UNDERSTANDING COVID19

A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers

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Living with Disability Research Centre

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12th October 2022

UCD Centre
for Disability Studies

UCD School of Psychology

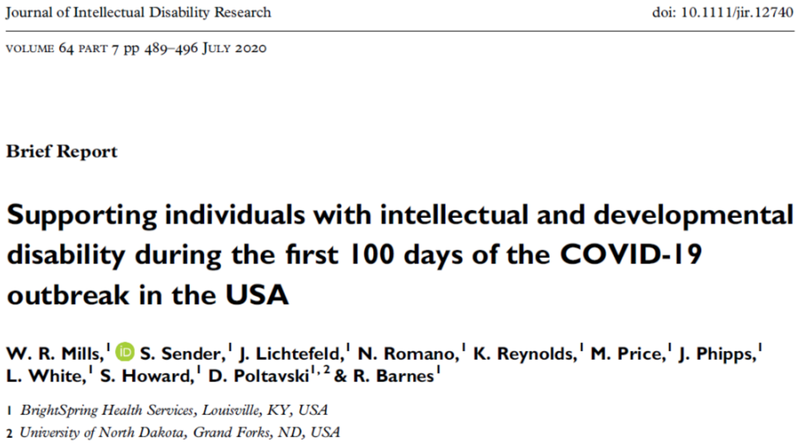
Acknowledgements

Thanks to:

- Prof Chris Bigby for the invitation to speak today.
- Our funder, the Health Research Board.
- Our 27 co-investigators from across the globe.
- Our participants.

Early studies

Mills et al (2020) described significant efforts of a provider supporting 11,000 individuals in the first 100 days of the pandemic. 66 people were diagnosed, 15 were hospitalized and three died.



Journal of Intellectual Disability Research doi: 10.1111/jir.12740

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Brief Report

Supporting individuals with intellectual and developmental disability during the first 100 days of the COVID-19 outbreak in the USA

W. R. Mills,[1] S. Sender,[1] J. Lichtefeld,[1] N. Romano,[1] K. Reynolds,[1] M. Price,[1] J. Phipps,[1] L. White,[1] S. Howard,[1] D. Poltavski[1,2] & R. Barnes[1]

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Buono et al (2021) report that within 20 days of case zero in a research centre and clinical hospital in Italy, 109 patients were diagnosed with Covid-19, six of whom later died (CFR 5.5%)

Contents lists available at ScienceDirect

Research in Developmental Disabilities

journal homepage: www.elsevier.com/locate/redevdis

ELSEVIER

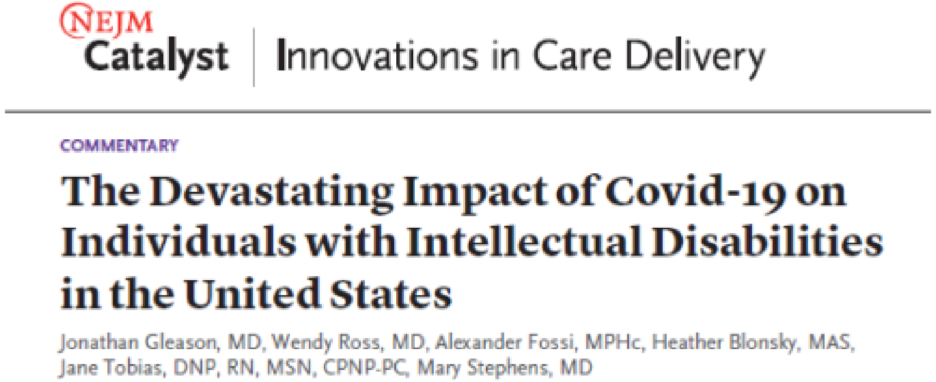
Clinical management of individuals with Intellectual Disability: The outbreak of Covid-19 pandemic as experienced in a clinical and research center Research in Developmental Disabilities

Serafino Buono[a,*], Marinella Zingale[a], Santina Città[a], Vita Mongelli[a], Grazia Trubia[a], Giovanna Mascali[a], Paola Occhipinti[a], Enrica Pettinato[a], Raffaele Ferri[b], Catalda Gagliano[b], Donatella Greco[c]

Elevated mortality and morbidity

Population-based and health register-based studies of almost 65 million individuals revealed people with intellectual and developmental disabilities (128,000) reporting higher rates of:

- Diagnosis (3.1% vs 0.9%)
- Hospitalization if diagnosed (63.1% vs 29.1%)
- Intensive care unit stays (14.5% vs 6.3%)
- Mortality (8.2% vs 3.8%)



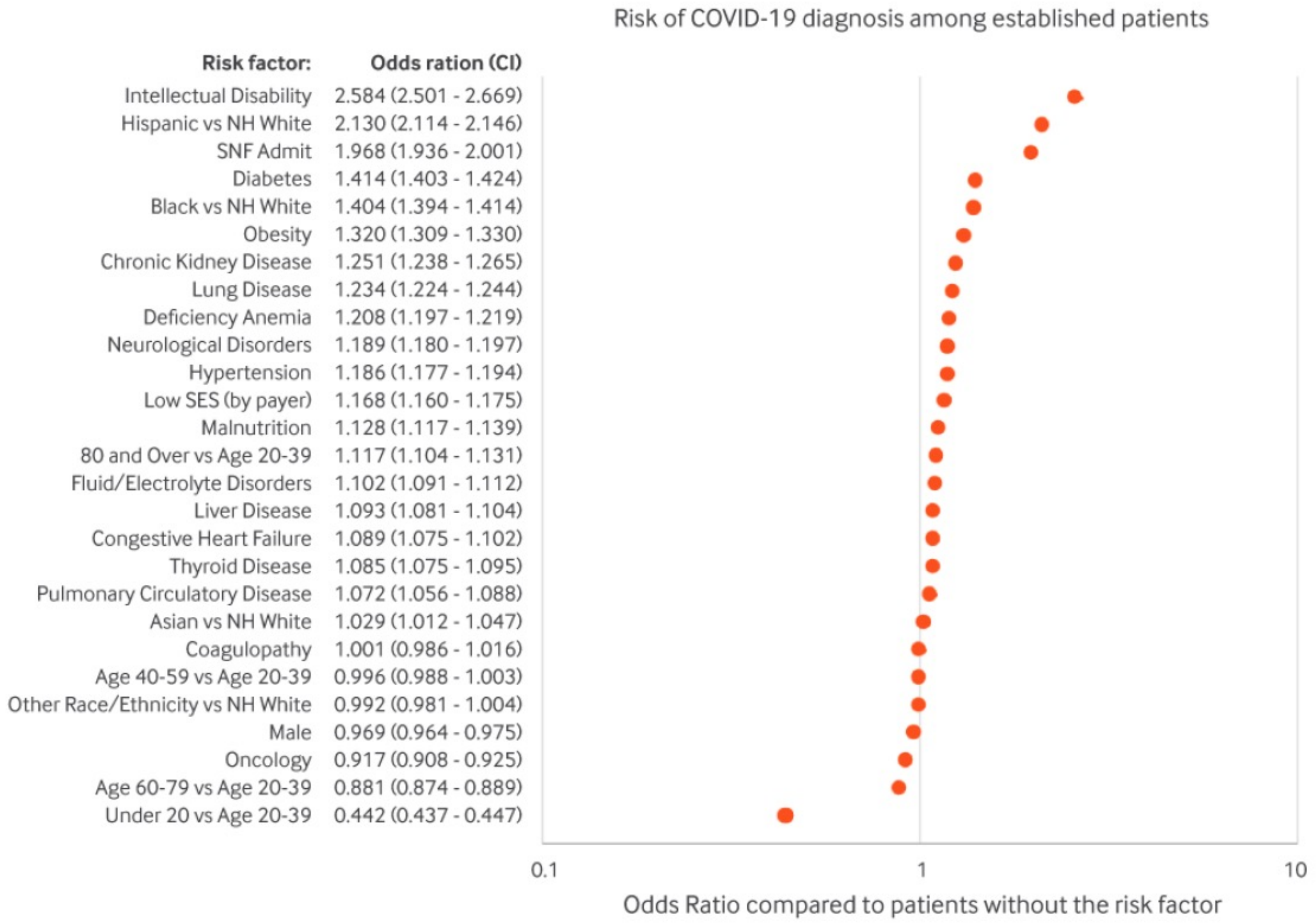
NEJM Catalyst | Innovations in Care Delivery

