An audit of the well-being of staff working in intellectual disability settings in Ireland during the COVID-19 pandemic

Abstract

Purpose – The severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) has infected millions of people worldwide. Individuals with intellectual disability are at a disproportionate risk of mortality, given the health inequalities they experience. This puts a significant burden of responsibility on staff who support these individuals. Consequently, this study aims to establish a baseline of the well-being of staff working in intellectual disability services in Ireland during the COVID-19 pandemic. Design/methodology/approach – An online survey was carried out using the Copenhagen Burnout Inventory, a brief measure of depression (Patient Health Questionnaire-9) and a brief measure of anxiety (General Anxiety Disorder-7).

Findings – In total, 285 staff in the Republic of Ireland completed the survey. These staff reported moderate levels of personal and work-related burnout and mild levels of anxiety and depression. Higher mean scores were recorded across scales from staff who worked in independent living settings and from staff who supported individuals with challenging behaviour.

Originality/value – This study, an audit, provides initial data on the well-being of staff working with individuals with intellectual disability in Ireland during the COVID-19 pandemic. It highlights that employers need to consider staff well-being, given the levels of personal and work-related burnout, and anxiety and depression that were found. This is particularly true for staff who work in independent living settings and with adults with challenging behaviour. Future research should focus on proactive strategies for improving staff well-being in the short term, given the current resurgence of COVID-19 in Ireland.

Keywords: Ireland, Burnout, Intellectual disability, Audit, Staff, COVID-19

Background

The impacts of the severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2) and the development of coronavirus disease (COVID-19) affect all groups in society. Although certain chronic diseases are associated with poorer outcomes (Jordan, 2020), this is a new disease, with relatively little known about it in general terms. Evidence suggests that people who live in residential care facilities are at a higher risk of acquiring COVID-19 (Comas- Herrera et al., 2020). An early international review in 18 countries (Australia, Austria, Belgium, Canada, Denmark, France, Germany, Hungary, Ireland, Israel, Portugal, Slovenia, South Korea, Sweden, England and Wales (UK), Northern Ireland (UK), Scotland (UK) and the USA) with more than 100 deaths from COVID-19 estimated that the number of deaths in residential care facilities as a proportion of all deaths ranges from 24% in Hungary to 85% in Canada (Comas-Herrera et al., 2020). To date, there has been little reporting of COVID-19 trends for people with an intellectual disability, although it is considered that COVID-19 appears to present a greater risk to people with intellectual disability and at a younger age (Turk et al., 2020; Hatton, 2020).

Inferences made from publicly available UK data (Hatton, 2020) suggest people with intellectual disabilities were five times more likely to die from COVID-19 during the peak of the pandemic in England (24 March–12 May 2020). This profile fits with a meta-analysis that included 46,248 patients with a laboratory-confirmed COVID-19 diagnosis in China: this suggested that people with the most severe disease were more likely to have hypertension (odds ratio 2.36 (95% CI 1.46–3.83)), respiratory disease (2.46 (1.76–3.44)) and cardiovascular disease (3.42 (1.88–6.22)) (Yang et al., 2020). In this vein, it is highly probable that people with an intellectual disability are at a disproportionate risk of developing more severe complications from a biological and health disparity perspective (Alexander, 2020; Gulati et al., 2020; McMahon and Hatton, 2020) and are more likely to die from COVID-19 than the general population. In Ireland, the Health Service Executive (HSE) has identified people with a "learning disability" as being in a high-risk group irrespective of medical comorbidity (HSE, 2020) which is in contrast to current UK advice (National Health Service [NHS], 2020).

