

Breakout session 2: Access to support and services

17th March 2022



Breakout session 2: Access to support and services

Chair: Sarah Polack	
Chi Kin Kwan	Difficulties pertaining to people with intellectual disabilities in using public services during the COVID-19 pandemic
Yashoda Sharma	A Survey of the Challenges Faced by Individuals with Disabilities and Unpaid Caregivers During the COVID-19 Pandemic
Vu Quynh Mai	Exploring the socioeconomic impacts to people with disabilities in Vietnam during the COVID-19 pandemic
Carol Rivas	Intersectionality findings from the CICADA study exploration of the pandemic experiences of disabled people from minoritised ethnic groups
Q&A	

Chi Kin Kwan
City University, Hong Kong

Difficulties pertaining to people with intellectual disabilities in using public services during the COVID-19 pandemic

Difficulties pertaining to people with intellectual disabilities in using public services during the COVID-19 --- pandemic

Chi Kin KWAN

City University of Hong Kong

Background

- The needs of people with intellectual disabilities are often insufficiently recognized by mainstream society, causing this population to be excluded from society and daily life activities.
- It was reported that people with intellectual disabilities in Hong Kong were more confined, had less exercise, and spent less time outdoors during the COVID-19 pandemic (Chinese University of Hong Kong 2021).
- The levels of severity related to these challenges that people with intellectual disabilities faced were significantly greater in Hong Kong than the international average (Chinese University of Hong Kong 2021).

Method

- In this qualitative study, we conducted focus group sessions with 17 social workers and 12 carers (including mothers, fathers, and sisters) supporting people with intellectual disabilities.
- Two rounds of focus groups, corresponding to four sessions in total, were conducted in April and May 2021, when the fourth wave of COVID-19 in Hong Kong was largely under control.

Findings

The social-emotional needs of people with intellectual disabilities were intensified by the disruption of social services

“At home [she was] more frustrated. Not being able to go [to the day activity center] made her lose her temper from time to time. It would be better for her if she could go back to the center.”

(Alex, father of a service user at day activity center)

“At first he did not have emotional problems. But staying home for a long time made him bored and uncooperative. Thus, carers certainly became frustrated, and some conflicts were unavoidable.”

(Betty, sister of a service user at sheltered workshop)

They received limited benefit from the use of video conferencing services

“[We] tried to use Zoom to deliver [our] activities. Volunteers were online, asking our members to [do] this and that. But the members were not able to follow. It was perhaps due to their limited cognitive ability and poor concentration. Hence, using Zoom is not effective for them.”

(Andy, social worker, day activity center cum hostel)

“No interaction at all, just like watching television. They [essentially] sat there watching television.”

(David, social worker, day activity centre cum hostel)

They encountered significant difficulties in complying with preventive measures.

“Not wearing [face] masks was common [among service users] during the outbreak. Basically they did not know how to wear [face masks].”

(Bonnie, social worker, day activity centre cum hostel)

“During the pandemic, I escorted a service user going [for a] medical appointment. As this service user was not willing to wear a mask, when we went into [the doctor’s room], the doctor shouted ‘I won’t serve you; leave immediately!’ We left with difficult feelings.”

(David, social worker, day activity centre cum hostel)

Conclusion

- “There can be no quality without equity.” (Feely, 2020, p. 503)
- To promote inclusiveness in the public sphere, a culture of accessibility must be fostered among public servants.
- To achieve equity in public service, universal design should be emphasized during the planning stage, and the experiences of people with intellectual disabilities should be carefully considered from the outset.

Yashoda Sharma
University Health Network, Canada

A Survey of the Challenges Faced by Individuals
with Disabilities and Unpaid Caregivers During the
COVID-19 Pandemic

**International Center for Evidence in Disability
Conference on Disability and COVID-19**

**A Survey of the Challenges Faced by
Individuals with Disabilities and Unpaid
Caregivers During the COVID-19
Pandemic**

Yashoda Sharma, MScPT, PT, PhD student

Acknowledgements: Alison Whiting and Dr. Tilak Dutta

Presentation Outline

① **Introduction**

② **Methods**

③ **Results**

④ **Discussion**

Introduction


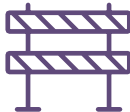
Introduction – Canadian Population

- Growing number of individuals with disabilities in Canada
- Many require assistance → unpaid caregivers (friends, family, neighbors)





Introduction – Preliminary COVID-19 Research

Individuals with Disabilities

- Health care access 
- Barriers to social engagement 

Unpaid Caregivers

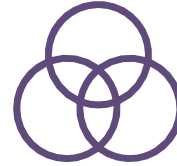
- Fatigue & Burnout 
- Lack of caregiver support 

Introduction – Gaps & Objectives

Gaps



Understanding
of challenges



Similarities



What support
is needed?



Objectives

①

Identify & compare
challenges

②

Identify potential
solutions

Methods

Methods – Data Collection & Analysis

Data Collection

- Online survey
- Anonymous responses
- Open & closed ended questions

Data Analysis

- NVivo
- Inductive thematic analysis
- Surveys analysed separately and thematic maps compared

Results

Results – Participant Characteristics

Demographics

- Individuals with disabilities & unpaid caregivers
- 111 participants total
 - 68 individuals with disabilities & 43 unpaid caregivers
- Predominantly female, “White or Caucasian”
- > 75% between 31-70 years of age



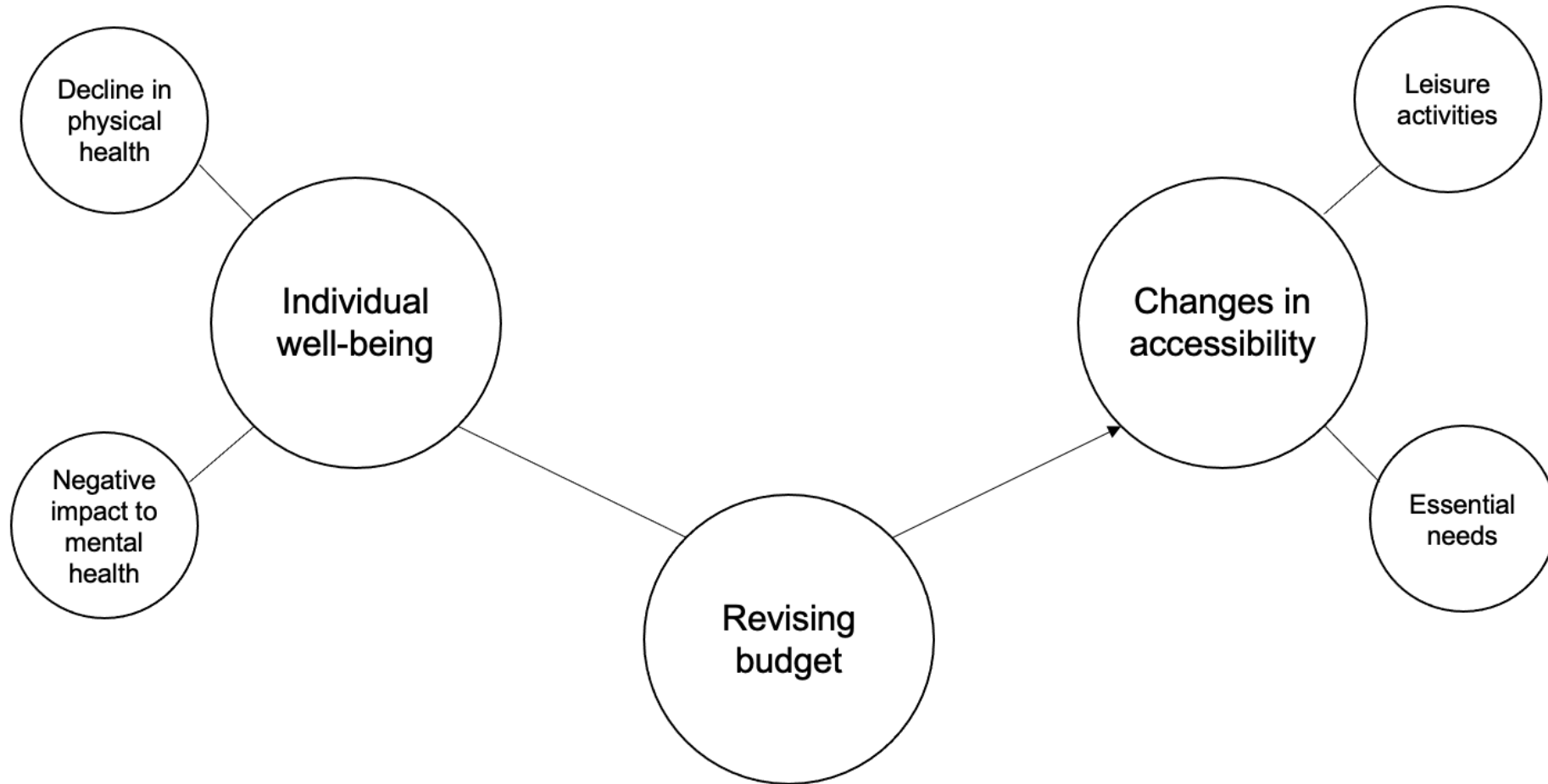
Results – Individuals with Disabilities

Level of functioning

- 52.3% extreme problems joining community activities (n=65)
- 47.7% extreme problems with fatigue/energy (n=65)
- Range of impairments



Results – Individuals with Disabilities

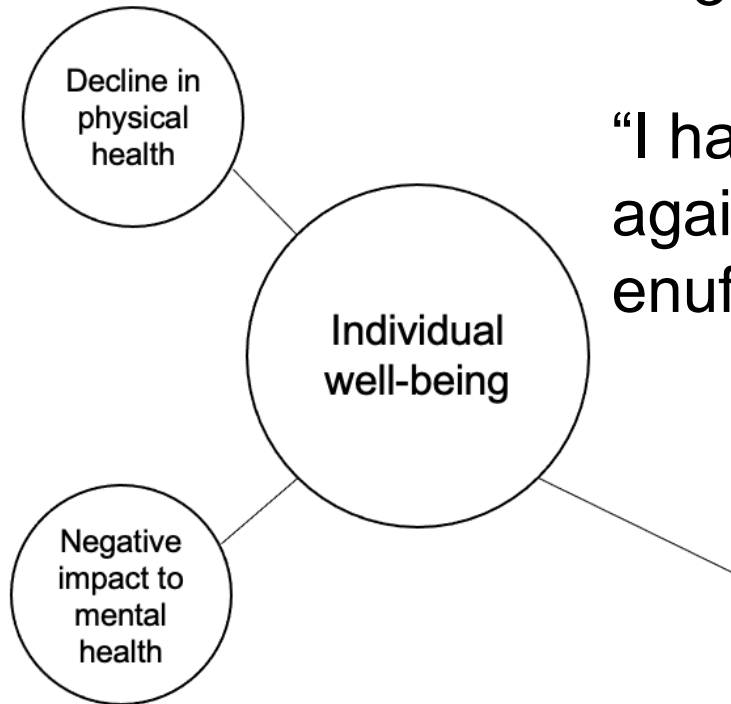


Results – Individuals with Disabilities

Decline in physical health.