COMMENTARY

The Devastating Impact of Covid-19 on Individuals with Intellectual Disabilities in the United States

Jonathan Gleason, MD, Wendy Ross, MD, Alexander Fossi, MPHc, Heather Blonsky, MAS, Jane Tobias, DNP, RN, MSN, CPNP-PC, Mary Stephens, MD

ID was strongest risk factor for contracting COVID-19



Risk of COVID-19 diagnosis among established patients

Risk factor:	Odds ration (CI)
Intellectual Disability	2.584 (2.501 - 2.669)
Hispanic vs NH White	2.130 (2.114 - 2.146)
SNF Admit	1.968 (1.936 - 2.001)
Diabetes	1.414 (1.403 - 1.424)
Black vs NH White	1.404 (1.394 - 1.414)
Obesity	1.320 (1.309 - 1.330)
Chronic Kidney Disease	1.251 (1.238 - 1.265)
Lung Disease	1.234 (1.224 - 1.244)
Deficiency Anemia	1.208 (1.197 - 1.219)
Neurological Disorders	1.189 (1.180 - 1.197)
Hypertension	1.186 (1.177 - 1.194)
Low SES (by payer)	1.168 (1.160 - 1.175)
Malnutrition	1.128 (1.117 - 1.139)
80 and Over vs Age 20-39	1.117 (1.104 - 1.131)
Fluid/Electrolyte Disorders	1.102 (1.091 - 1.112)
Liver Disease	1.093 (1.081 - 1.104)
Congestive Heart Failure	1.089 (1.075 - 1.102)
Thyroid Disease	1.085 (1.075 - 1.095)
Pulmonary Circulatory Disease	1.072 (1.056 - 1.088)
Asian vs NH White	1.029 (1.012 - 1.047)
Coagulopathy	1.001 (0.986 - 1.016)
Age 40-59 vs Age 20-39	0.996 (0.988 - 1.003)
Other Race/Ethnicity vs NH White	0.992 (0.981 - 1.004)
Male	0.969 (0.964 - 0.975)
Oncology	0.917 (0.908 - 0.925)
Age 60-79 vs Age 20-39	0.881 (0.874 - 0.889)
Under 20 vs Age 20-39	0.442 (0.437 - 0.447)

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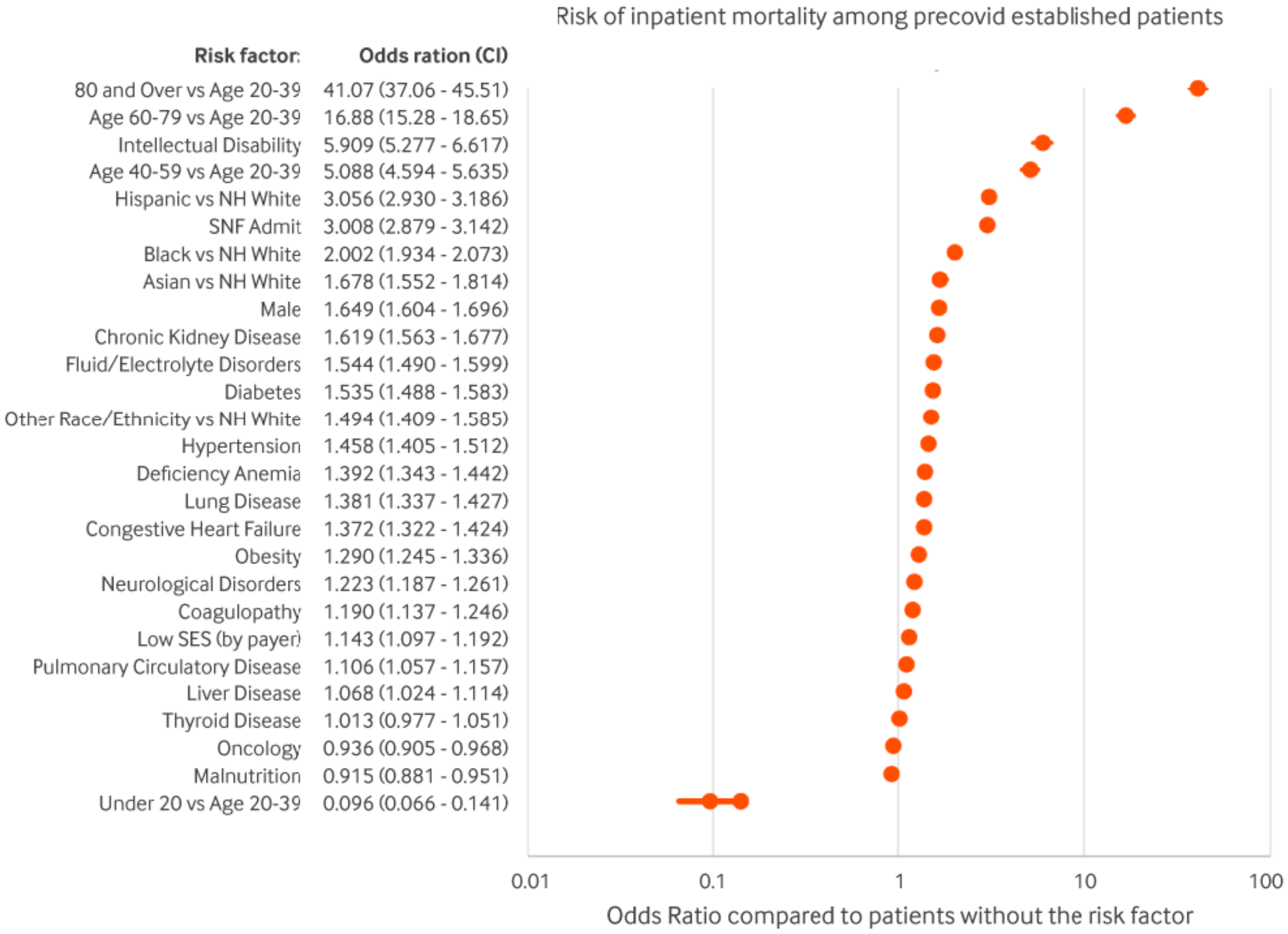
ID was strongest risk factor other than age for mortality due to COVID-19

Risk of Covid-19 Mortality — All Established Patients


Risk of inpatient mortality among precovid established patients

Risk factor:	Odds ration (CI)
80 and Over vs Age 20-39	41.07 (37.06 - 45.51)
Age 60-79 vs Age 20-39	16.88 (15.28 - 18.65)
Intellectual Disability	5.909 (5.277 - 6.617)
Age 40-59 vs Age 20-39	5.088 (4.594 - 5.635)
Hispanic vs NH White	3.056 (2.930 - 3.186)
SNF Admit	3.008 (2.879 - 3.142)
Black vs NH White	2.002 (1.934 - 2.073)
Asian vs NH White	1.678 (1.552 - 1.814)
Male	1.649 (1.604 - 1.696)
Chronic Kidney Disease	1.619 (1.563 - 1.677)
Fluid/Electrolyte Disorders	1.544 (1.490 - 1.599)
Diabetes	1.535 (1.488 - 1.583)
Other Race/Ethnicity vs NH White	1.494 (1.409 - 1.585)
Hypertension	1.458 (1.405 - 1.512)
Deficiency Anemia	1.392 (1.343 - 1.442)
Lung Disease	1.381 (1.337 - 1.427)
Congestive Heart Failure	1.372 (1.322 - 1.424)
Obesity	1.290 (1.245 - 1.336)
Neurological Disorders	1.223 (1.187 - 1.261)
Coagulopathy	1.190 (1.137 - 1.246)
Low SES (by payer)	1.143 (1.097 - 1.192)
Pulmonary Circulatory Disease	1.106 (1.057 - 1.157)
Liver Disease	1.068 (1.024 - 1.114)
Thyroid Disease	1.013 (0.977 - 1.051)
Oncology	0.936 (0.905 - 0.968)
Malnutrition	0.915 (0.881 - 0.951)
Under 20 vs Age 20-39	0.096 (0.066 - 0.141)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Highest risk of mortality in congregated settings