This potential susceptibility to COVID-19 presents significant challenges for staff who provide support to these individuals. There is a significant body of work that has highlighted the challenges that staff encounter while supporting people with intellectual disability outside of pandemic times (Hatton et al., 2001; Rose and Rose, 2005; Mills and Rose, 2011; Ryan et al., 2019). More recently, Willner et al. (2020) have highlighted that during the strict "lockdown" period in the UK, carers of adults and, particularly, children with intellectual disability, had extremely high levels of mental health problems. Therefore, it would be reasonable to conclude that the current global situation is likely to have a distinct impact on the well-being of paid carers, particularly as they:

- balance their own physical and mental healthcare needs;
- align their duty to support people with an intellectual disability to other, especially familial, responsibilities;

work in an environment where individuals are "cocooning" (staying inside one's home, insulated from perceived danger, instead of going out, known as "shielding" in the UK); and are restricted in terms of support.

As far as we are aware, there is currently no evidence about the well-being of staff working in intellectual disability services during the COVID-19 pandemic in Ireland. Consequently, this audit was undertaken over a two-week period in May 2020 when the easing of COVID- 19 restrictions began in the Republic of Ireland to identify a baseline understanding of the well-being of staff working in intellectual disability services during the COVID-19 pandemic.

Methods

Participants

The data for this audit was collected online using a Crowdsignal survey. Four closed health and social care Facebook forums of professionals who support people with an intellectual disability in Ireland were asked to take part. Data were collected from 21 May 2020 until 2 June 2020.

Ethical considerations

We followed the NHS Health Research Authority guidelines in conjunction with UK's Medical Research Council online decision-making tool to determine if this survey required ethical approval (www.hra-decisiontools.org.uk/ethics/), as suggested by the Irish Health Research Board (2020). As the survey did not involve randomisation, changing treatment or patient care from accepted standards, or set out to produce transferable or generalisable results, this was determined to be an audit rather than research and, therefore, not to require ethical approval. An information sheet was included in the online questionnaire that set out the anonymous, voluntary nature of the survey. This also included information regarding helpful resources for respondents about COVID-19 and about health and well-being more broadly if they felt they required support.

Materials

Along with general demographic questions (e.g. gender, occupation), this survey used three measures to measure well-being; the Copenhagen Burnout Inventory (CBI) (Kirstensen et al., 2005); the Patient Health Questionnaire (PHQ-9), a brief measure for depression (Kroenke et al., 2001); and the General Anxiety Disorder-7 (GAD-7), a brief measure for anxiety (Spitzer et al., 2006). The CBI is a 19-item, three-subscale self-report measure that provides a comprehensive overview of general (personal burnout), work- related (work burnout) and client/patient (client burnout) burnout that has demonstrated good psychometric properties (Kirstensen et al., 2005; Borritz et al., 2006; Trush et al., 2020). For the three subscales, a scoring system of 0–100 is used. Any score of 50–74 is considered to be moderate burnout, 75–99 is high and a score of 100 is considered severe burnout. For both the PHQ-9 and GAD-7, scores of 0–4 represented minimal or no depression or anxiety, 5–9 mild levels, 10–14 moderate levels, 15þ severe (with an additional level in the PHQ-9 of 20–27 representing very severe depression).

In addition, respondents were also asked to answer three questions:

1. if they supported individuals who had behaviours that challenge (yes/no). Challenging behaviour was defined as "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities" (Emerson, 2001);
2. on a scale of 0–10, how anxious they were about contracting COVID-19 at work? (A score of 0 was suggestive of not anxious at all, while 10 was suggestive of extreme anxiety); and
3. on a scale of 0–10, how supported they felt by their employer about keeping themselves and the people they support safe during the COVID-19 pandemic? (a score of 0 was suggestive of very unsupported, while 10 was suggestive of extremely well supported).

Analysis

All data was exported from Crowdsignal into a CSV file and imported into SPSS version 25. Scores for the CBI, PHQ-9 and GAD-7 were computed, and descriptive statistics (mean, standard deviation, range) were calculated. Line and stack bar charts were produced to assist interpretation.