- 37.10% of participants

“I have more pain because I am less active so again don't get dressed. Hard to stand long enuf to make a meal”



Negative impact to mental health.

- 95.16% of participants

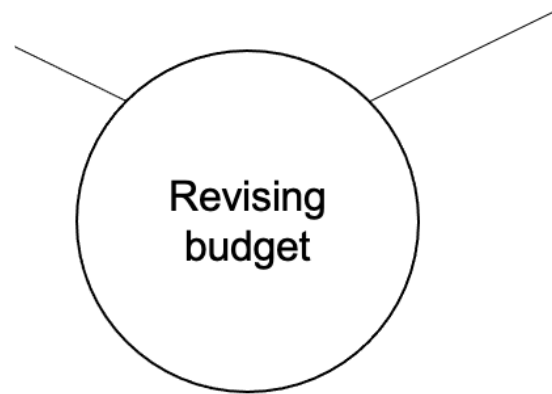
“I’ve been suicidal again after a long time of doing better and I would attribute that mainly to the restrictions and stress that covid has brought to my life.”

Results – Individuals with Disabilities

Revising budgets

- 74.19% of participants

“Cannot afford take out so sometimes don't eat.
Sometimes not [enough] money for grocery[ies] so
don't eat.”



Results – Individuals with Disabilities

Leisure activities.

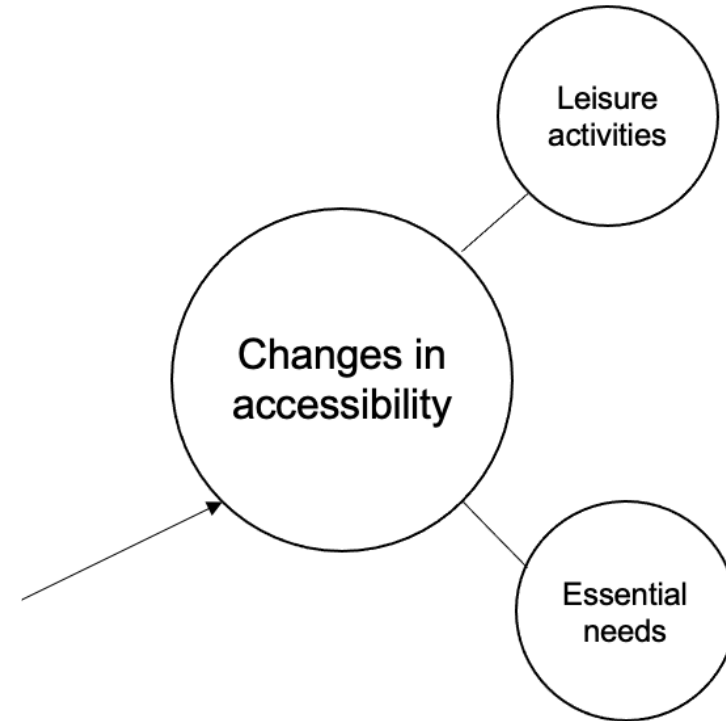
- 66.13% of participants

“can’t join any groups that would be fun because everything is closed down and even if it was open I am too scared....”

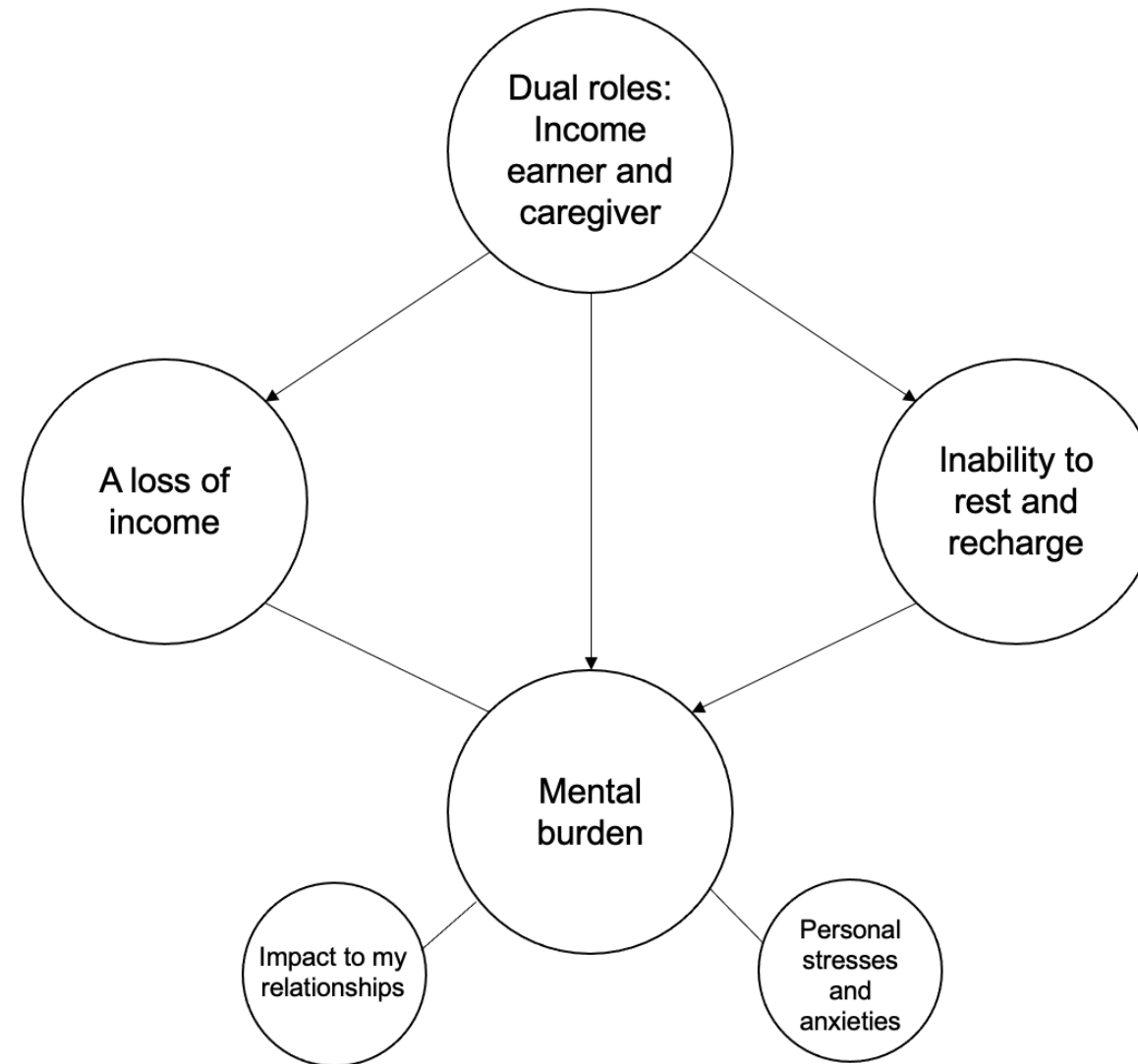
Essential needs.

- 90.32% of participants

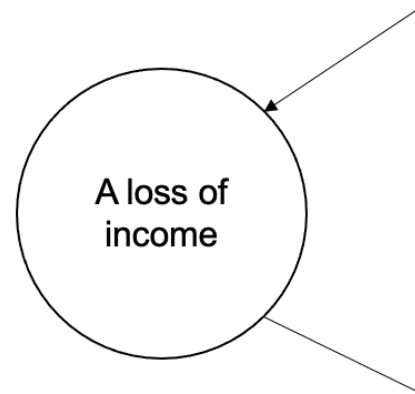
“Cannot just walk in a see my doctor anymore have to do facetime which is ridiculous especially if you have lumps how can they see and feel over facetime?”



Results – Unpaid Caregivers



Results – Unpaid Caregivers

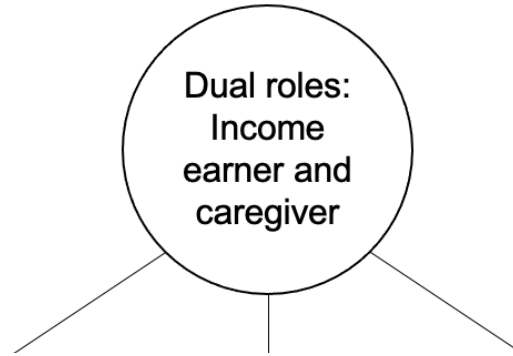


A loss of income.

- 65.71% of participants

“Now I’m no longer paid because my caregiving is now full time”

Results – Unpaid Caregivers



Dual roles: Income earner and caregiver

- 48.57% of participants

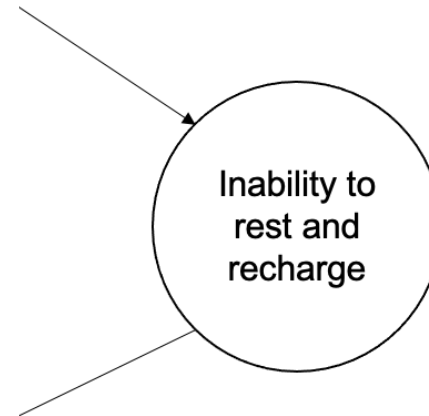
“I have committed [sic] 80% of my down time to the person i care for so i dont have time to do even a part time job”

Results – Unpaid Caregivers

Inability to rest and recharge

- 65.71% of participants

“Lack of respite care available which means less time for chores, cleaning and leisure activities”



Results – Unpaid Caregivers

Impact to my relationships.