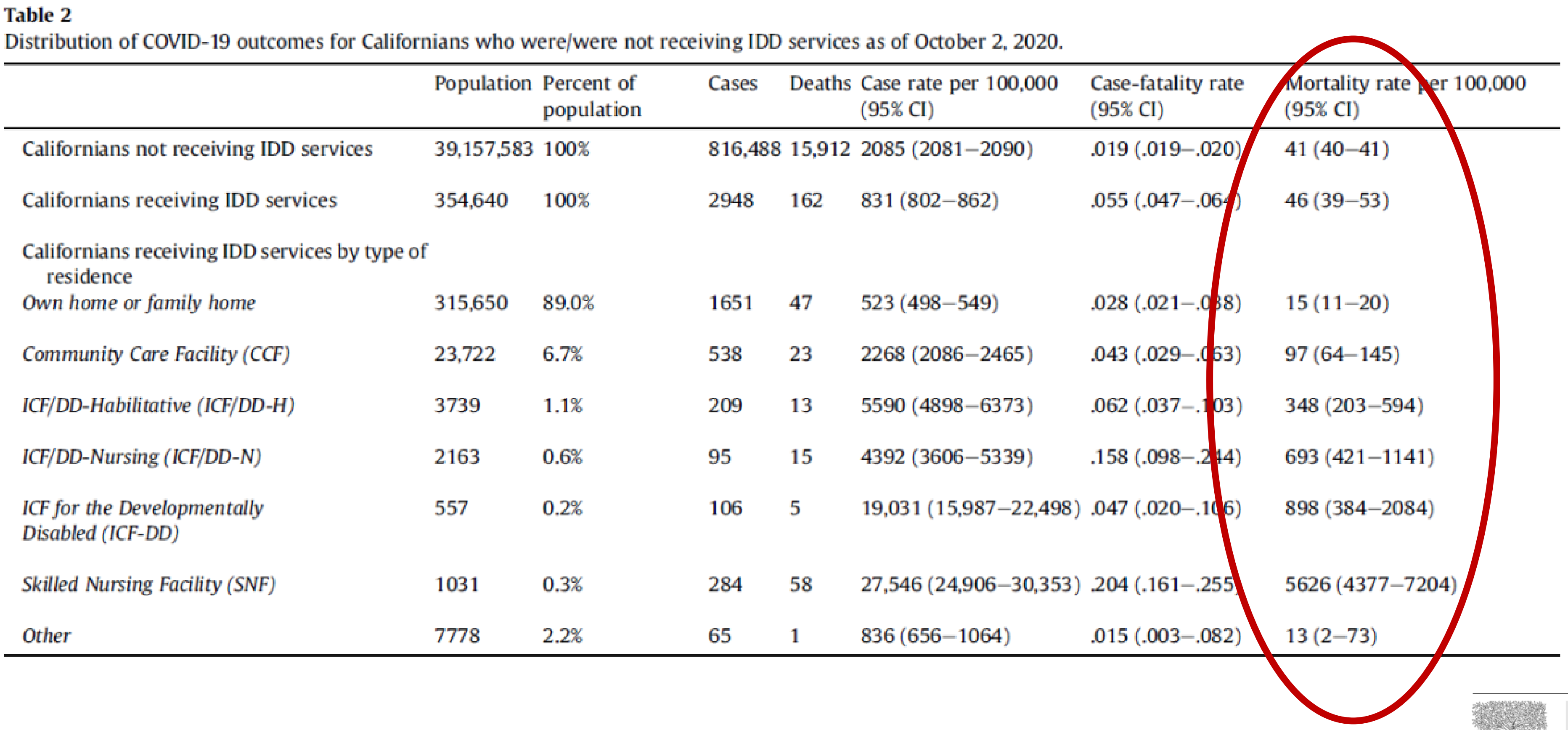

Table 2
Distribution of COVID-19 outcomes for Californians who were/were not receiving IDD services as of October 2, 2020.

	Population	Percent of population	Cases	Deaths	Case rate per 100,000 (95% CI)	Case-fatality rate (95% CI)	Mortality rate per 100,000 (95% CI)
Californians not receiving IDD services	39,157,583	100%	816,488	15,912	2085 (2081–2090)	.019 (.019–.020)	41 (40–41)
Californians receiving IDD services	354,640	100%	2948	162	831 (802–862)	.055 (.047–.064)	46 (39–53)
Californians receiving IDD services by type of residence							
Own home or family home	315,650	89.0%	1651	47	523 (498–549)	.028 (.021–.038)	15 (11–20)
Community Care Facility (CCF)	23,722	6.7%	538	23	2268 (2086–2465)	.043 (.029–.063)	97 (64–145)
ICF/DD-Habilitative (ICF/DD-H)	3739	1.1%	209	13	5590 (4898–6373)	.062 (.037–.103)	348 (203–594)
ICF/DD-Nursing (ICF/DD-N)	2163	0.6%	95	15	4392 (3606–5339)	.158 (.098–.244)	693 (421–1141)
ICF for the Developmentally Disabled (ICF-DD)	557	0.2%	106	5	19,031 (15,987–22,498)	.047 (.020–.106)	898 (384–2084)
Skilled Nursing Facility (SNF)	1031	0.3%	284	58	27,546 (24,906–30,353)	.204 (.161–.255)	5626 (4377–7204)
Other	7778	2.2%	65	1	836 (656–1064)	.015 (.003–.082)	13 (2–73)

Californian study comparing mortality rates from population-based datasets of developmental disability services and general population (Landes et al, 2021)

Contents lists available at ScienceDirect

Disability and Health Journal

journal homepage: www.disabilityandhealthjnl.com

Brief Report

COVID-19 outcomes among people with intellectual and developmental disability in California: The importance of type of residence and skilled nursing care needs

Scott D. Landes, PhD [a, *], Margaret A. Turk, MD [b], Ashlyn W.W.A. Wong, BA [c]

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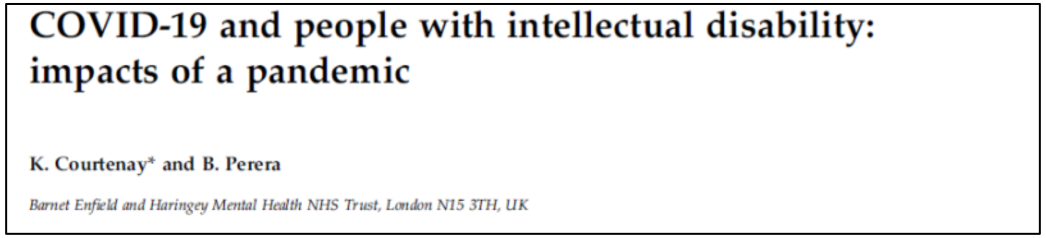
Contributors to elevated risk

- Higher incidence of somatic and mental health conditions
- Cramped living arrangements
- Living with vulnerable and elderly family members
- Requiring high level of personal care and staff contact
- Challenges with disruption to routine
- Challenges in sourcing information and self-advocacy



COVID-19 and people with intellectual disability: impacts of a pandemic

K. Courtenay* and B. Perera

Barnet Enfield and Haringey Mental Health NHS Trust, London N15 3TH, UK

Rationale for present study

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

UNCRPD affirms the rights of people with disabilities to full inclusion and participation in all aspects of life.

Article 26 requires signatories to ***‘organise, strengthen and extend support services’.***

CRPD
CONVENTION
ON THE RIGHTS
OF PERSONS
WITH DISABILITIES

Rationale for study

American Association for Intellectual and Developmental Disabilities (AAIDD).