Results

In sum, 285 paid staff who worked in intellectual disability settings in the Republic of Ireland completed the audit. Of the respondents, 89.8% (n = 256) were female, while 9.5% (n = 27) were male. Figure 1 identifies the general demographics and occupational status of this sample, while Figure 2 outlines participant work setting and type of support provided. The majority of respondents were nurses (n = 134), health-care assistants (n = 64) and social care workers (n = 59). Most respondents worked in residential or congregated care settings (total n = 167) with adults with an intellectual, physical or sensory disability.

+++ Insert Figure 1 and 2 here ++++

On the CBI, across all types of settings where respondents worked, the participants reported moderate levels of burnout (a mean score of!50) on the personal and work-related subscales (range of setting means 50.54–57.92). Respondents who worked in independent settings (i.e. where one person lives alone with support/shared lives setting and live in carer settings) and provided direct care had the highest personal burnout scores (M = 57.92, SD = 18.73, n = 20), while respondents who were office based had the highest work-related burnout score (M = 55.10, SD = 16.32, n = 20). Across all work areas, there was little client-related burnout reported (mean range 16.19–27.35). The scores for the GAD-7 and PHQ-9 suggested that all respondents across all settings were on average reporting mild levels of anxiety and depression at the time of answering the survey, while people who were working in independent settings were reporting moderate levels of anxiety and depression. Table 1 provides a detailed summary of scores.

Figure 3 displays the mean scores across the CBI, GAD-7 and PHQ-9 for respondents who do not (n = 35) and do (n = 235) work with people whose behaviour is described as challenging. The former reported lower mean scores across all scales.

Figure 4 displays mean scores of how anxious respondents were about contracting COVID-19 at work and how supported they felt by their employer to keep themselves and the people they support safe. Respondents who worked in home care or were a personal assistant reported higher levels of anxiety about contracting COVID-19, and they felt the least supported by their employer. By contrast, allied health professionals reported that they were less anxious and felt more supported by their employer.

+++ Insert Table 1 and figure 3 and 4 here ++++

Discussion

This audit has many limitations that need to be kept in mind when considering its findings. First, the online self-selecting recruitment process may result in respondents who have higher levels of stress being more motivated to respond. Second, the same process may restrict participation from those who use online resources less and do not participate in Facebook group(s). Third, given the audit and non-generalisable nature of this survey, no inferential analysis has been undertaken. In this regard, we cannot determine that the levels of burnout, anxiety and depression observed in this data are distinct from pre-existing or pre-COVID-19 times.

However, the audit has identified that paid staff who are providing support to persons with intellectual disability across a variety of environments are reporting moderate levels of burnout and mild to moderate levels of anxiety and depression. The data also suggest that paid staff who work in more independent settings are reporting higher levels of anxiety and depression. These findings may be more pronounced for staff who support individuals with challenging behaviours. There is a significant body of evidence that examines associations between challenging behaviour and staff well-being (Chung and Corbett, 1998; Mills and Rose, 2011; Flynn et al., 2018) with mixed findings. Flynn et al. (2018) found little direct association between staff exposure to aggressive challenging behaviour and work-related well-being, but noted that emotional exhaustion and positive work motivation were substantially influenced by working environment. This may suggest how organisations may help support their staff on an individual and service-wide basis during the COVID-19 pandemic.

Considering the overall impact of COVID-19, including the number of deaths in care settings, it is not surprising to find that staff who work in these areas are at a high risk of burnout and anxiety/depression. This could lead to considerable health problems, which would impact support, staffing levels, retention and outcomes for people with intellectual disability. It is generally accepted that scores of 10 and above in the PHQ-9 and GAD-7 are sufficiently high to warrant further investigation

(Manea et al., 2020; Spitzer et al., 2006). Given that PHQ-9 and GAD-7 scores observed in the current audit are below 10 for the majority of respondents, this may provide an opportunity for employers to:

immediately focus on and prioritise the well-being of staff with the highest scores working in independent or more isolated settings and/or with individuals with challenging behaviour; and

implement pre-emptive strategies to try and maximise the mental well-being of staff working in this area more broadly.