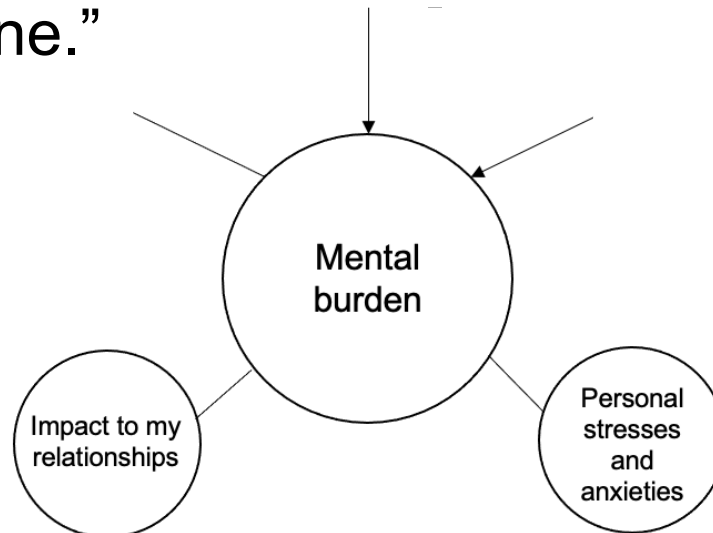
- 57.14% of participants

“I have only seen 7 family members and no friends since March. I don’t see people because I cannot afford to take COVID to my loved one.”

Personal stress and anxiety.

- 85.71% of participants.

“Increased stress and anxiety and social [sic] thoughts due to financial hardship due to lack of financial support for the child with disabilities”



Results – Unpaid Caregivers

Findings	Individuals with Disabilities	Unpaid Caregivers
Negative impact to mental health	COVID-19 + isolation	Predominantly workload
Financial challenges	Job site/job closure	Predominantly increased caregiving duties
Negative impact to physical health	Related to medical care	Related to exhaustion + fatigue
Changes in accessibility	Doctors, dentists, and special services	Respite care

Discussion

Discussion – Potential Solutions

- ① Safe and continued access of respite care
- ② Offering medical services in more ways than virtual
- ③ Revising current financial assistance programs for individuals with disabilities and unpaid caregivers
- ④ Improving communications of available support programs

Discussion – Limitations

Limitations

- Online advertising & survey
- Sample size
- Primarily self-report Women and Caucasians

Discussion - Takeaways

- **Individuals with disabilities:** challenges related to well-being (mental and physical health), accessing essential services and finances
- **Unpaid caregivers:** challenges related to mental health, finances, self-care, and workload
- **Four potential solutions identified**

References

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Exploring the socioeconomic impacts to people with disabilities in Vietnam during the COVID-19 pandemic



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COVID-19 & Disability in Vietnam

*Exploring the socioeconomic impacts to
people with disabilities in Vietnam
during the COVID-19 pandemic*



MAI VU

COVID-19 & disability: Global study

London school of hygiene and tropical medicine works with:

- **Vietnam: Hanoi University of Public Health**
- Bangladesh: BRAC Institute of Governance and Development
- Uganda: Makerere University
- Zambia: University of Zambia
- Ghana: University of Ghana
- Turkey: Relief International; Mülteciler Derneği; Istanbul Sehir University
- India: Public Health Foundation India
- Kenya: University of Nairobi
- Maldives: LSHTM local site
- Afghanistan: independent consultant

Overall objective

To **explore the experiences** of people with disabilities in Vietnam during the COVID-19 pandemic and **identify possible strategies** to better promote the inclusion of people with disabilities in response activities

Adjust for Vietnam

To **explore the experiences** of people with disabilities in Vietnam during the COVID-19 pandemic and **identify possible response strategies** for PWD compare with **general population**

Design

Quantitative study

- A probabilistic quota-based sampling approach
- Sample size: **1000**
- Sites: 3 megacities in the North, Central and South
- Mean of implementation: Telephone

Qualitative study

- In-depth interview
- Sample size: 23 PWDs and 9 related stakeholders
- Site: as above
- Mean of implementation: Virtually

THE SURVEY

Consent

Select respondent

Background questions

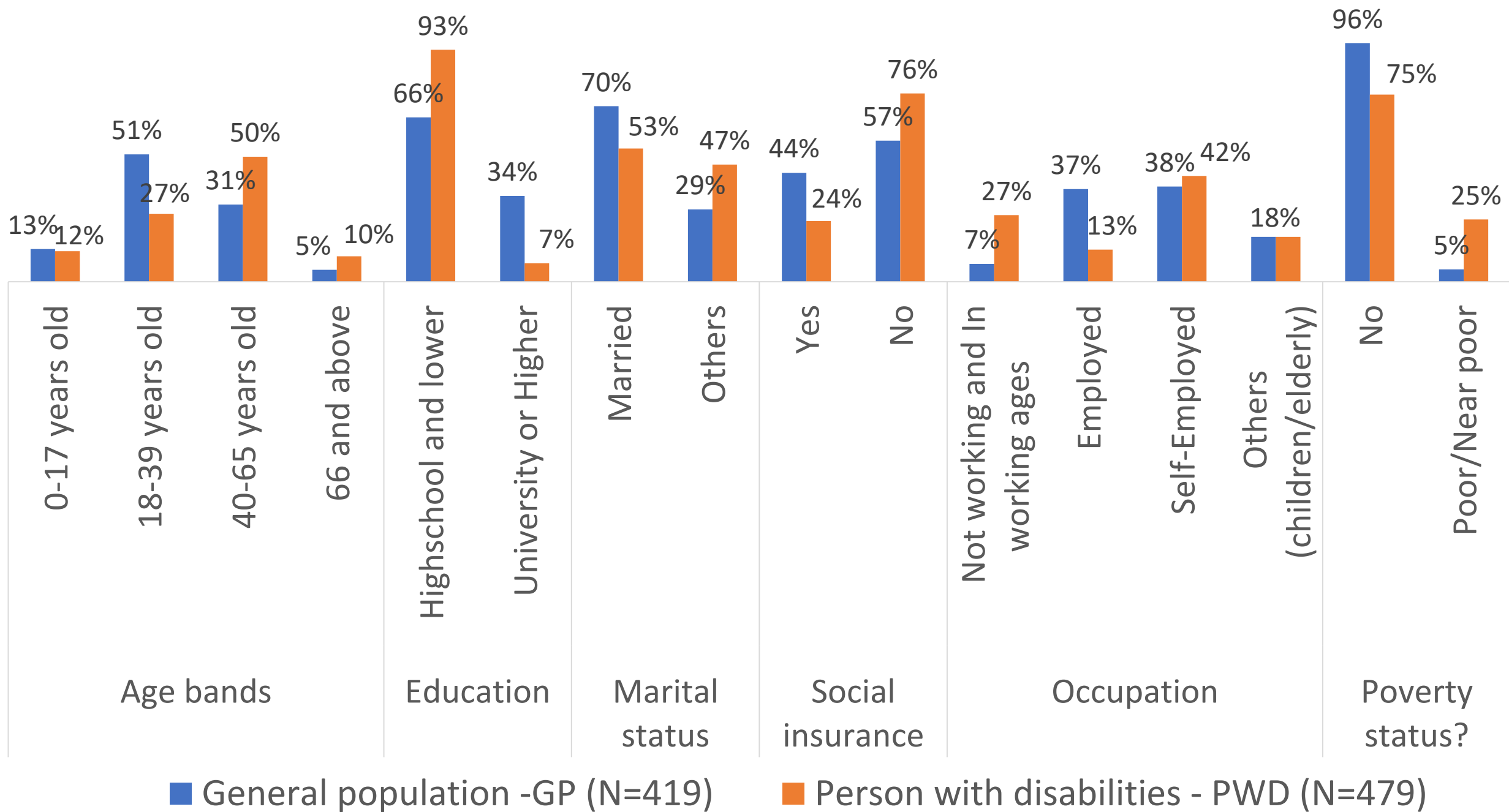
Screening for disability: Washington short question

Socioeconomic impacts

- Health: EQ-5D-5L, DASS-21
- Working status
- Education (for HH with kids, 6-17 years old)
- Healthcare
- Special services for PWD (only for PWD)
- Others: wellbeing, etc

Support during COVID-19

Sample characteristics



Characteristics of People with Disabilities group

- Disabilities Certificate: 413
- Self-reported: 29
- Identified from WSQ: 95

Type & Level of disabilities*

Mobility: 28.4% A – 10.2% C

Vision: 10.9% A – 10.7% C

Communicate: 12.5% A – 7.5%

Cognition: 11.6% A – 6.1% C

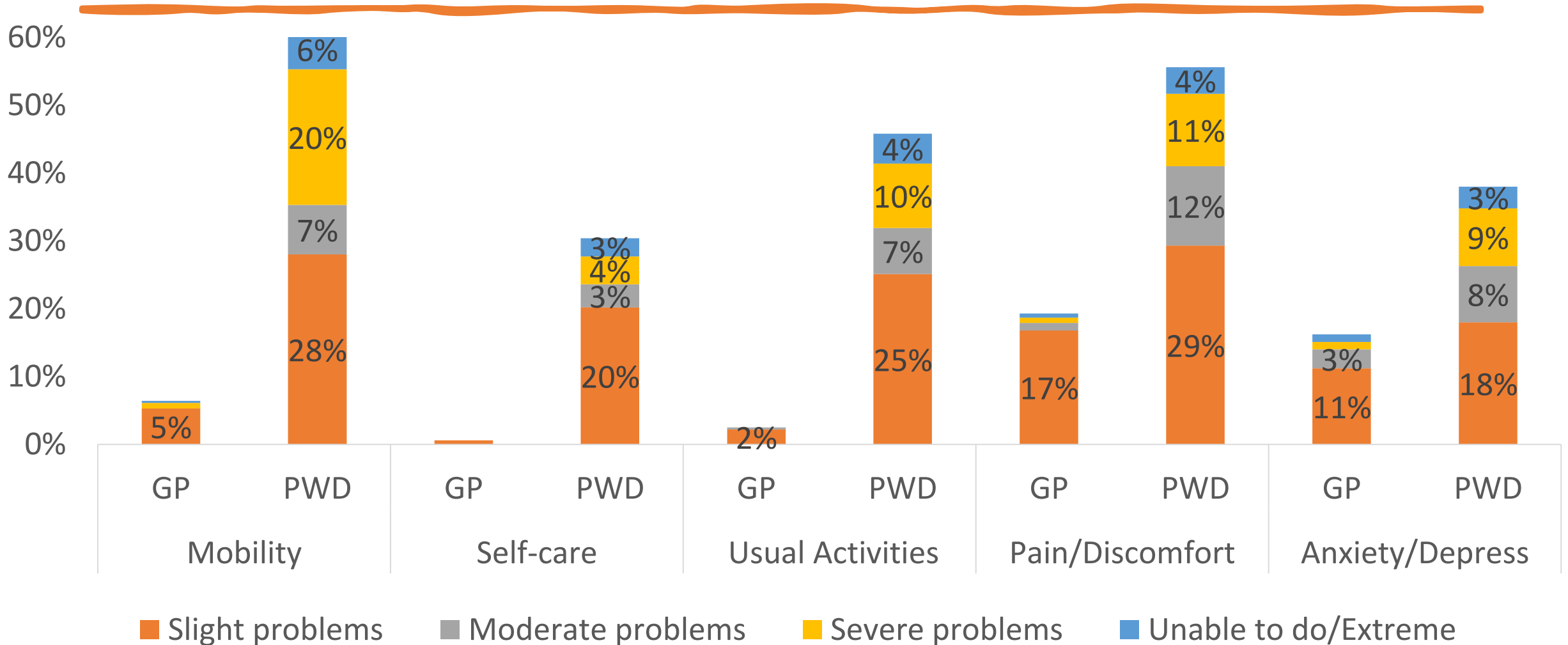
Hearing: 7.5% A – 4.4% C

Self-care: 6.9% A – 5.4% C



**A: A lot of difficulty;*

C: Can't do at all

Your Health Today? (EQ-5D-5L)



