# How many factors affected DCPs ability to perform job?

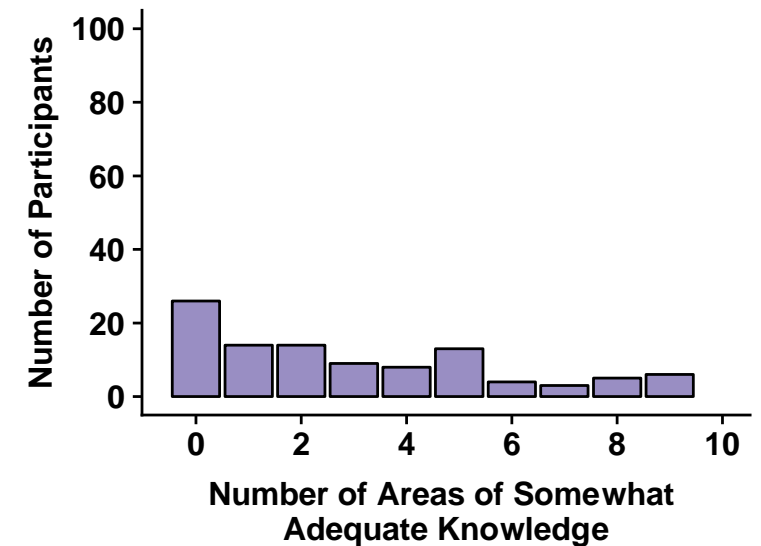
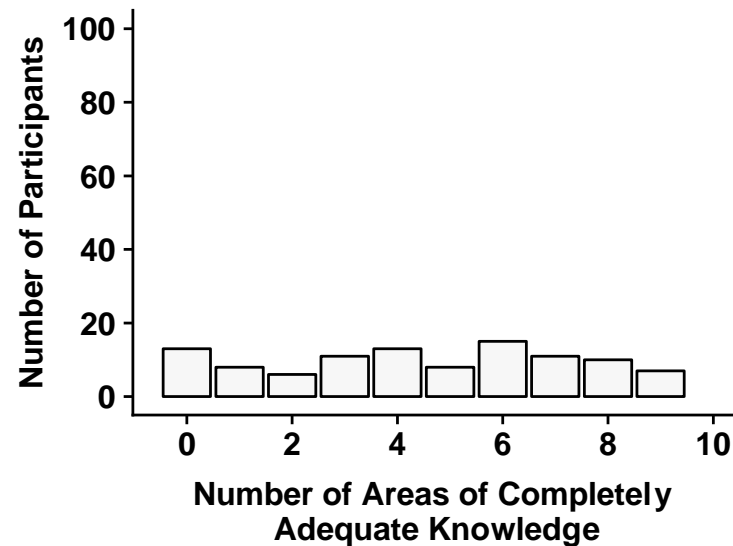
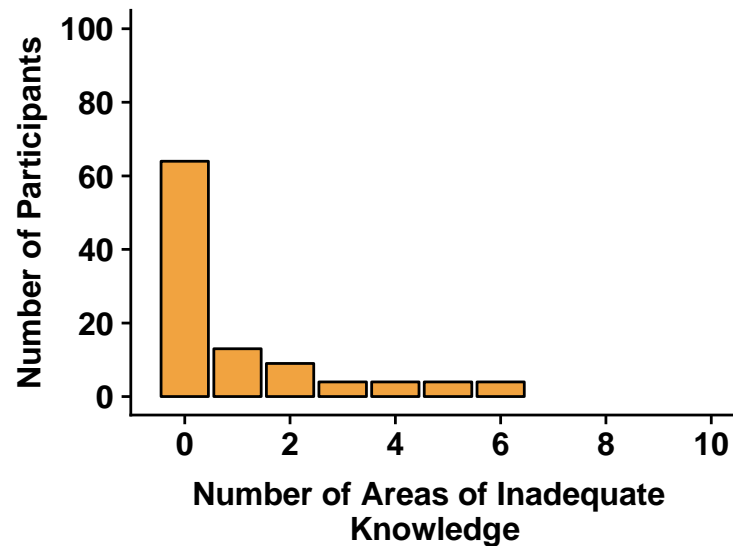
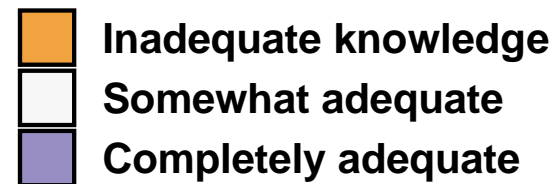
## Effect on job performance

- Negatively affected job performance
- Hasn't affected job performance
- Positively affected job performance