Initial synthesis (Maben and Bridges, 2020) and research (Zhao et al., 2020) concerning nursing staff may offer a useful starting point. Research undertaken during the initial COVID-19 outbreak in China suggests that there needs to be an inclusive environment where open and accessible leadership creates a culture of psychological safety where staff feel they have someone to turn to (Zhoa et al., 2020). Such an environment may provide a foundation for promoting psychological well-being and maintaining sound mental health. Equally, Maben and Bridges (2020) reinforce the critical need for appropriate leadership while additionally highlighting the need to focus on physiological and safety needs, peer support, team support and long-term recovery support needs.

In respect of feeling anxious about contracting COVID-19 at work and feeling supported by your employer to keep yourself and the people you support safe during the COVID-19 pandemic, a noticeable difference was observed between respondent groups. Home care workers and personal assistants had higher and lower mean scores on both of these variables than the other work categories. This suggests they may feel more anxious about contracting COVID-19 at work and feel more unsupported by their employer to keep themselves and the people they support safe during the COVID-19 pandemic. There is a strong evidence base illustrating the precarious and poor working conditions that home workers and personal assistants experience more broadly (Genet, 2011; Hussein, 2016). This again, therefore, represents an important area for future research and development.

Implications for practice

While no general inferences can be made from this audit data, it does support a need for future research to consider the mental health and well-being of staff who support individuals with an intellectual disability. This audit found concerning scores suggesting that some of this workforce is under significant pressure from a personal and work-related burnout perspective. Alongside this, the mild to moderate levels of anxiety and depression are also a cause for concern.

In this vein, we urge employers to ensure that there are appropriate supports in place in the event of a second wave of the COVID-19 pandemic that is currently (as of October 2020) resurging in Europe. This is particularly true where staff are home care or personal assistants, working in independent settings and/or supporting individuals with challenging behaviour.

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Table 1: CBI, GAD-7 and PHQ-9 scores according to respondents' area of employment

Area of employment	CBI Subscale	Mean	SD	n	Wellbeing Scales	Mean	SD	n
Acute Setting (e.g Inpatient hospital, mental health)	Personal Burnout	**50.76**	20.14	11	**GAD-7**	**7.64**	6.90	11
	Work Related Burnout	**52.27**	17.07	11	**PHQ-9**	**8.63**	7.67	11
	Client Related Burnout	31.44	27.35	11				
Community support service (e.g. peripatetic community multidisciplinary team)	Personal Burnout	**50.54**	17.69	20	**GAD-7**	**7.05**	6.92	20
	Work Related Burnout	**50.42**	14.38	20	**PHQ-9**	**7.60**	6.73	20
	Client Related Burnout	31.25	16.19	20				20
Non direct care setting e.g. office based, administration, academic, research	Personal Burnout	**51.49**	22.08	20	**GAD-7**	**6.57**	5.18	14
	Work Related Burnout	**55.10**	16.32	20	**PHQ-9**	**5.8**	4.99	15
	Client Related Burnout	26.49	21.16	20				
Congregated setting (a facility with 10 or more residents)	Personal Burnout	**51.52**	22.63	46	**GAD-7**	**7.06**	6.01	46
	Work Related Burnout	**51.55**	18.06	46	**PHQ-9**	**8.06**	6.62	44
	Client Related Burnout	27.36	20.33	46				
Large residential / group home setting (where 5 to 9 people live together)	Personal Burnout	**52.69**	22.09	76	**GAD-7**	**7.68**	6.24	74
	Work Related Burnout	**52.38**	20.56	75	**PHQ-9**	**7.90**	6.46	73
	Client Related Burnout	34.08	26.66	75				
Residential / group home setting (where up to 4 people live together)	Personal Burnout	**51.32**	20.01	76	**GAD-7**	**6.85**	5.81	73
	Work Related Burnout	**53.87**	16.21	76	**PHQ-9**	**7.34**	6.04	74
	Client Related Burnout	35.47	24.33	76				
Independent living, shared lives, live in carer setting	Personal Burnout	**57.92**	18.73	20	**GAD-7**	**10.40**	6.48	20
	Work Related Burnout	**51.49**	14.93	20	**PHQ-9**	**11.15**	6.93	20
	Client Related Burnout	34.58	22.46	20				