Health related
Quality of life
&
Mental health

	General Population	People with Disabilities
VAS (Mean, SD) 	87.2 (13.4)	66.5 (21.7)
EQ-5D-5L (Mean, SD) 	1.0 (0.1)	0.8 (0.3)
Stress (%)	6.1%	27.1%
Anxiety (%)	10.6%	37.6%
Depression (%)	3.9%	28.3%

COVID-19 Impacts to Work and Income

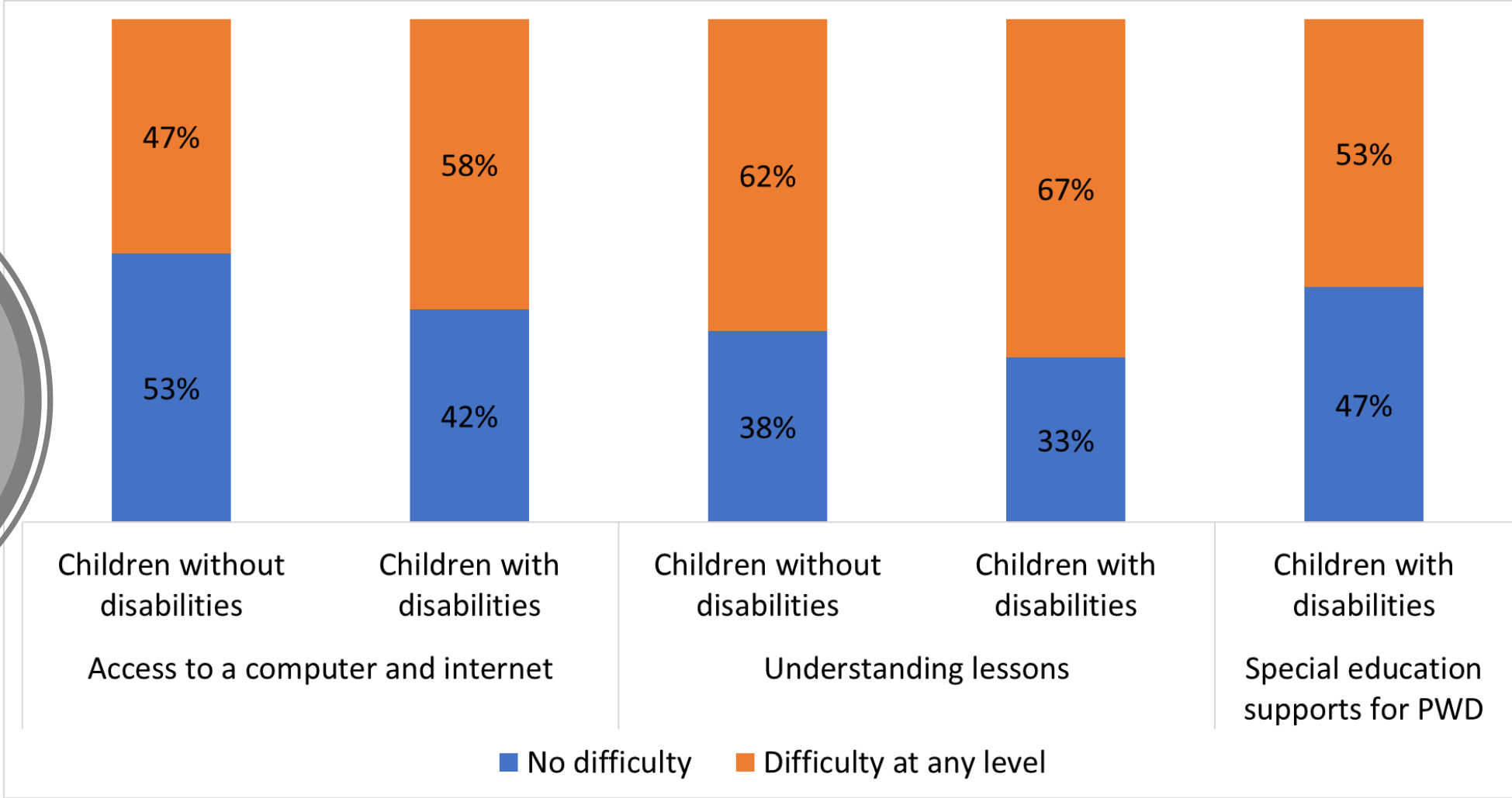
Item (Among working group)	General population	Person with disabilities	p-value
Working status during COVID-19 *			<0.001
No change	293 (88.3%)	176 (66.2%)	
Lose job	39 (11.7%)	90 (33.8%)	
Change in working time during COVID-19 **			0.020
No change	52 (17.7%)	14 (8.0%)	
Stop working	47 (16.0%)	26 (14.8%)	
Reduce working time	123 (42.0%)	90 (51.1%)	
Increase working time and remain the same income	71 (24.2%)	46 (26.1%)	
Change in household income**			<0.001
Higher	27 (6.5%)	2 (0.5%)	
Unchanged	139 (33.6%)	97 (21.9%)	
Lower	248 (59.9%)	344 (77.7%)	

Notes: *: P from T-test; **: P from Anova test

COVID-19 Impacts to Education


Item	Children without disabilities (N=421)	Children with disabilities (N=72)	p-value
Attending school?			<0.001
Yes	396 (98.8%)	51 (86.4%)	
Yes, but interrupt during COVID-19	5 (1.2%)	3 (5.1%)	
Not ever attending	0 (0.0%)	5 (8.5%)	
Why not attending school during COVID-19?			0.10
School closed	1 (20%)	0 (0%)	
Inaccessible online learning	0 (0%)	2 (67%)	
Others	4 (80%)	1 (33%)	
School offers distance learning?			0.003
Yes	405 (99.3%)	49 (94.2%)	
No	3 (0.7%)	3 (5.8%)	

Difficulties with online learning



During COVID-19 restriction, Person with disabilities has (<i>REF: GP</i>):	OR	[95% conf. interval]	
A lot of worse on essential food	4.10	2.89	5.81
A lot of worse on access to healthcare	3.45	2.28	5.22
A lot of worse on household finances	3.38	2.57	4.46
A lot of worse on well-being	2.51	1.85	3.40
A lot of worse on social life	2.29	1.62	3.24

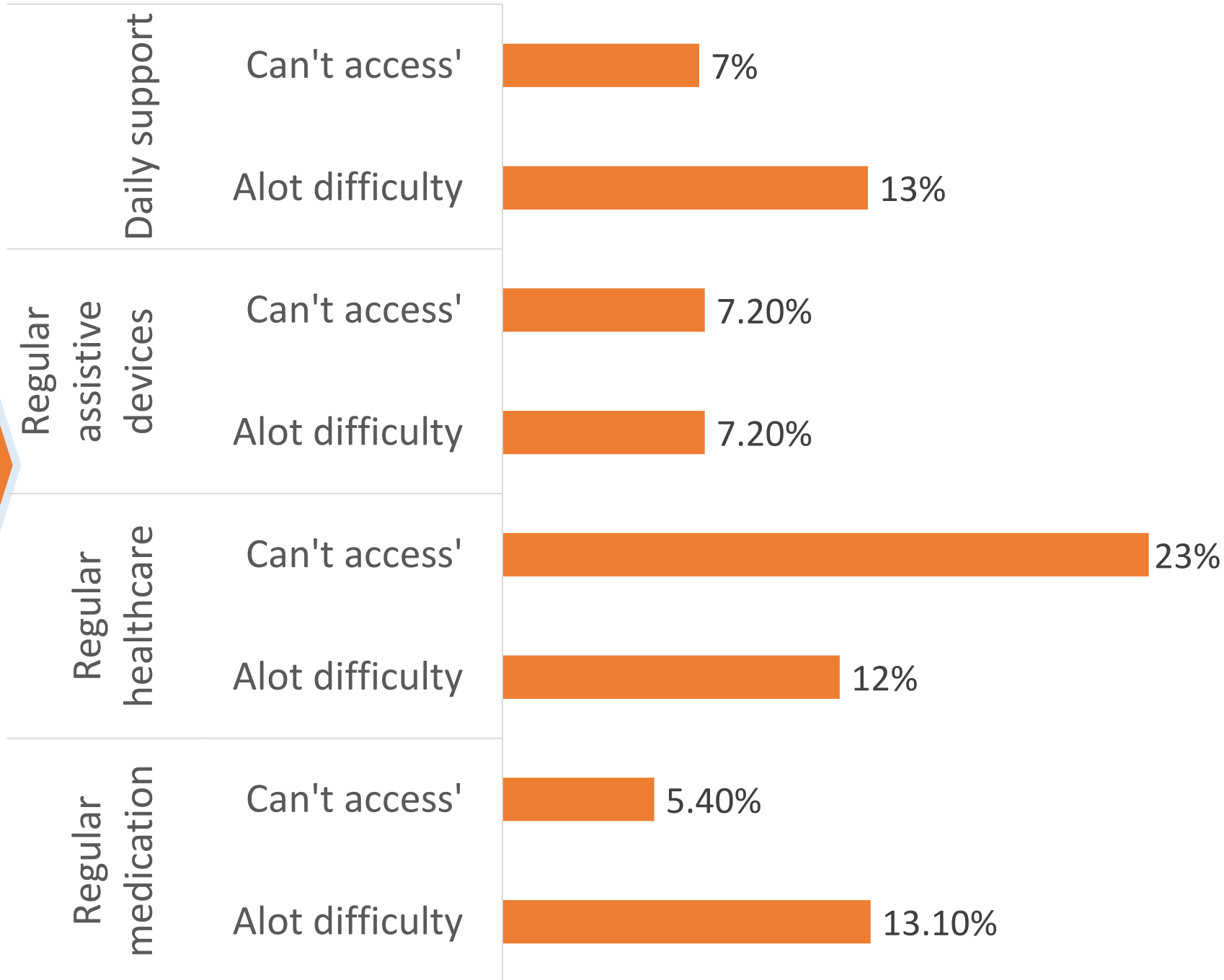
Impact to daily life during COVID-19 restriction