# How adequate are different areas of COVID19-related knowledge?

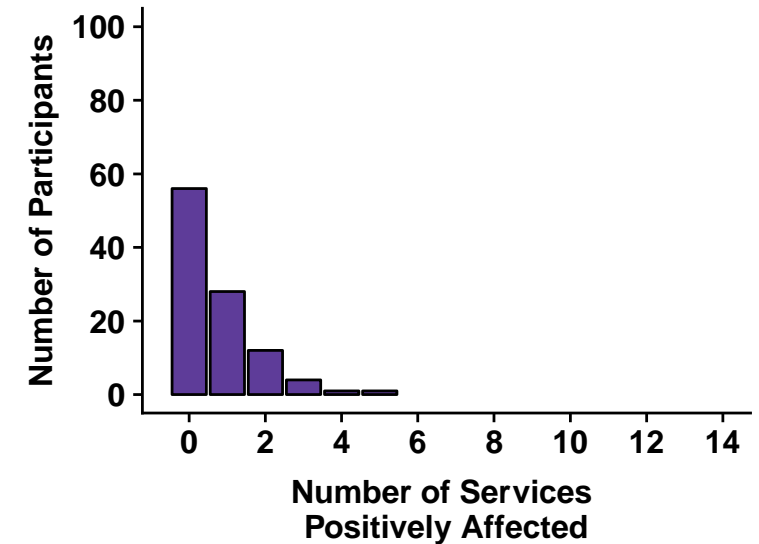
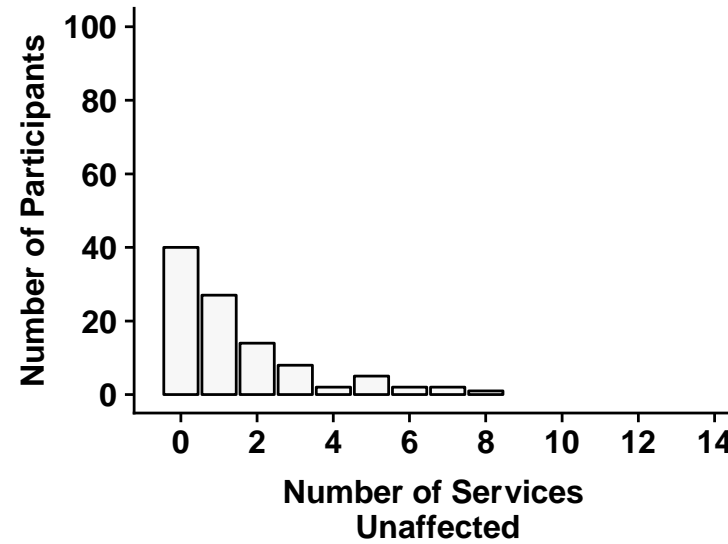
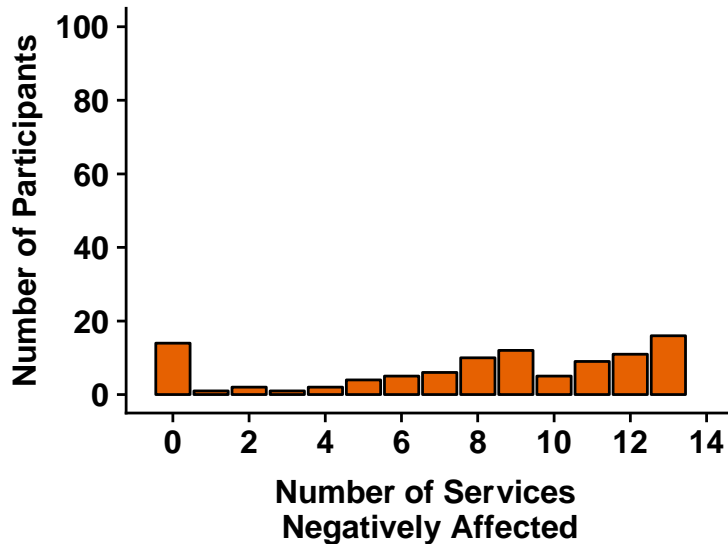
## Adequacy of knowledge