***Bold mean scores indicate above normal range**

Figure 1: Demographic and occupational status of respondents (n-285)

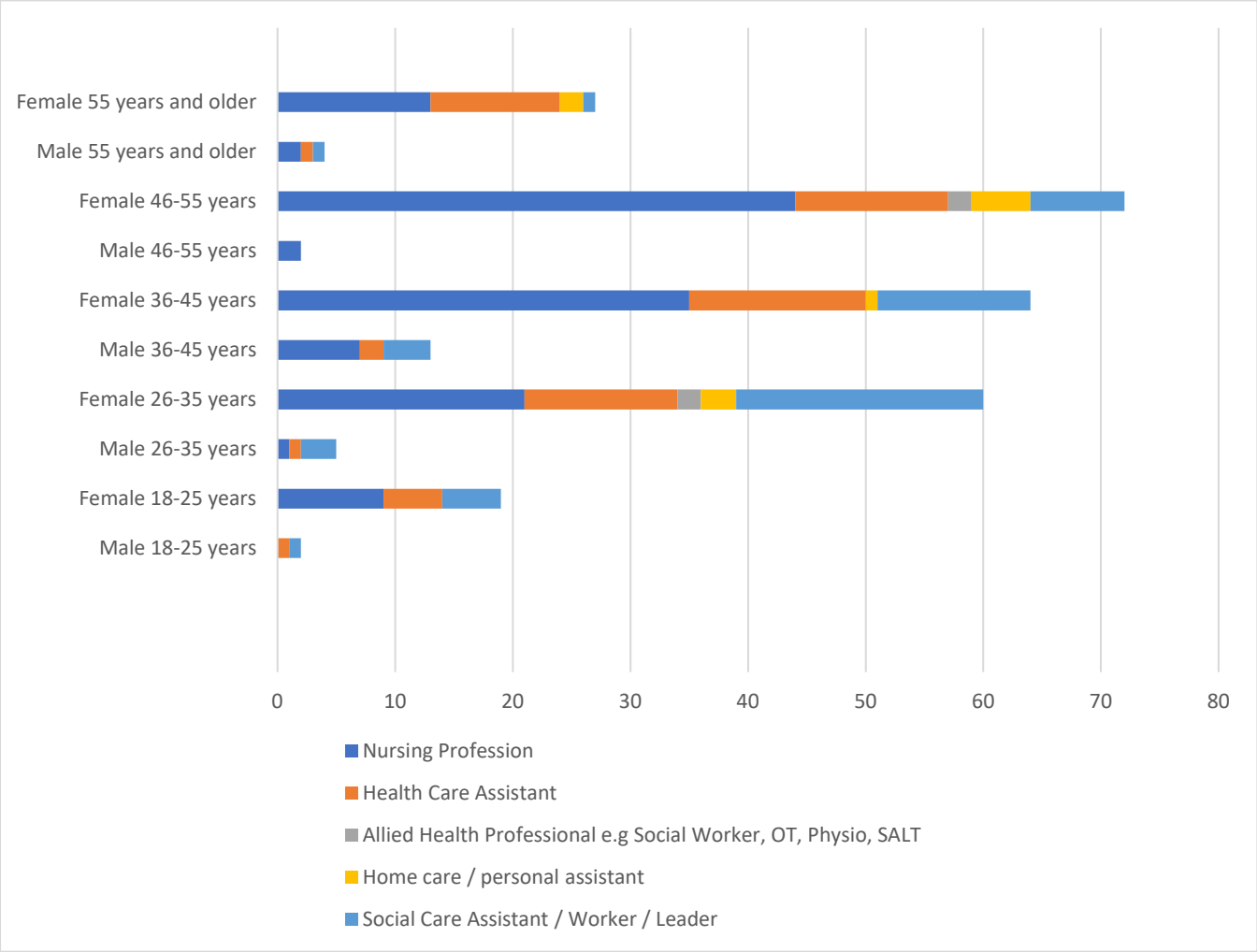

Figure 2: Participants' work setting, and type of support provided (n=285)