Support needs models argues that **“people with intellectual disability are people who require the provision of ongoing, extraordinary patterns of support”.**

“if supports were removed, people with ID would not be able to function as successfully in typical activities and settings”

INTELLECTUAL AND DEVELOPMENTAL DISABILITIES VOLUME 47, NUMBER 2: 135–146 | APRIL 2009

Conceptualizing Supports and the Support Needs of People With Intellectual Disability

James R. Thompson, Valerie J. Bradley, Wil H. E. Buntinx, Robert L. Schalock, Karrie A. Shogren, Martha E. Snell, and Michael L. Wehmeyer, with Sharon Borthwick-Duffy, David L. Coulter, Ellis (Pat) M. Craig, Sharon C. Gomez, Yves Lachapelle, Ruth A. Luckasson, Alya Reeve, Scott Spreat, Marc J. Tassé, Miguel A. Verdugo, and Mark H. Yeager

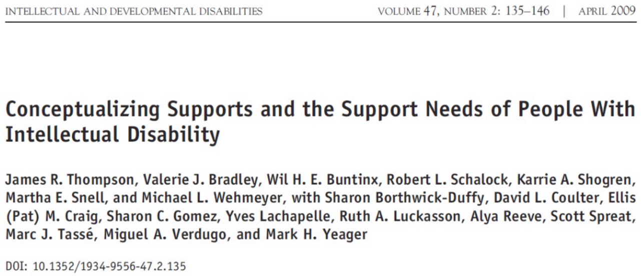
DOI: 10.1352/1934-9556-47.2.135

Rationale for study

COVID-19 caused disruption to ‘ongoing extraordinary patterns of support’ received by people with IDD.

Our study aimed to document this disruption and its impact on individuals with intellectual and developmental disabilities and their caregivers.

aaidd



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Who we are:

This research was undertaken by a group of researchers who are members of IASSIDD's Comparative Policy and Practice SIRG.

Others joined and we are hopeful to continue our global network into future studies.

COMPARATIVE POLICY & PRACTICE
SPECIAL INTEREST GROUP

iassidd

(if you'd like to join the Comparative Policy and Practice SIRG email christine.linehan@ucd.ie – we are global and going places ☺)

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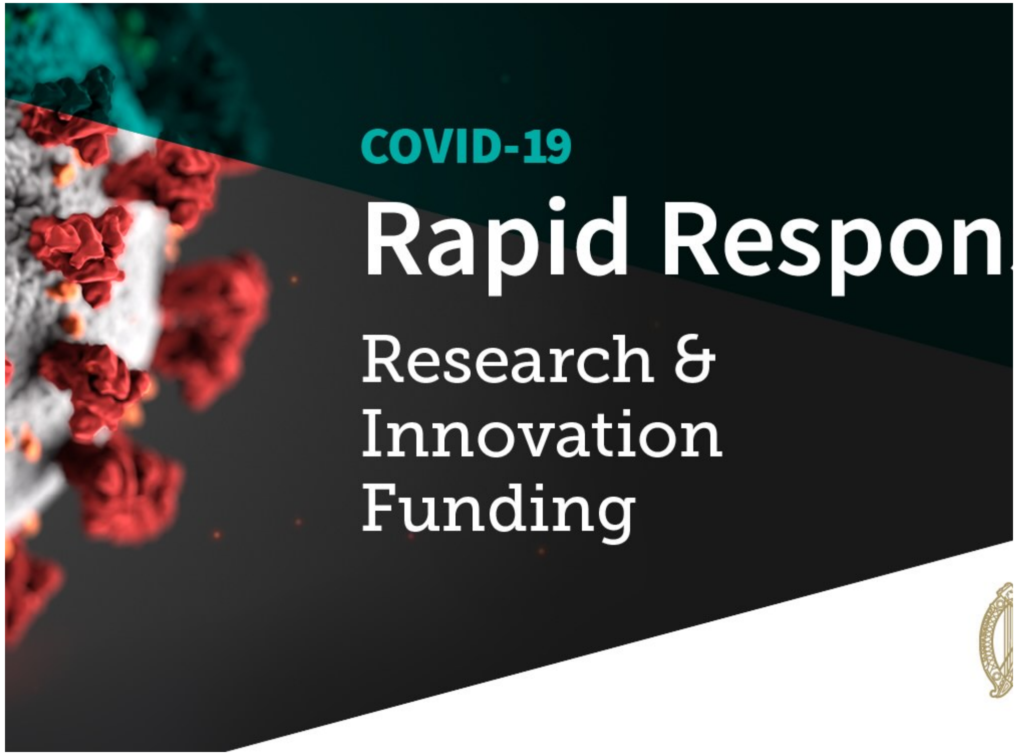
A funding opportunity

In May 2020, the Irish Government allocated funding for Covid-19 research to the three largest funding bodies in Ireland.

350 ‘rapid applications’ of which 26 were funded in Round 1.



Data management and open publishing

COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers

Contributors: Christine Linehan, Gail Birkbeck, Tal Araten-Bergman, Jennifer Baumbusch, Julie Beadle-Brown, Christine Bigby, Valerie Bradley, Michael Brown, Femmianne Bredewold, Masauso Chirwa, Jialiang Cui, Marta Godoy-Giménez, Tiziano Gomiero, Šárka Kanova, Thilo Kroll, Henan Li, Mac MacLachlan, Jayanthi Narayan, Finiki Nearchou, Adam Nolan, Mary-Ann O'Donovan, Flavia H. Santos, Jan Šiška, Tim Stainton, Magnus Tideman, Jan Tossebro

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Identifier: DOI 10.17605/OSF.IO/GK2VF

HRB Open Research

HRB Open Research 2020, 3:39 Last updated: 12 OCT 2020

STUDY PROTOCOL

COVID-19 IDD: A global survey exploring family members' and paid staff's perceptions of the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers.

Previously titled: COVID-19 IDD: A global survey exploring the impact of COVID-19 on individuals with intellectual and developmental disabilities and their caregivers

Christine Linehan[1], Tal Aranten-Bergman[2], Jennifer Baumbusch[3], Julie Beadle-Brown[4], Christine Bigby[2], Gail Birkbeck[5], Valerie Bradley[6], Michael Brown[7], Femmianne Bredewold[8], Masauso Chirwa[9], Jialiang Cui[10], Marta Godoy Gimenez[11], Tiziano Gomiero[12], Sarka Kanova[13], Thilo Kroll[14], Mac MacLachlan[15], Brigit Mirfin-Vietch[16], Jayanthi Narayan[17], Finiki Nearchou[18], Adam Nolan[1], Mary-Ann O'Donovan[19], Flavia H. Santos[18], Jan Siska[20], Tim Stainton[3], Magnus Tideman[21,22], Jan Tossebro[23]

Study Protocol

https://hrbopenresearch.org/collections/coronavirus

Research Questions

What are the experiences of caregivers, family and staff, and the people they support during the pandemic?

Do these experiences differ by living arrangement and jurisdiction?

Bespoke survey

Language	Back-translated into 15 languages and hosted on a server in Ireland.
Launch	Survey piloted and launched September 2020.
Take Part	Participants could access via any digital device; phone, iPad, laptop etc.