# How many services are clients using differently during COVID19?

## Changes in Service Use

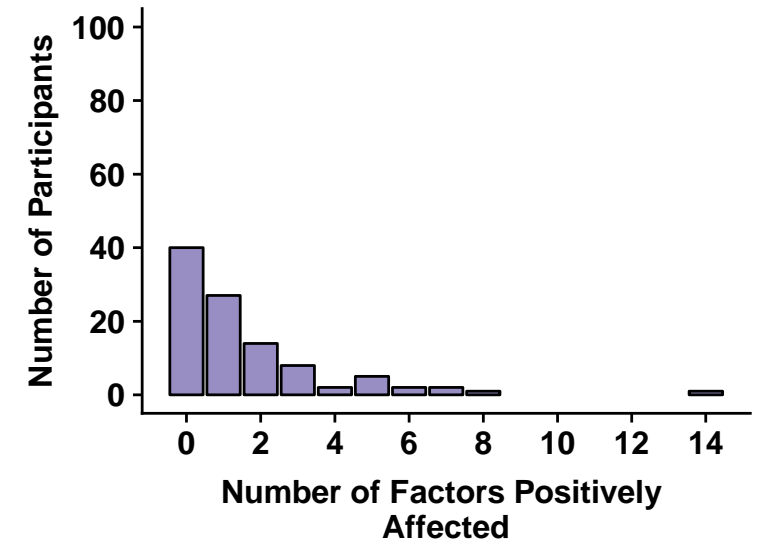
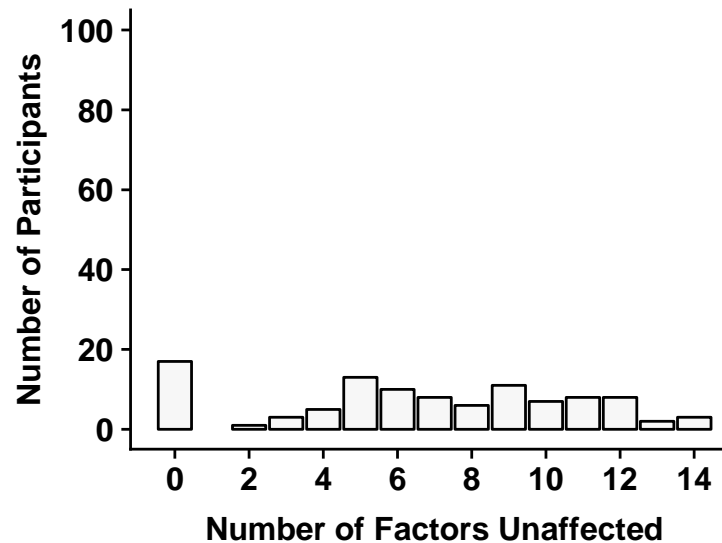
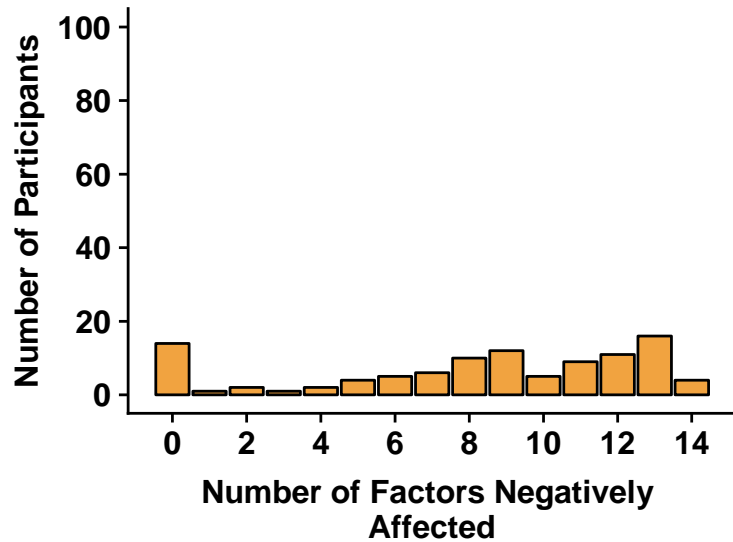
- Clients are no longer using service
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- I don't know



# How many factors are affecting service use?

## Effect on Service Use

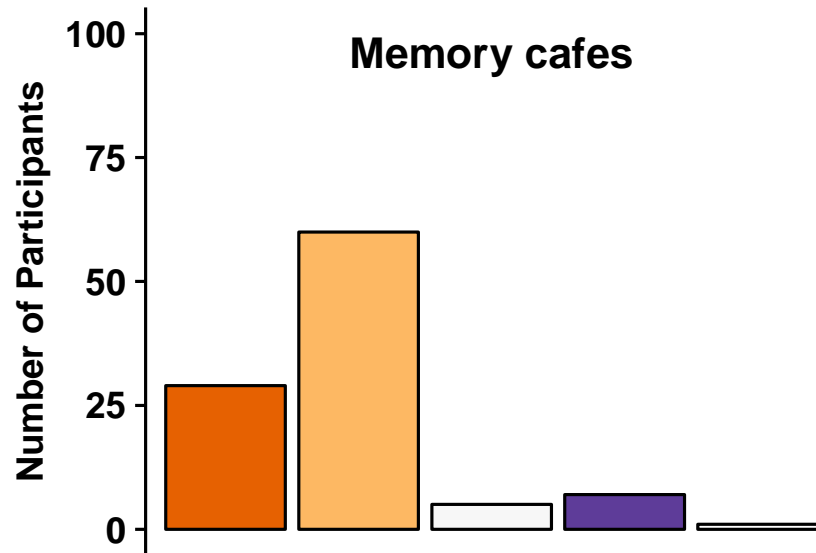
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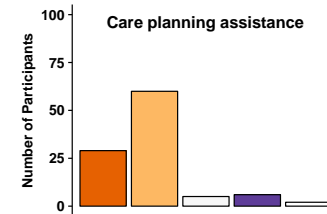
# Unavailable services

## Service Availability

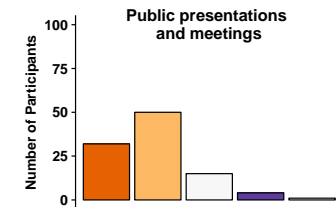
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- Service is less available
- Availability hasn't changed
- Service is more available
- I don't know