Difficulties during COVID-19 restriction

During COVID-19 restriction, Person with disabilities has (REF: GP):	OR	[95% conf. interval]	
Traveling to the C19 vaccination site	24.80	11.46	53.69
Interactions with C19 vaccination staffs	9.27	4.59	18.71
Handwashing and hygiene	4.00	2.24	7.15
Getting C19 vaccine information	3.98	2.47	6.43
Waiting at the C19 vaccine site	2.68	1.82	3.95
Getting a C19 vaccine appointment	2.21	1.42	3.45
Social distancing	1.93	1.47	2.54
Wearing a mask/face	1.56	1.10	2.21

**%PWD's NOT
able to access**





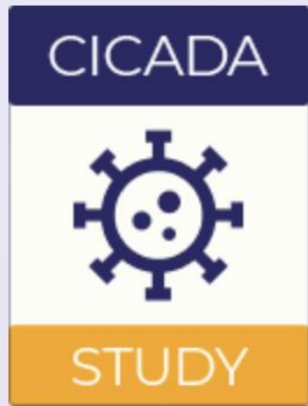
Thankyou!



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Intersectionality findings from the CICADA study
exploration of the pandemic experiences of
disabled people from minoritised ethnic groups



Coronavirus Intersectionalities

We are exploring the pandemic experiences of people with a long term condition or disability from ethnic minority groups, with a focus on health and social care.

Intersectionality findings from the CICADA study exploration of the pandemic experiences of disabled people from minoritised ethnic groups

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Social Research Institute UCL London

The CICADA Study is sponsored by University College London (UCL) and funded by the National Institute for Health Research (NIHR) HS&DR programme (NIHR132914). The views expressed are those of the study team/author(s) and not necessarily those of the sponsor or of NIHR or the Department of Health and Social Care.

Why an intersectionality approach?

- Disabled people from minoritised ethnic groups are more likely than other groups to:
 - face issues accessing support and services,
 - die from COVID-19,
- due to multiple structural, contextual and individual social determinants of health.
- Not additive.
- A deeper understanding of their intersection is vital to:
 - reduce inequities, and
 - avoid faulty assumptions of sameness or othering.

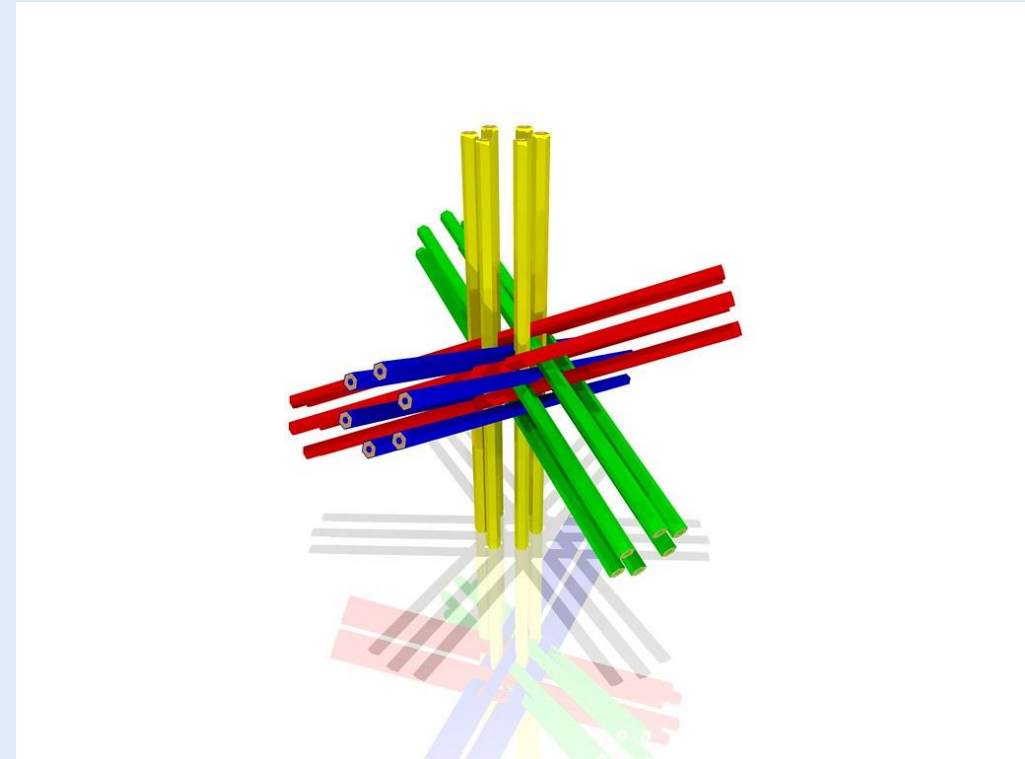


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Categories and intersectionality

McCall 2005, pp. 1773–1774

- **‘intra-categorical’** - to make *visible* group dynamics that were previously made invisible in thinking of a group category as homogeneous
- **‘anti-categorical’** - challenges intersectional relationships and notions of identity as fixed
- **‘inter-categorical’** - provisionally adopts existing analytical categories to document relationships of inequality



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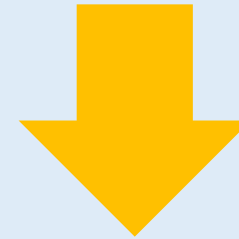
The CICADA-ME Study aims

Coronavirus Intersectionalities: Chronic Conditions And Disabilities And Migrant/Ethnic Minoritisation

Aim

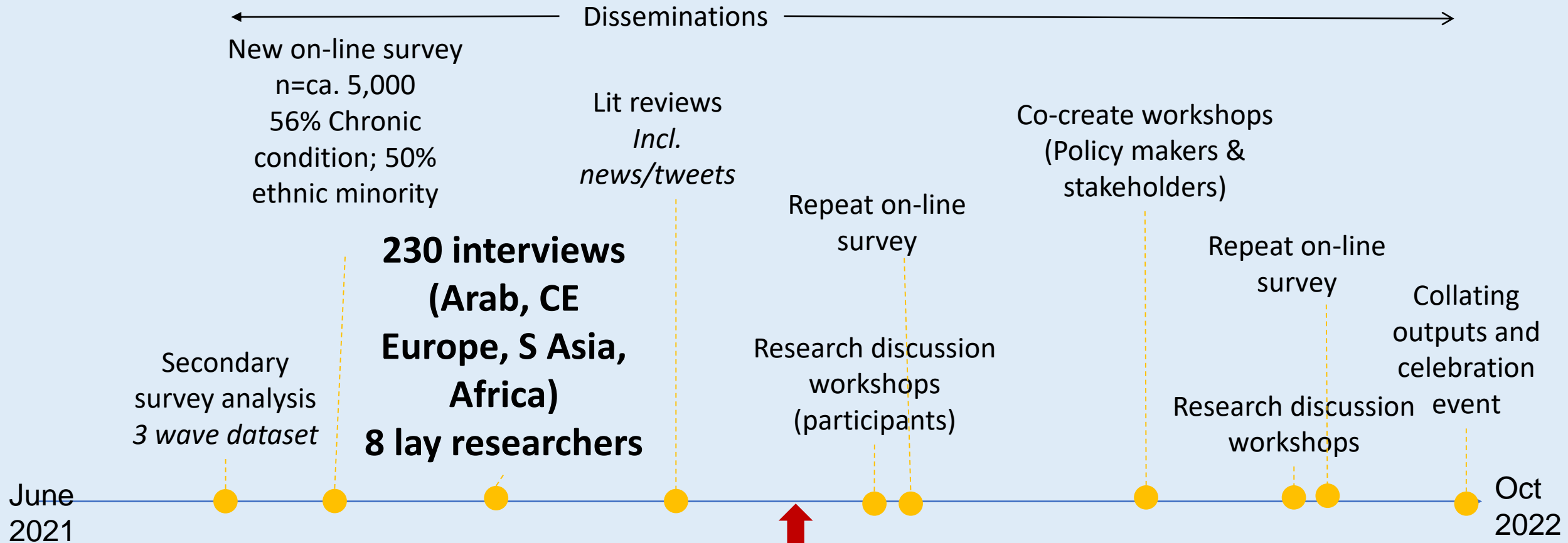
To improve understanding of pandemic-related issues faced by ethnic minoritised groups with chronic conditions (including long COVID) in daily living, mental & physical health

- Impact of discrimination
- How to provide better services
- Coping strategies, strengths & solutions
- How health behaviour is impacted by sources of information & effect on vaccine uptake



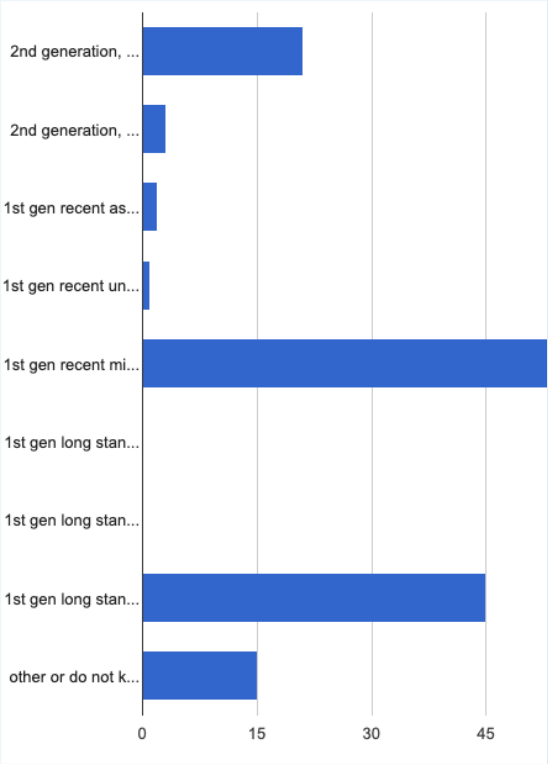
Informing guidelines
Making recommendations (including digital)
Designing interventions for health & social care policy & practice