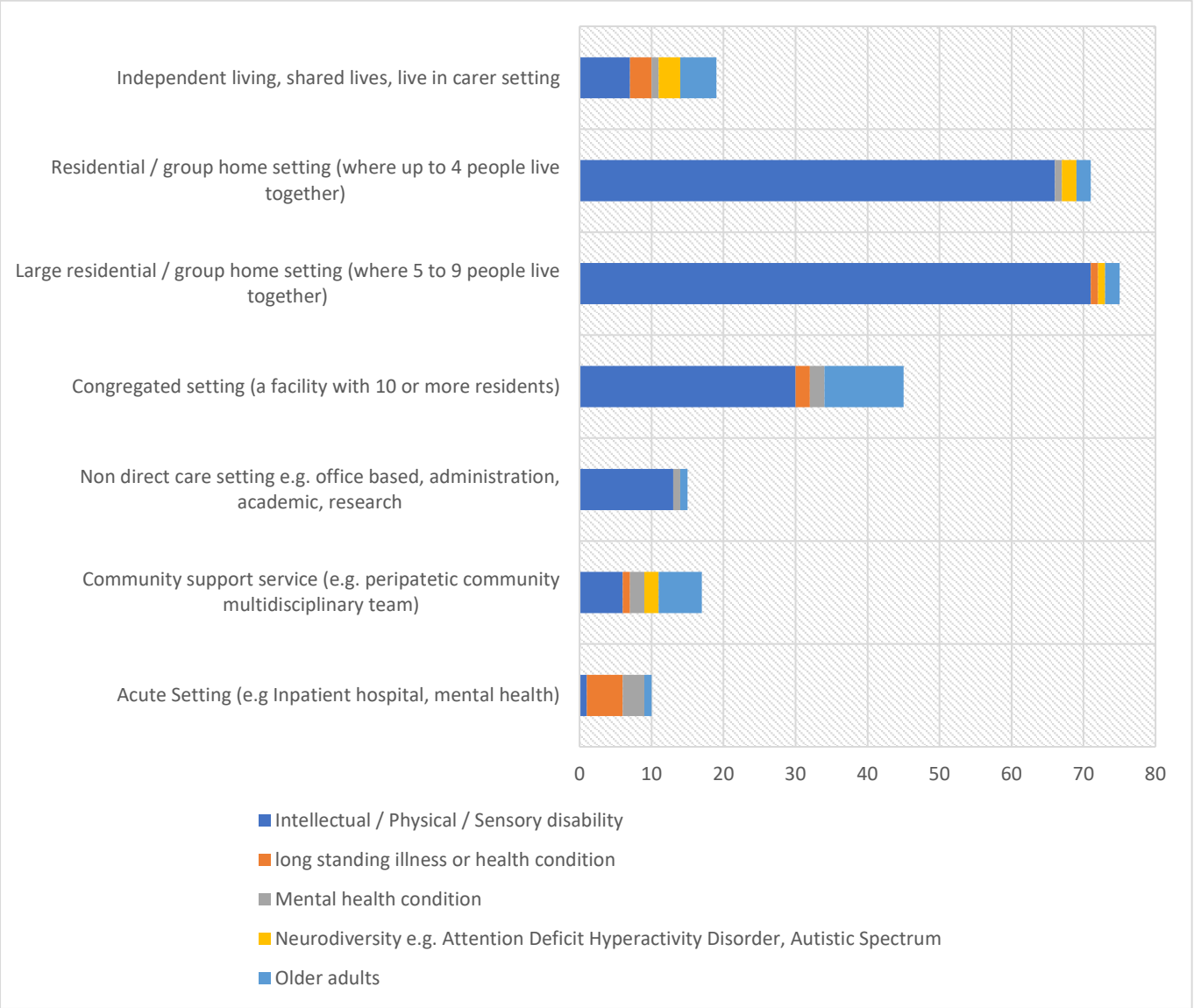

Figure 3: Mean scores of the CBI, GAD-7 and PHQ-9 scales for respondents who support people with challenging behaviour