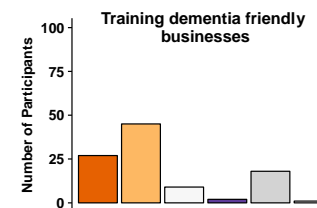
### Care planning assistance



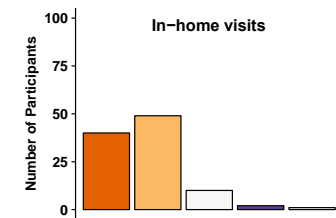
### Public presentations & meetings



### Training dementia-friendly businesses



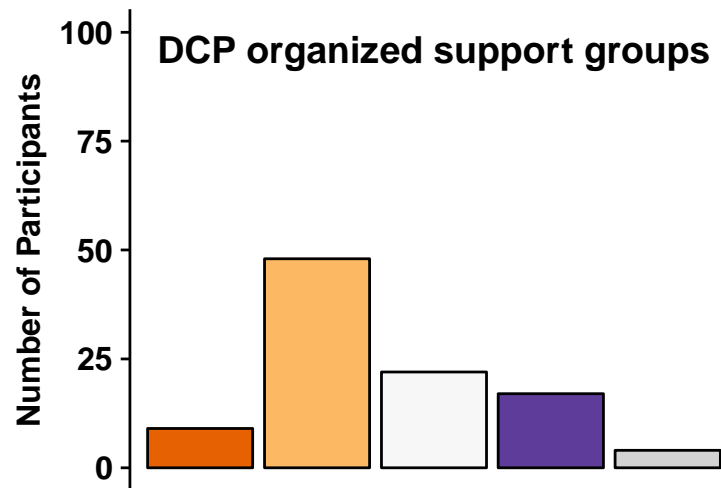
### In-home visits



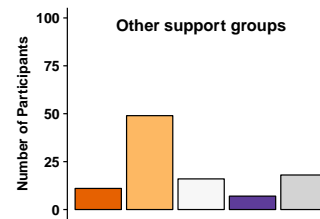
# Limited services

## Service Availability

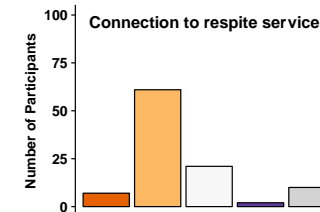
- Service is not available
- Service is less available
- Availability hasn't changed
- Service is more available
- I don't know



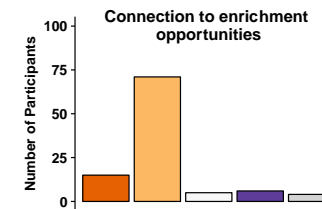
### Other support groups



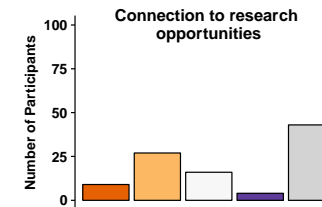
### Connection to respite services



### Connection to enrichment opportunities



### Connection to research opportunities

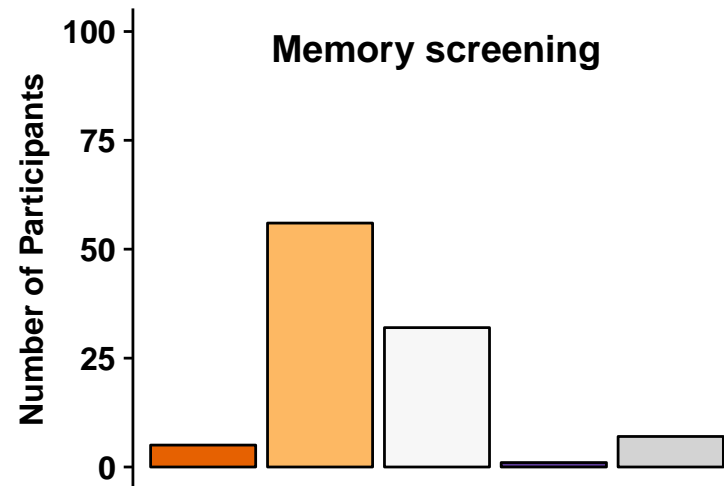




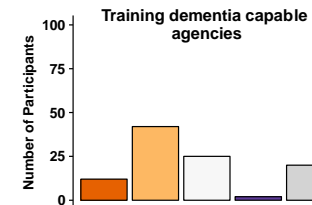
# Less affected services

## Service Availability

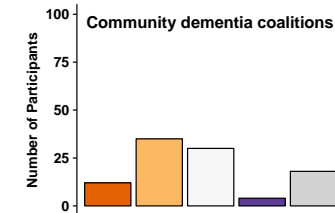
- Service is not available
- Service is less available
- Availability hasn't changed
- Service is more available
- I don't know