Our approach and progress to date

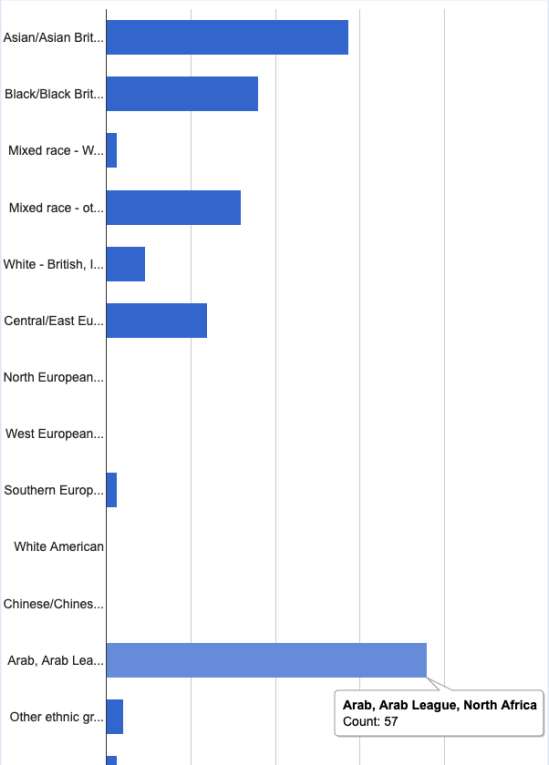


Participants

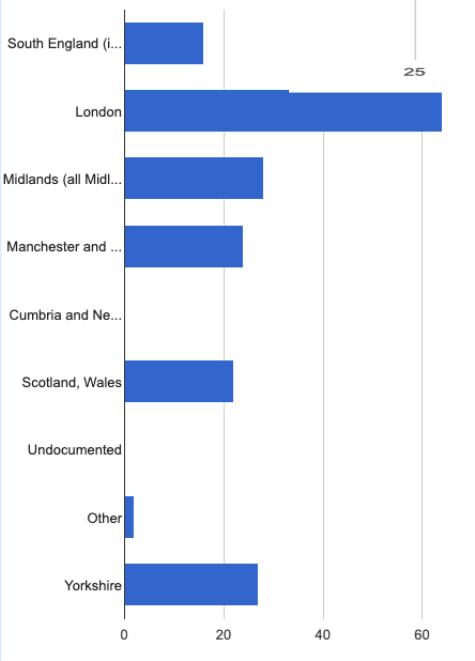
Citizenship status



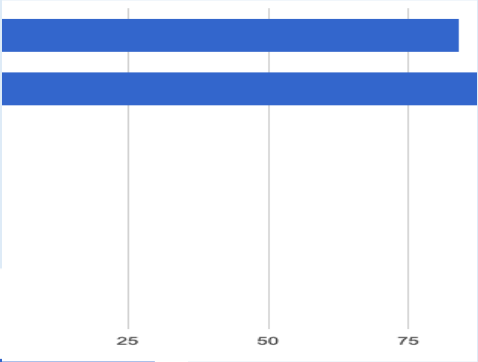
Ethnicity



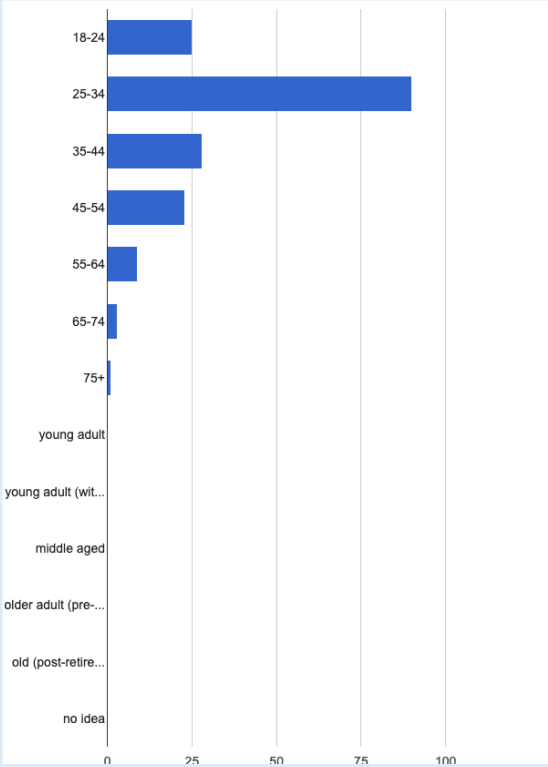
Area



Gender

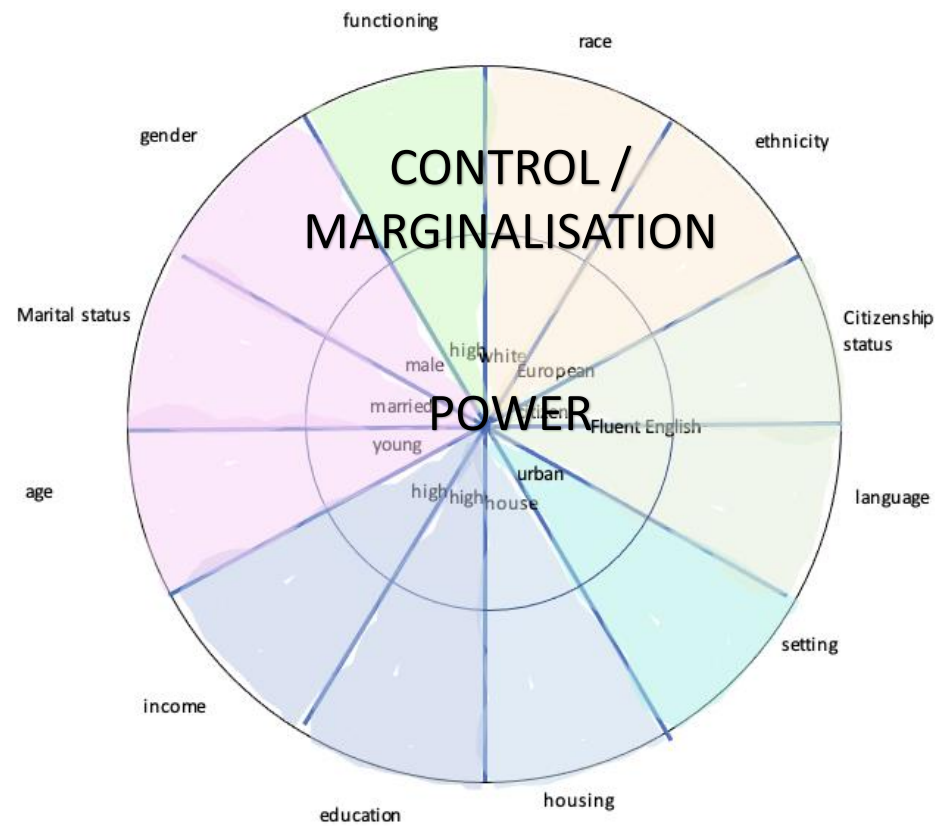


Age



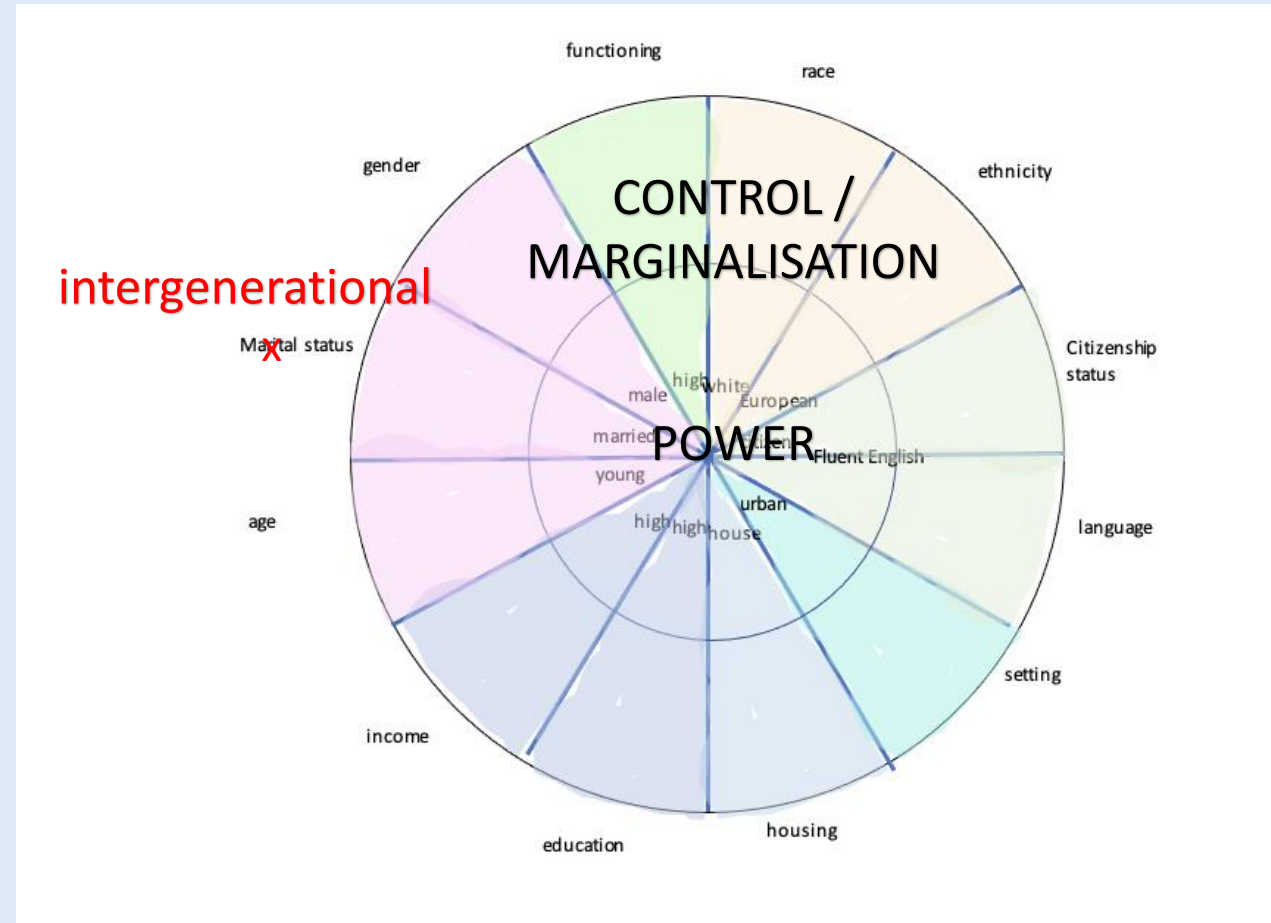
Power and control wheel

First developed by the Domestic Abuse Intervention Project in Duluth, Minnesota in 1984 to help describe the experience of victims of intimate partner violence (domestic violence) and the tactics perpetrators used.