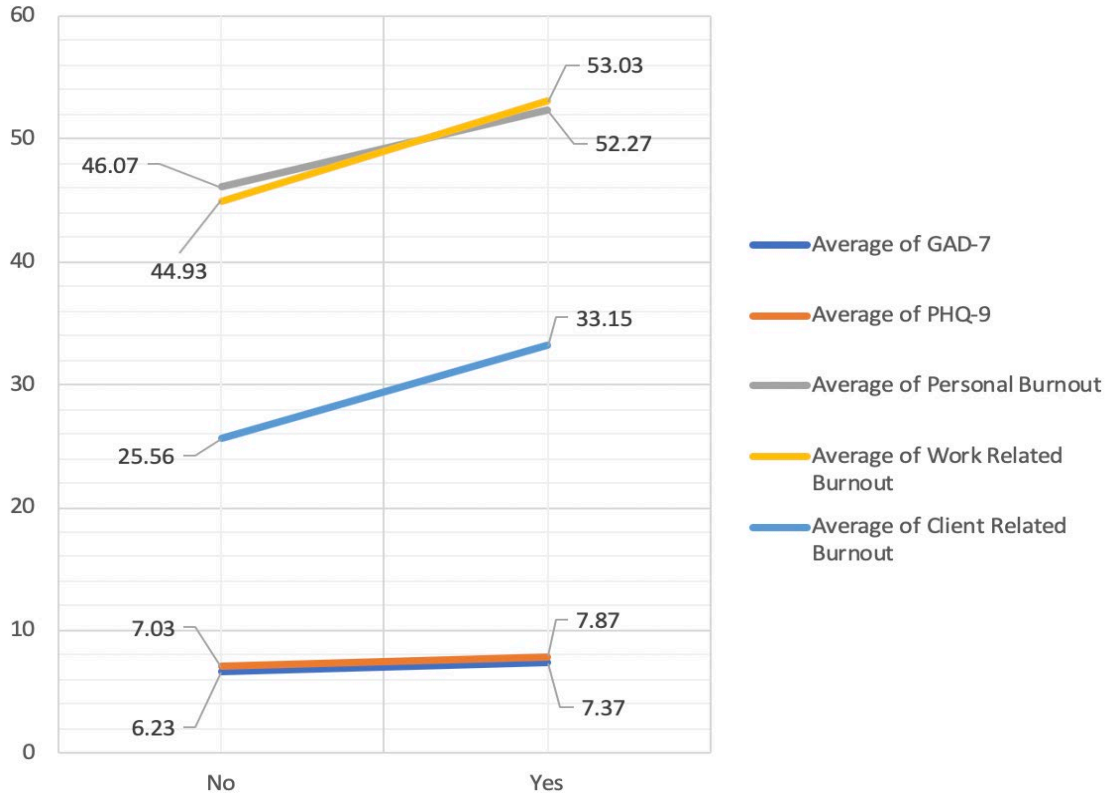

Figure 4: Mean scores of the how respondents felt about (1) contracting COVID 19 at work and; (2) about how supported they felt by their employer