Brazilian Portuguese, Czech, Dutch, English, French Canadian, German, Greek, Hebrew, Hindi, Italian, Mandarin, Norwegian, Nyanja, Spanish, Sweden

Survey sections

Section 1:

Demographics – you and the person(s) you support

Section 2:
Organisational Practices in your workplace (management only)

Section 3:

Local Practices in your workplace (local/unit staff only)

Section 4:

Local Practices for family caregivers (family only)

Section 5:

Access to information and training

Section 6:

Experiences of Covid 19 – caregiver and supported person

Section 7:

Impact of Social Distancing

Section 8:

Standarised scales on anxiety/depression and impact of events

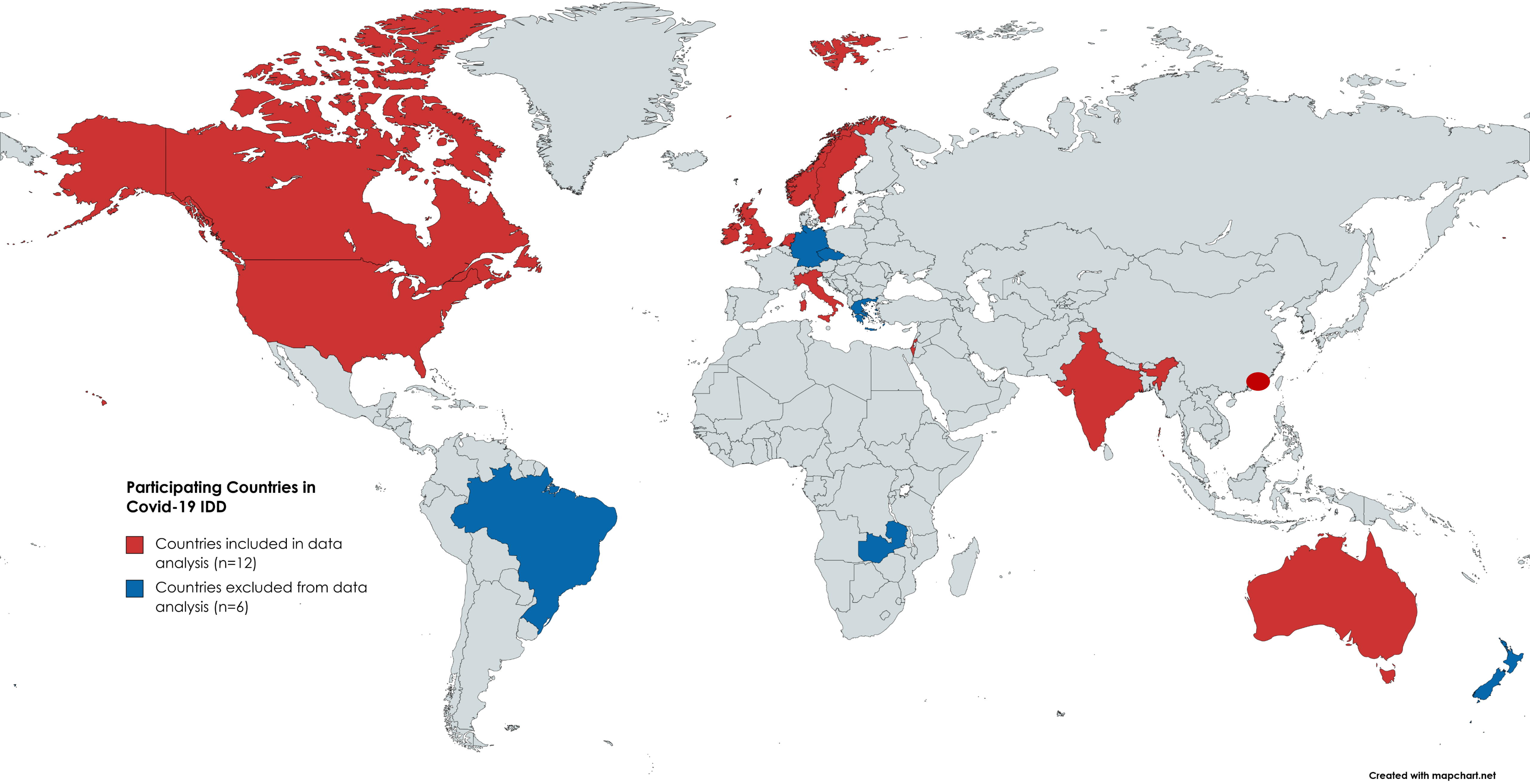
Participating sample: a study limitation

We did not seek the participation of individuals with disabilities

At the time of grant submission and data collection, contact with advocacy groups and disability support services was extremely limited for most partners.

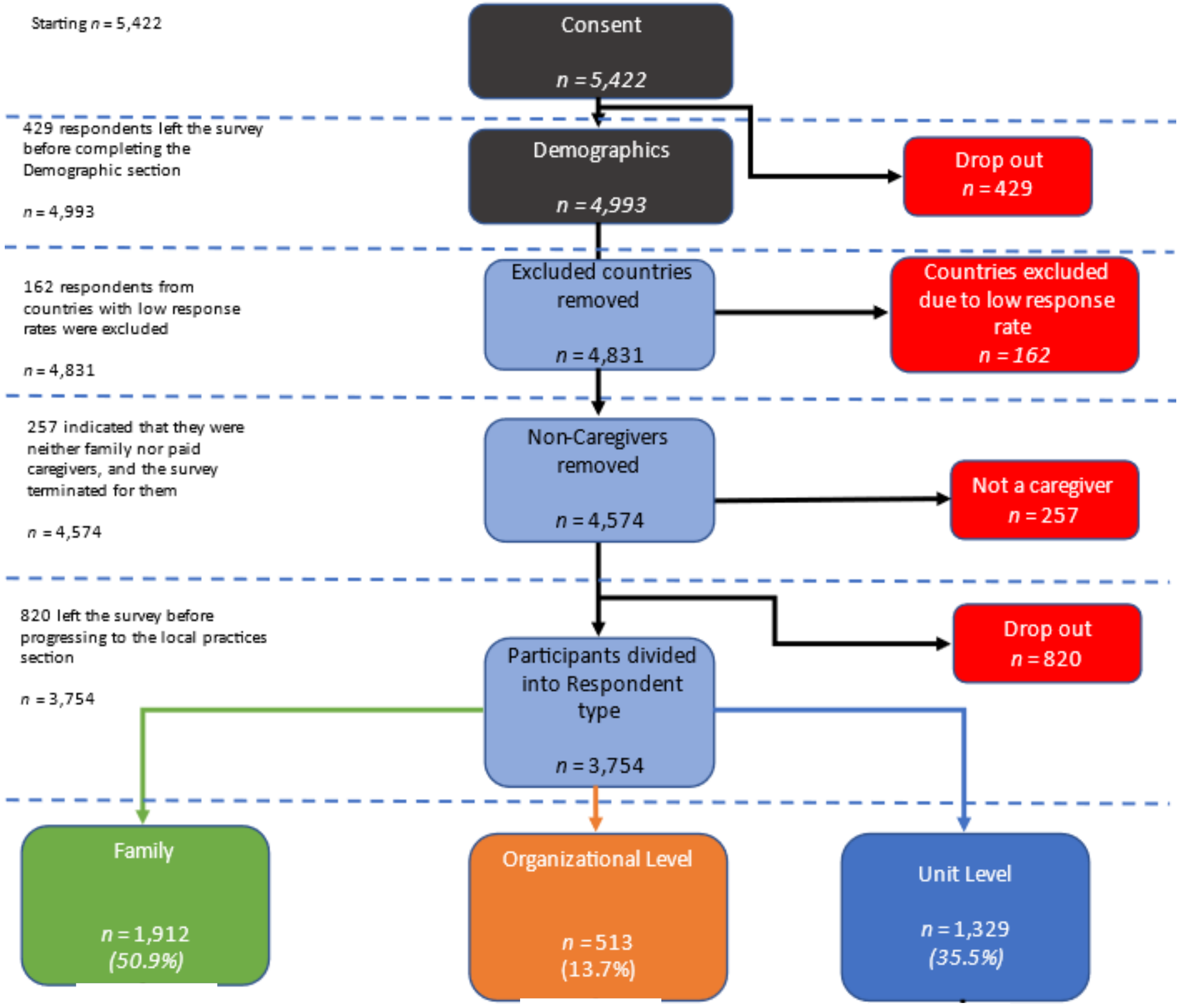
We agreed this survey would include input from international advocates at Inclusion International.