## Training dementia capable agencies



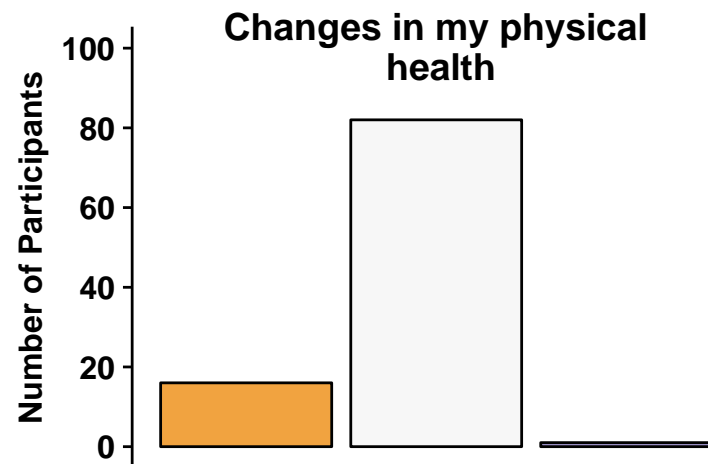
## Community dementia coalitions



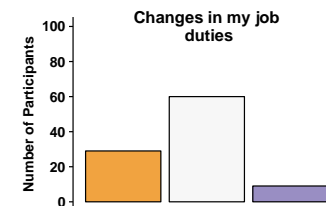
# Factors with moderate negative effect on DCP performance

## Effect on job performance

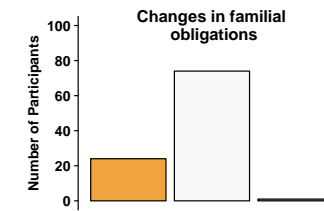
- Negatively affected job performance
- Hasn't affected job performance
- Positively affected job performance



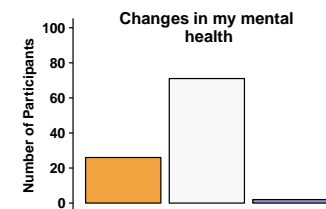
## Changes in job duties



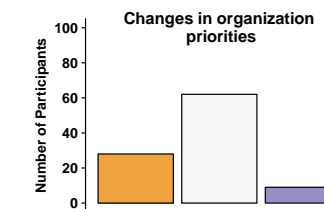
## Changes in familial obligations



## Changes in mental health

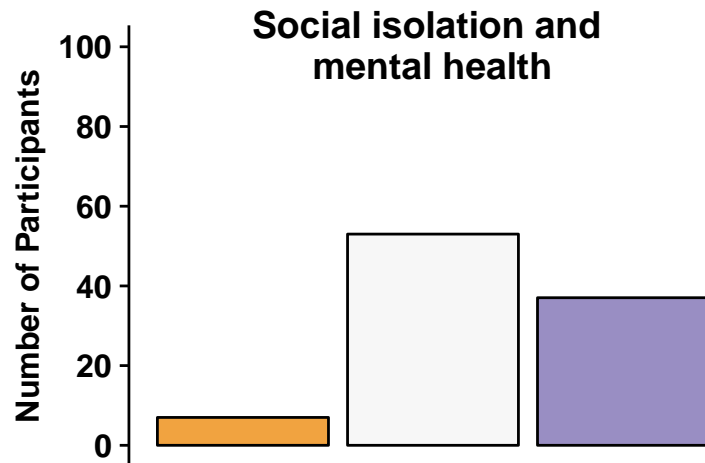
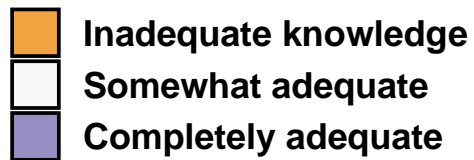


## Changes in organization priorities

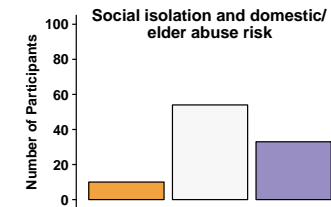


# Well understood topics

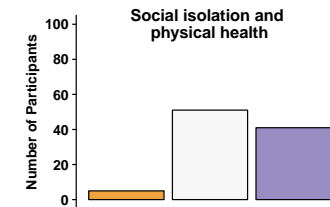
## Adequacy of knowledge



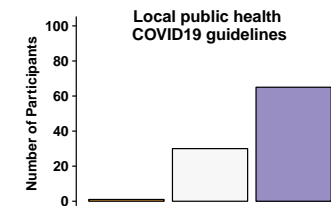
## Social isolation and domestic/elder abuse