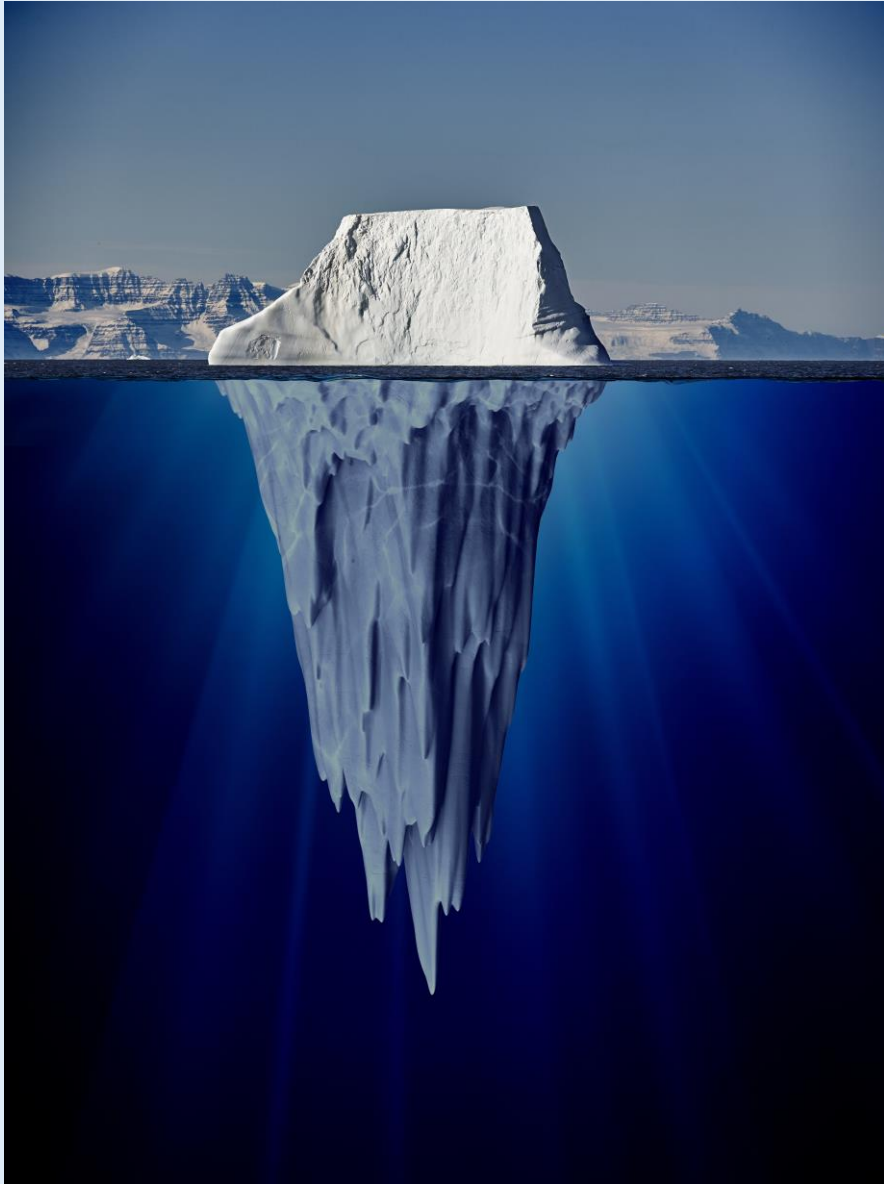
Power and control wheel cont.

The power and control wheel was developed by the Domestic Abuse Intervention Project in Duluth, Minnesota in 1984 to help describe the experience of victims of intimate partner violence (domestic violence) and the tactics that perpetrators used.



intergenerational

Surface and deep culture



Surface culture:

food, clothes, music, festivals, flags, art, literature

Deep culture:

the unspoken rules of social norms and psychosocial influences for a person or community.

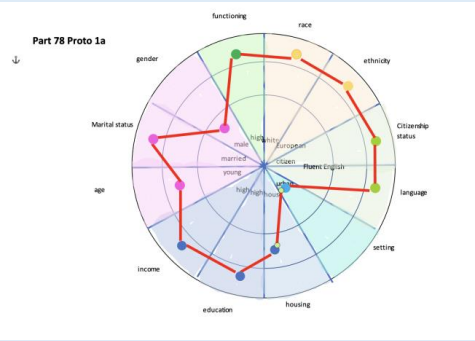
e.g. attitudes towards elders, cleanliness, concepts of time, personal space, rules about eye contact and showing emotions, child-rearing, marriage, health beliefs, definitions of kin,

decision-making, concepts of self, world view, spirituality, justice, social roles, sin, death, preference of competition or cooperation.

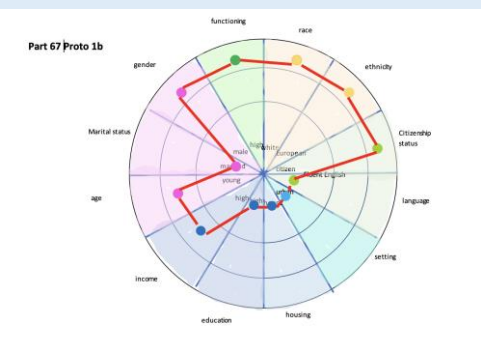
Ref: Resnicow K, Baranowski T, Ahluwalia JS, Braithwaite RL. Cultural sensitivity in public health: defined and demystified. *Ethnicity & Disease*. 1999;9:10–21.

Findings

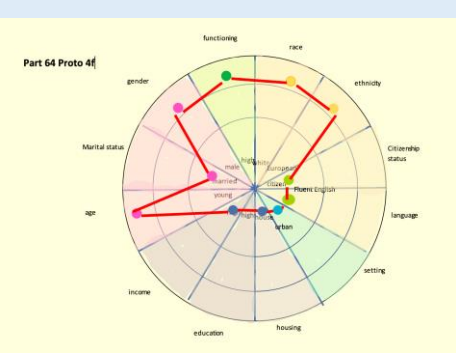
Race, disability, citizen,
SES, demog



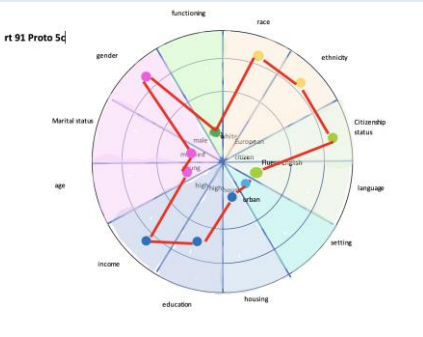
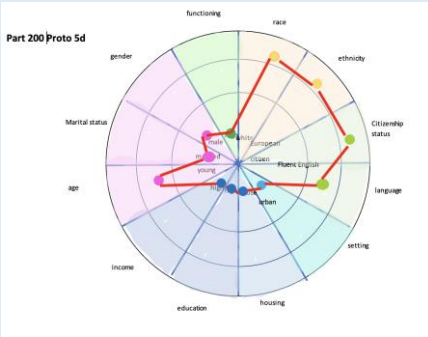
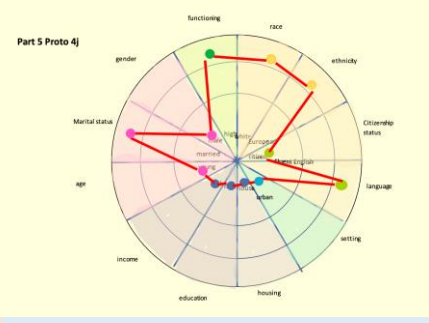
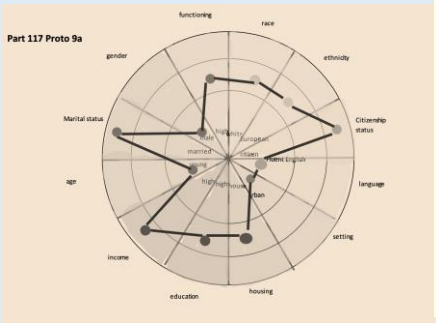
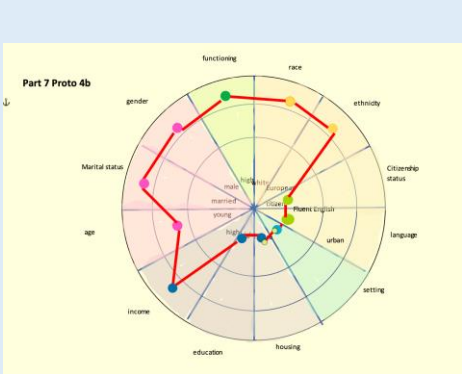
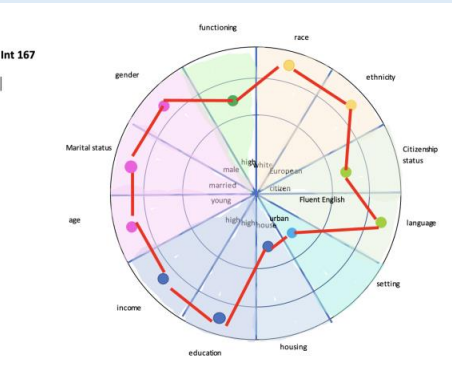
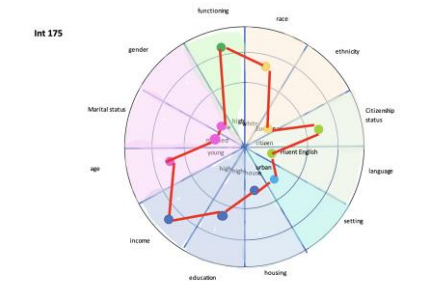
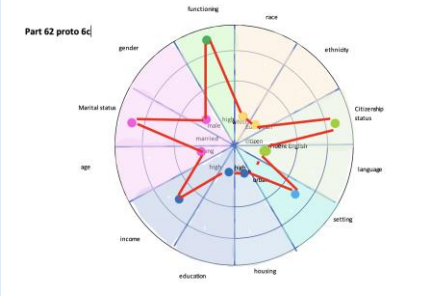
Race, disability,
citizen, demog