We also agreed that many of the partners would be following up with research projects directly seeking the views of people with intellectual and developmental disability – two such projects have been conducted in Ireland.



https://mapchart.net/world.html

Survey Response Rate: Useable Data



Starting *n* = 5,422

429 respondents left the survey before completing the Demographic section

n = 4,993

162 respondents from countries with low response rates were excluded

n = 4,831

257 indicated that they were neither family nor paid caregivers, and the survey terminated for them

n = 4,574

820 left the survey before progressing to the local practices section

n = 3,754

Participants

3,754 overall

1,912 family members

1,329 direct support professionals

513 management

Participants

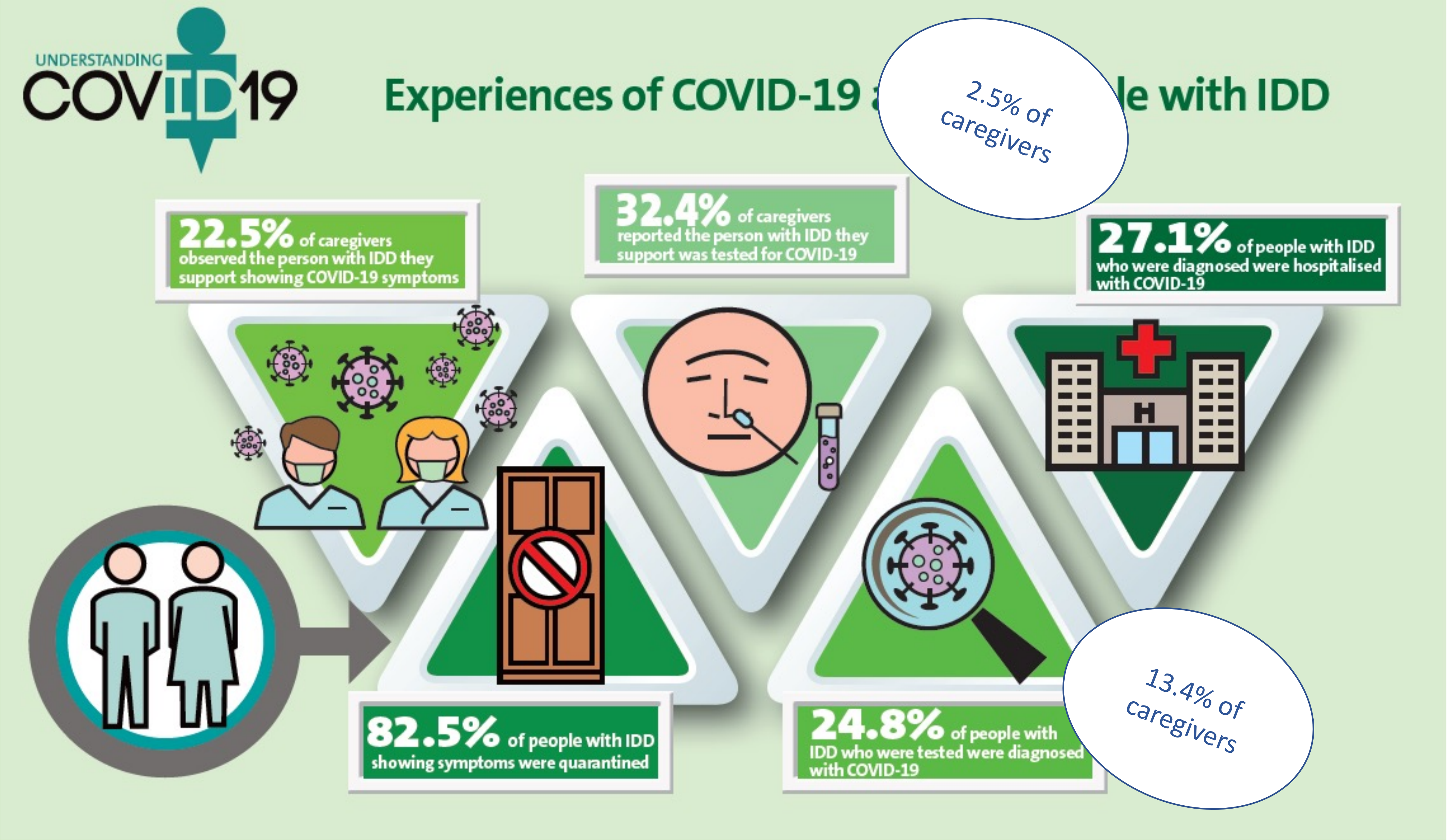
	Family		Unit Staff		Organisational Staff		Total	
	N	%	N	%	N	%	N	%
Respondent Type	1912	50.9%	1329	35.4%	513	13.7%	3754	100.0%
Respondents' Country								
Sweden	340	17.8%	507	38.1%	72	14.0%	919	24.5%
Netherlands	255	13.3%	209	15.7%	30	5.8%	494	13.2%
Canada	261	13.7%	110	8.3%	88	17.2%	459	12.2%
USA	152	7.9%	58	4.4%	72	14.0%	282	7.5%
Hong Kong SAR	208	10.9%	47	3.5%	14	2.7%	269	7.2%
India	98	5.1%	77	5.8%	81	15.8%	256	6.8%
Ireland	167	8.7%	51	3.8%	35	6.8%	253	6.7%
Norway	92	4.8%	116	8.7%	11	2.1%	219	5.8%
Italy	106	5.5%	76	5.7%	22	4.3%	204	5.4%
Israel	75	3.9%	36	2.7%	49	9.6%	160	4.3%
Australia	78	4.1%	21	1.6%	28	5.5%	127	3.4%
UK	80	4.2%	21	1.6%	11	2.1%	112	3.0%

Restrictions

83% restrictions to and from family and friends

85% closures or reductions in day services, social and exercise activities

75% closures or reductions in educational programmes



Experiences of COVID-19 a

2.5% of caregivers

le with IDD

22.5% of caregivers observed the person with IDD they support showing COVID-19 symptoms

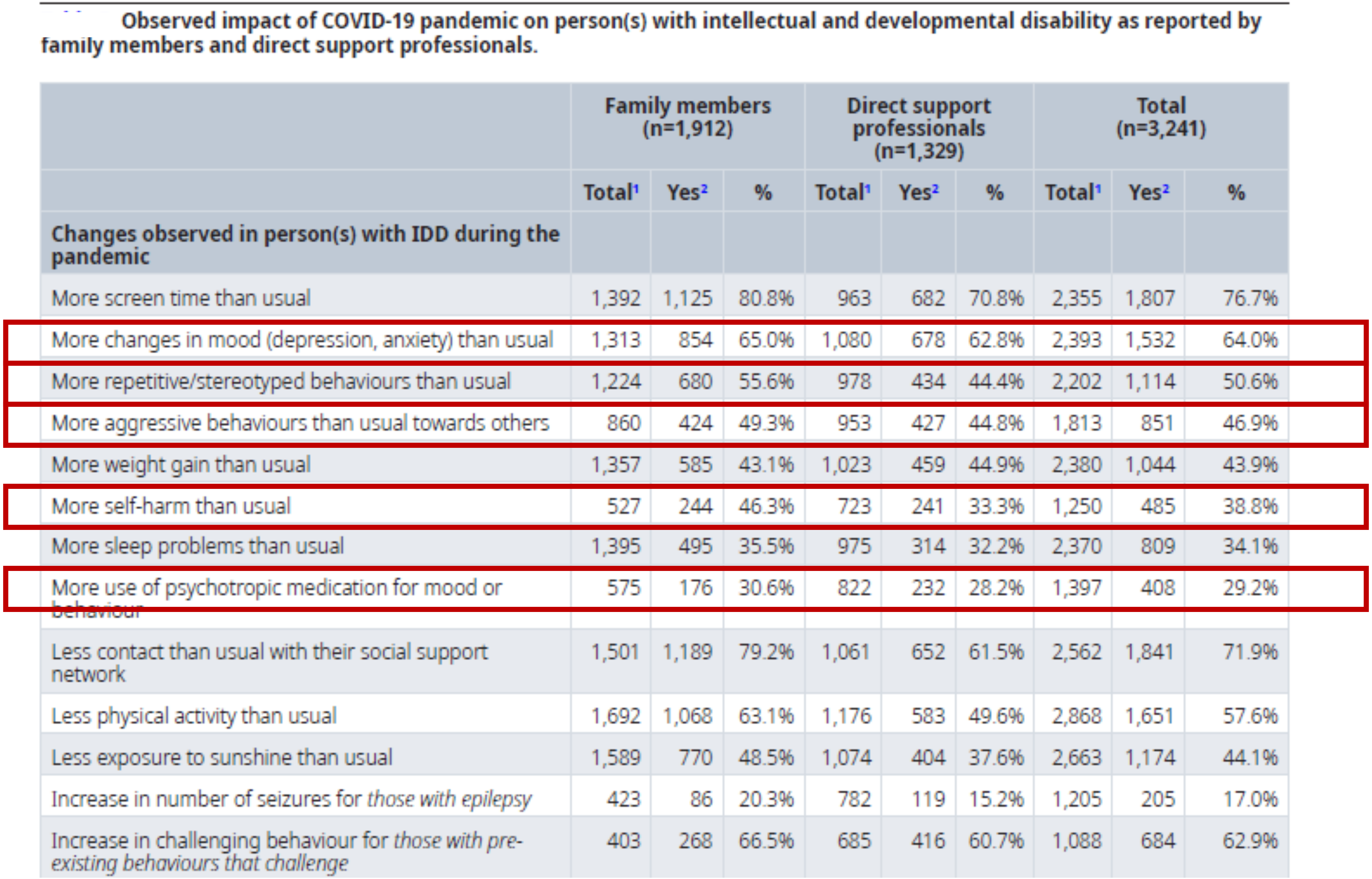
32.4% of caregivers reported the person with IDD they support was tested for COVID-19