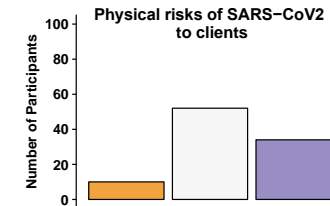
## Social isolation and physical health



## Local public health COVID19 guidelines

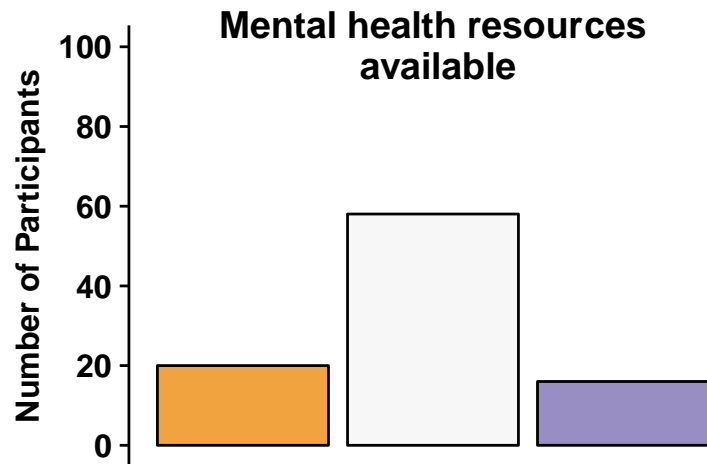
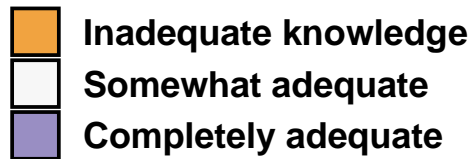


## Physical risks of SARS-CoV2 for clients

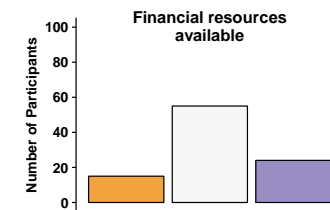


# Areas where more knowledge may be useful

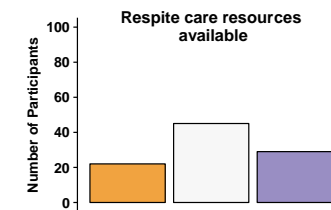
## Adequacy of knowledge



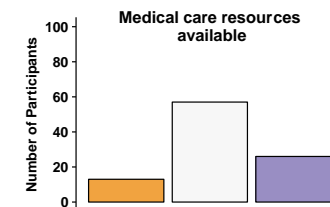
### Financial resources available



### Respite care resources available

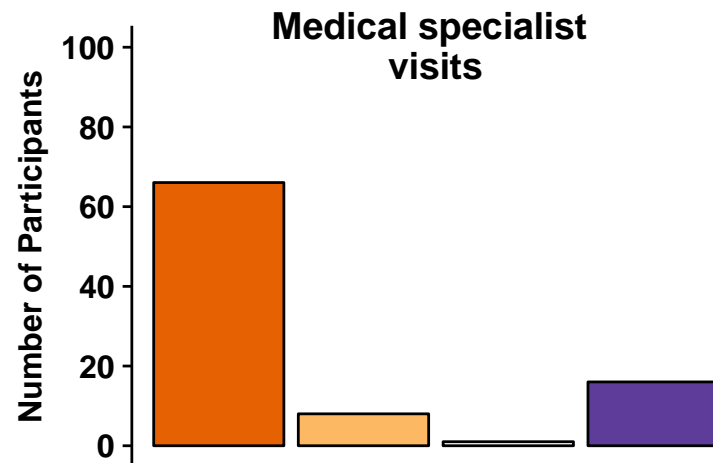
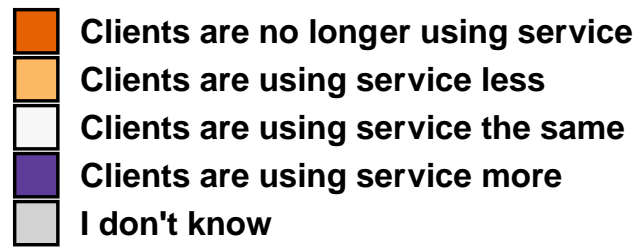