Race, disability, demog



Spikey



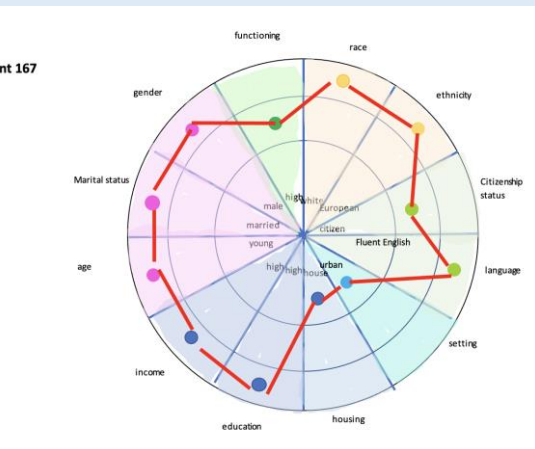
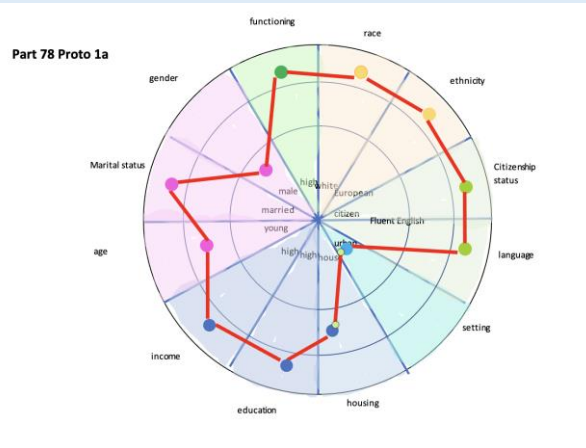
Race, disability, citizen, SES, demography

Did you access doctors online?

No, I am not aware of these things as I am **not educated** at all.....The public authority was just assisting individuals with the right **documentation**. The greatest change I did was stay inside my home like a **detainee**. I was drinking liquor to decrease depression.... I didn't have informal support. I have **no relatives here**. My **friends are like me terrified** to reveal their movements due to their **visa status**. (pt 78, Bangladeshi male)

the unspoken rules

I have **stayed mostly in my room** from the beginning as I have teenage grandchildren who keep going in and out of the house.... I could see neighbours passing by and other people from my community. Some would **shout up to me** that helped pass my time. I have not seen my doctor....the phone is always engaged, or it disconnects. ...It's like they don't care about us. Then I got very illthey sent an ambulance to take me to hospital. My son was not allowed to come with me. **You know, a lot of people were saying don't go to hospital because the old people they will give you an injection and you will die. I was scared because I couldn't speak or understand English. They told me I would see a doctor, a Pakistani doctor. Once he came and explained I felt more at ease.** (pt 167, Pakistani male)



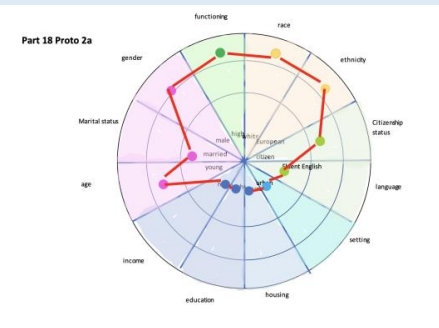
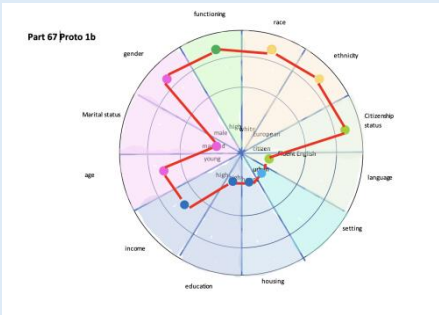
Race, disability, citizen, demography

When you know your rights when you can fight for yourself and have the support system [like me].... **cultural-linguistic capital**....[she pushed for referral to a top specialist]. This is costing the NHS so much, a lot of people won't get that, and that pisses me off.....They asked me, have you ever thought of killing yourself? I said, very clearly, I'm a Muslim, in my religion suicide is murder so for me it's not something I would ever contemplate. I said I would rather not be here. In my language, Urdu, we're a dramatic language, that doesn't mean I want to kill myself, it just means I don't want to be here. **If it was somebody from my country** they would know. But because of the metrics here, they had to take it very seriously. (pt 18, Arab/South Asian female)

the unspoken rules

The ways are very **Eurocentric**. I feel like culture and mannerisms from different parts of the world are not taken into account when medication is handed out or therapies are prescribed. (pt 67, Pakistani female)

The issues people of colour have with police and accessing services, I have not had to deal with. So it comes from the privilege an upper middle class background[after Covid] There have been times when police had stopped...an **amount of terror**. And because you are Brown, and you hear the stories ...even if you have not faced it before, the fear still exists. ... when you had to give your details at restaurants or cafes, it felt very much like **surveillance**. As someone who doesn't **trust** the authorities, because of where I come from, I did not believe the details would just be used for track and trace (pt 67, South Asian male).

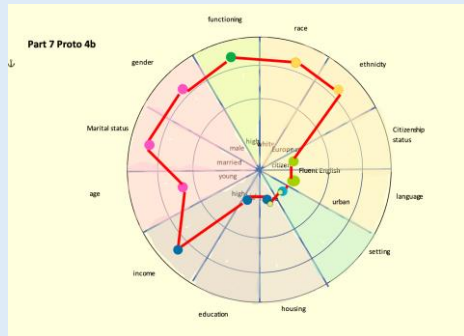
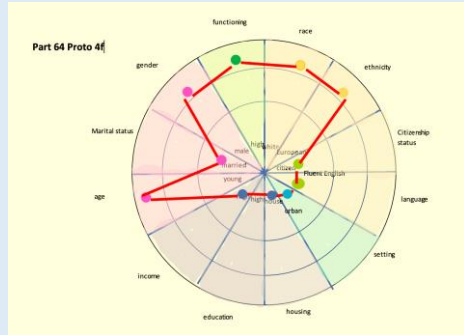


Race, disability, demog

I had to fight really hard the last six months with their service that provides a nurse ...They stereotype us. I'm not the norm <Asian> woman. An <Asian> woman doesn't make complaints. An <Asian> woman takes whatever the GP says and doesn't challenge them. ...They put a label on me, I'm too challenging, I'm too neurotic... (Pt 64, Indian female)

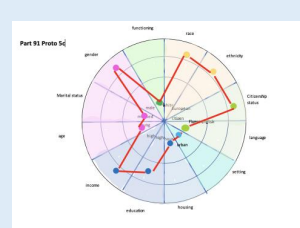
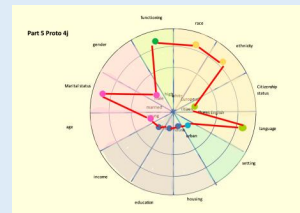
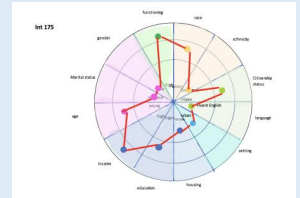
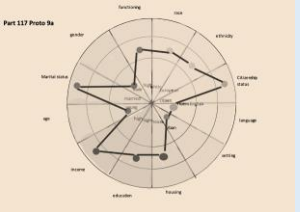
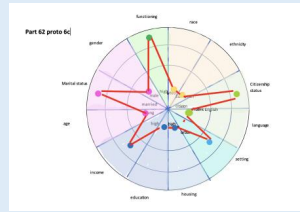
So, at the moment we only get one **food bank** ...delivery once a week, so that's been really useful, but it's been difficult because they don't really care about your ethnicity, **your religion, your culture, the dietary needs**. So, it's hard because we're a Muslim Bengali family and they give you stuff in tins, and obviously we were grateful ...but at the same time they would give us **non halal meat**, and things we couldn't eat that had to be disposed of. ...But you'd try and raise it with these places, and they didn't want to know.they'd make it like you were being ungrateful when you weren't. You just want to help and give suggestions. (pt 7, Bangladeshi female)

Things like the treatment I got was very British, western, and I eat with my fingers in my culture, and I wasn't allowed to do that because they said that's an **anorexic thing**. So, that I found quite discriminative because I felt penalised. And there were other things like I wanted a green apple and not a red apple because I felt safe, and they said that's an anorexic thing, and I said not that's my Autism. (Pt 9, South Asian female)



the unspoken rules

Spikey



I had a stroke in Slovakia [on a short visit] and had to translate my hospital report in English and they **[said that cannot be true]** and I said only you are doctors and in Slovakia we have no doctors!...Over the phone [so I do not know which doctor] ..I informed them I had a stroke, doctor replied to **go back to Slovakia** get treatment. I had to go to GP practice surgery and **write complaint**, when I have been here for 17 years. (pt 175, Roma male)

Then there is also the **fear of contracting the virus**, you have already a chronic condition, so you are like, “What will I do, what will I-?”.....so that one, that change of feelings really affected me, but after **consulting my GP**, he explained everything [about depression] so I got ok..... When I moved here, my accent was a little bit different so ... **I feared talking to people**. “What would they think of me?” (pt 62, Romanian male)

I felt the advice on NHS’s website and by NHS doctors are very helpful ...However, **sometimes it is not tailored to our condition and experiences in life**, so I also started speaking to the gym instructor on how to stay healthy during lockdowns. (pt 200, Daman male)

....there are many places I have to touch [...] a door or gate [...] they have the numbers to type and enter...It's a bus, or a bus stop, or something we just have to touch. **We rely on touch. It means everywhere you have to sanitise, and you can't sanitise every second.** (pt 5, Asian male)

Conclusions

- Our intersectionality typologies when combined with qualitative insights show that:
 - common categorisations of people (e.g. as being from particular ethnic or disability groups) over-homogenise experiences, and
 - social determinants of health both cut across these categories and vary within them,
 - more vulnerability factors are not simply additive.
- Different intersectional factors may be more relevant to different groups.
- Higher level intersectional categorisations should be used as markers of surface and deep cultural factors, for appropriate intervention.
- This approach is not intended to replace one form of categorisation with another but to interrogate and disrupt stereotyping. It is a work in progress.
- Such empirically-driven work on vulnerability, if refined, will give a more nuanced understanding of social forces influencing patient's health →, more patient-centred care and better outcomes.