27.1% of people with IDD who were diagnosed were hospitalised with COVID-19

82.5% of people with IDD showing symptoms were quarantined

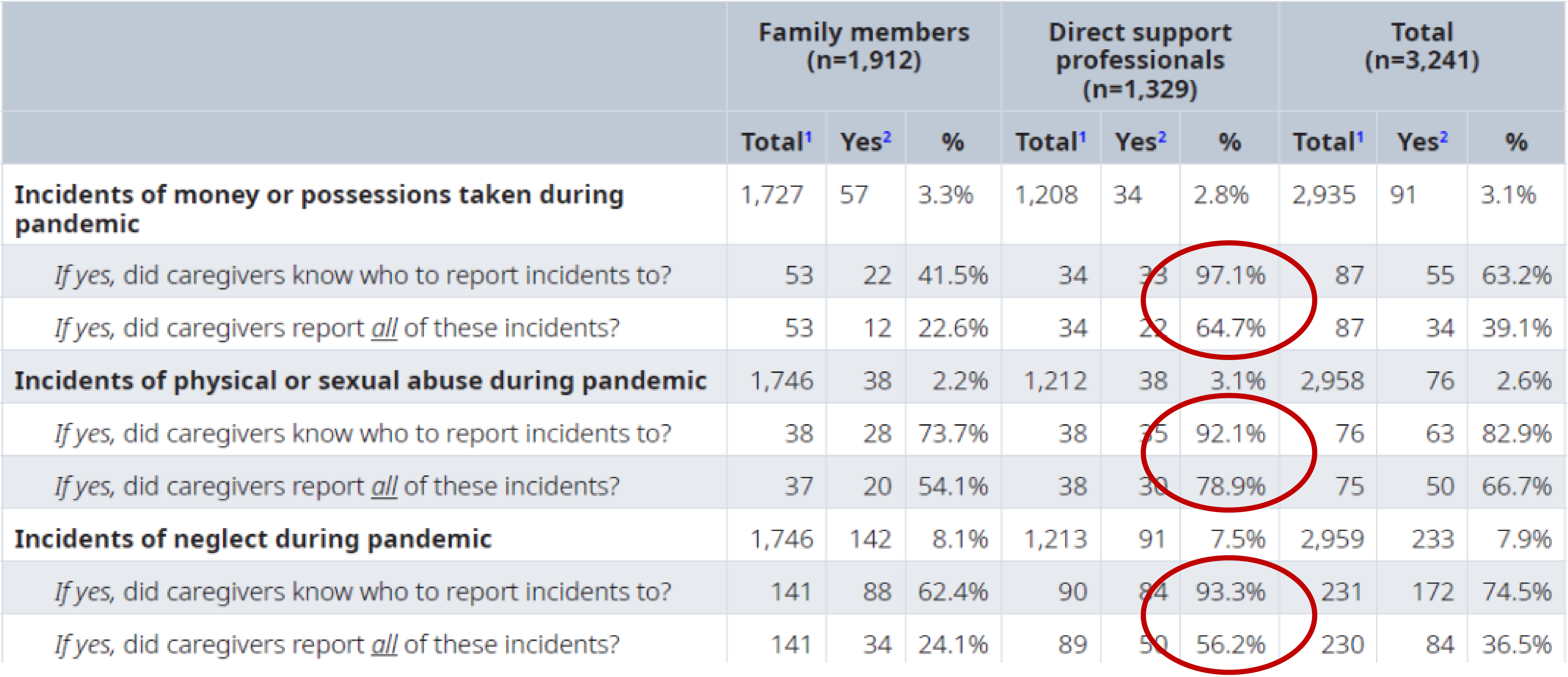
24.8% of people with IDD who were tested were diagnosed with COVID-19

13.4% of caregivers



Observed impact of COVID-19 pandemic on person(s) with intellectual and developmental disability as reported by family members and direct support professionals.

	Family members (n=1,912)			Direct support professionals (n=1,329)			Total (n=3,241)		
	Total[1]	Yes[2]	%	Total[1]	Yes[2]	%	Total[1]	Yes[2]	%
Changes observed in person(s) with IDD during the pandemic									
More screen time than usual	1,392	1,125	80.8%	963	682	70.8%	2,355	1,807	76.7%
More changes in mood (depression, anxiety) than usual	1,313	854	65.0%	1,080	678	62.8%	2,393	1,532	64.0%
More repetitive/stereotyped behaviours than usual	1,224	680	55.6%	978	434	44.4%	2,202	1,114	50.6%
More aggressive behaviours than usual towards others	860	424	49.3%	953	427	44.8%	1,813	851	46.9%
More weight gain than usual	1,357	585	43.1%	1,023	459	44.9%	2,380	1,044	43.9%
More self-harm than usual	527	244	46.3%	723	241	33.3%	1,250	485	38.8%
More sleep problems than usual	1,395	495	35.5%	975	314	32.2%	2,370	809	34.1%
More use of psychotropic medication for mood or behaviour	575	176	30.6%	822	232	28.2%	1,397	408	29.2%
Less contact than usual with their social support network	1,501	1,189	79.2%	1,061	652	61.5%	2,562	1,841	71.9%
Less physical activity than usual	1,692	1,068	63.1%	1,176	583	49.6%	2,868	1,651	57.6%
Less exposure to sunshine than usual	1,589	770	48.5%	1,074	404	37.6%	2,663	1,174	44.1%
Increase in number of seizures for *those with epilepsy*	423	86	20.3%	782	119	15.2%	1,205	205	17.0%
Increase in challenging behaviour for *those with pre-existing behaviours that challenge*	403	268	66.5%	685	416	60.7%	1,088	684	62.9%



	Family members (n=1,912)			Direct support professionals (n=1,329)			Total (n=3,241)		
	Total[1]	Yes[2]	%	Total[1]	Yes[2]	%	Total[1]	Yes[2]	%
Incidents of money or possessions taken during pandemic	1,727	57	3.3%	1,208	34	2.8%	2,935	91	3.1%
If yes, did caregivers know who to report incidents to?	53	22	41.5%	34	33	97.1%	87	55	63.2%
If yes, did caregivers report *all* of these incidents?	53	12	22.6%	34	22	64.7%	87	34	39.1%
Incidents of physical or sexual abuse during pandemic	1,746	38	2.2%	1,212	38	3.1%	2,958	76	2.6%
If yes, did caregivers know who to report incidents to?	38	28	73.7%	38	35	92.1%	76	63	82.9%
If yes, did caregivers report *all* of these incidents?	37	20	54.1%	38	30	78.9%	75	50	66.7%
Incidents of neglect during pandemic	1,746	142	8.1%	1,213	91	7.5%	2,959	233	7.9%
If yes, did caregivers know who to report incidents to?	141	88	62.4%	90	84	93.3%	231	172	74.5%
If yes, did caregivers report *all* of these incidents?	141	34	24.1%	89	50	56.2%	230	84	36.5%