### Medical care resources available

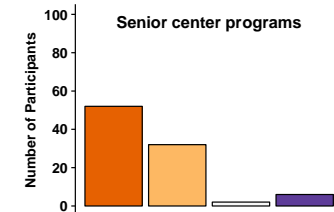


# Services that many clients are no longer using

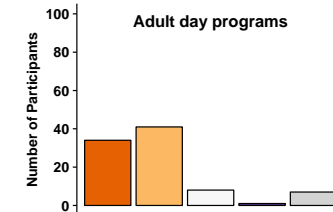
## Changes in Service Use



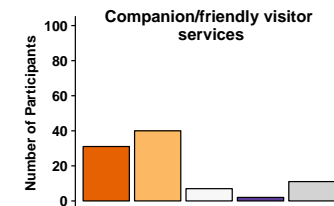
## Senior center programs



## Adult day programs

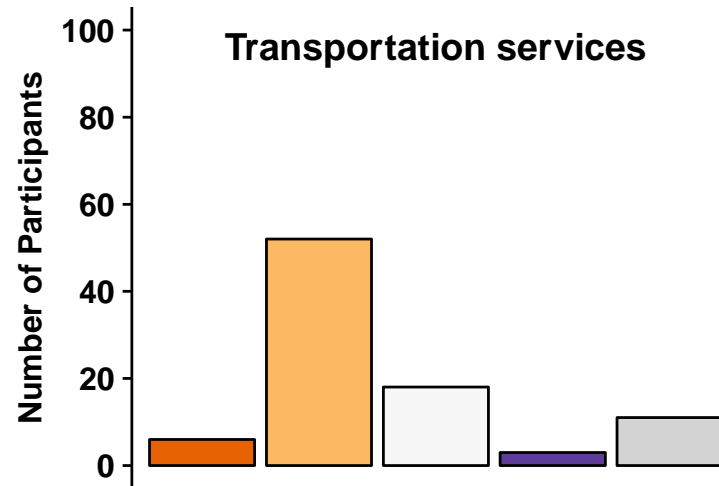
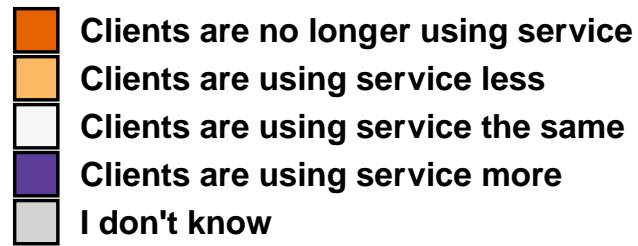


## Companion/friendly visitor services

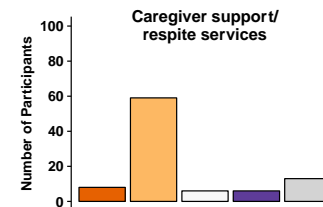


# Services most clients are using less

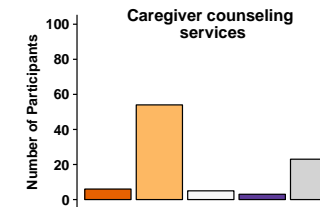
## Changes in Service Use



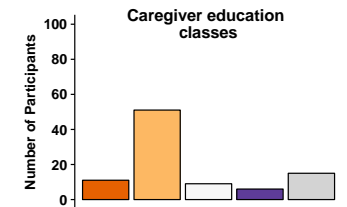
Caregiver support /respite services



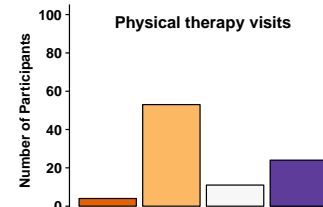
Caregiver counseling services



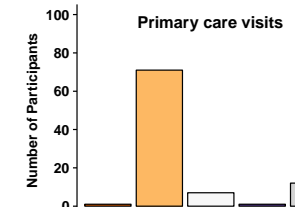
Caregiver education classes



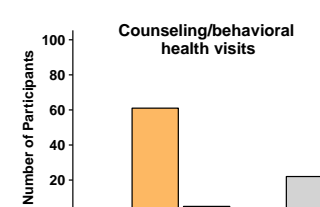
Physical therapy visits



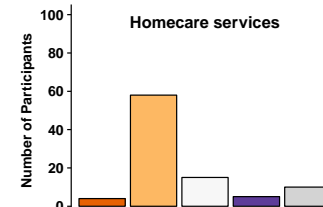
Primary care visits



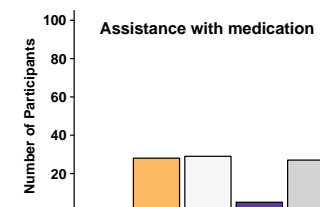
Counseling/ behavioral health visits



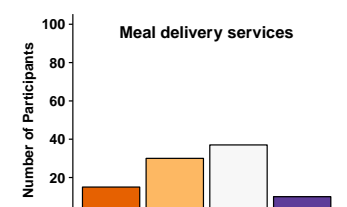
Homecare services



Assistance with medication

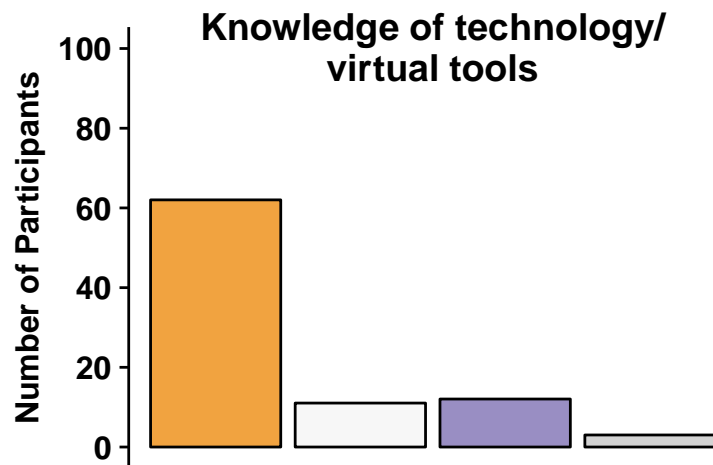
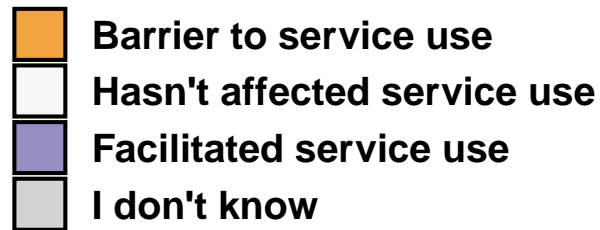


Meal delivery services

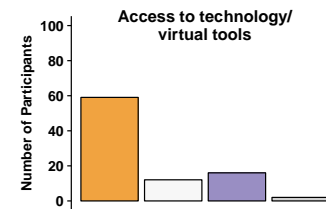


# Barriers for clients identified by most DCPs

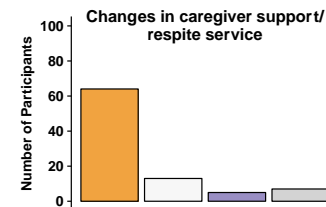
## Effect on Service Use



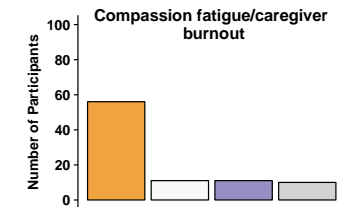
## Access to technology/virtual tools



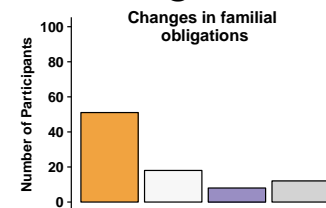
## Changes to caregiver support/respite service



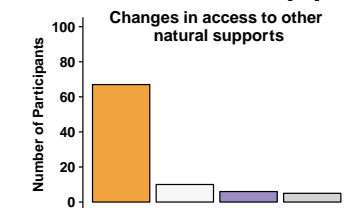
## Compassion fatigue/caregiver burnout



## Changes in familial obligations

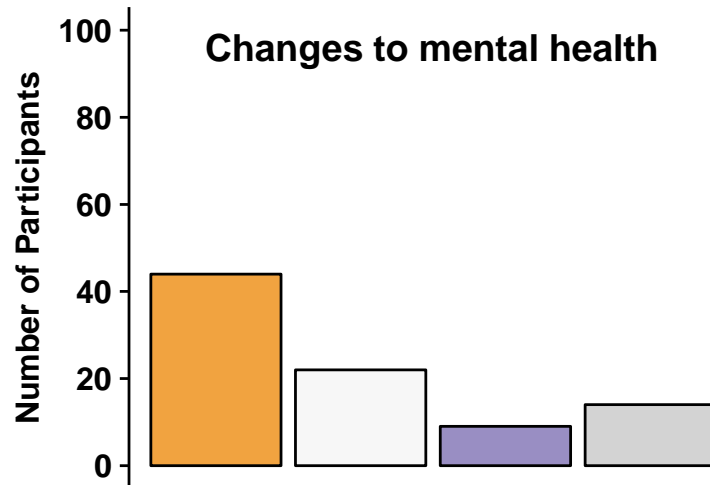
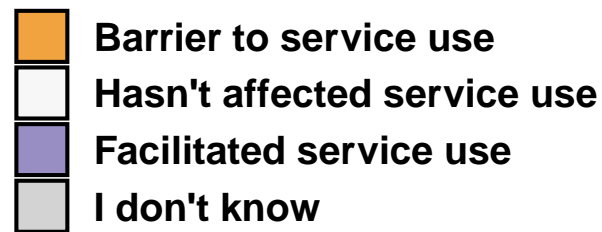


## Changes in access to other natural supports

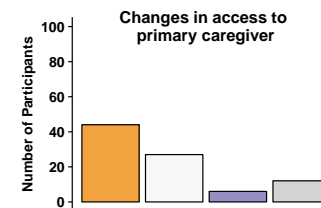


# Barriers for clients identified many DCPs

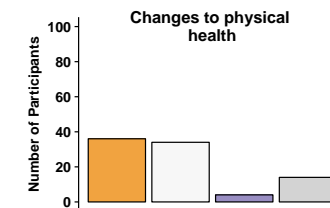
## Effect on Service Use



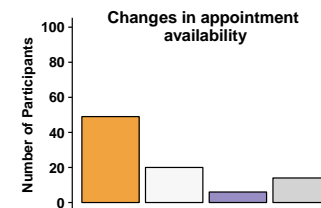
## Changes in access to primary caregiver



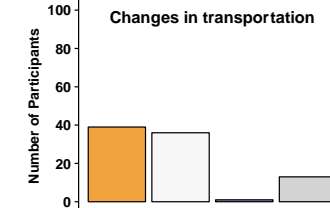
## Changes in physical health



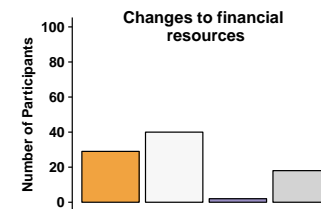
## Changes in appointment availability



## Changes in transportation



## Changes to financial resources



## Changes to employment status