Observed outcomes for supported persons with particular needs

63% observed an increase in behaviours that challenge

17% observed an increase in seizures

9% observed a decline in behaviours that challenge

3% observed a decline in seizures

Impact on direct staff working practices

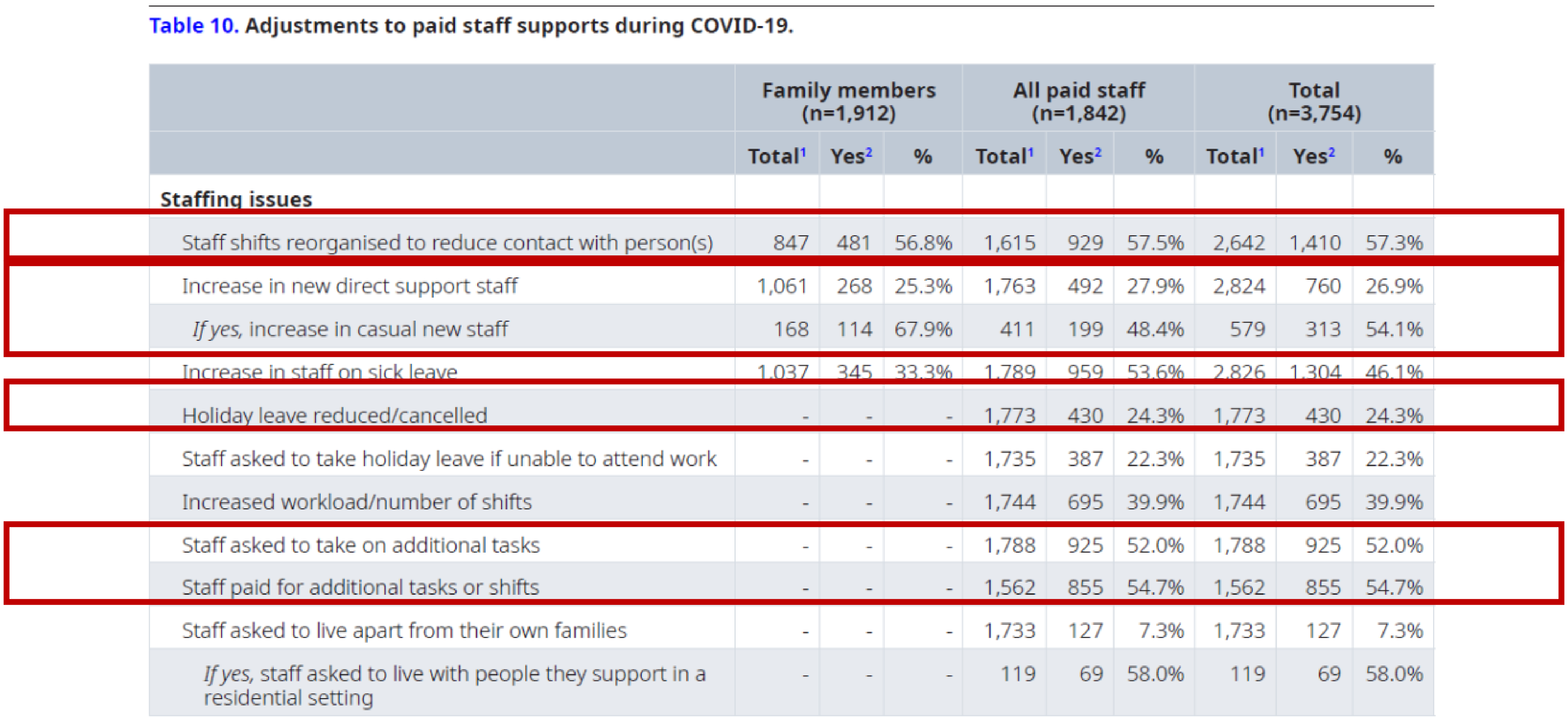
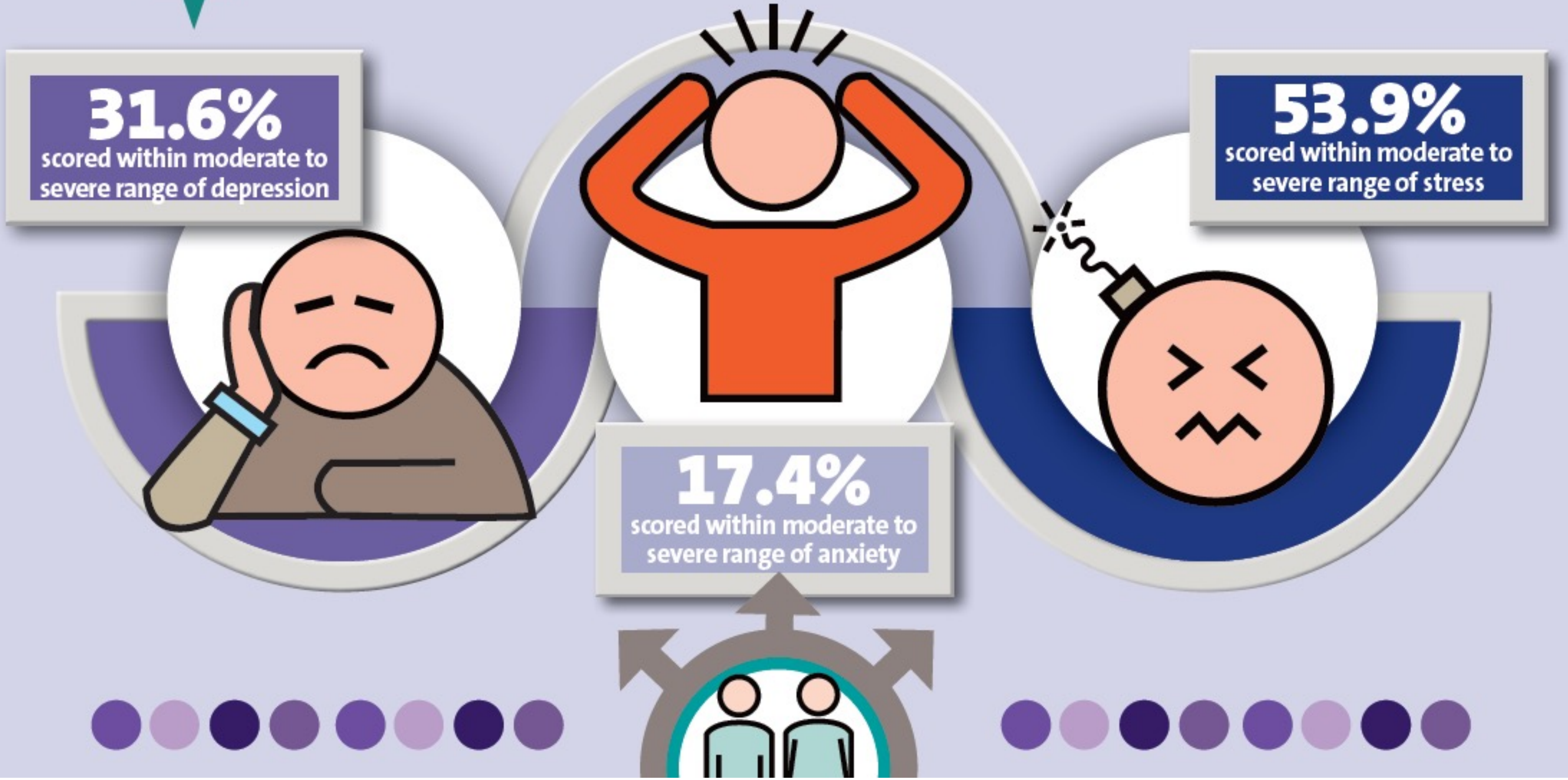


Table 10. **Adjustments to paid staff supports during COVID-19.**

	Family members (n=1,912)			**All paid staff (n=1,842)**			**Total (n=3,754)**		
	Total[1]	**Yes[2]**	**%**	**Total[1]**	**Yes[2]**	**%**	**Total[1]**	**Yes[2]**	**%**
Staffing issues									
Staff shifts reorganised to reduce contact with person(s)	847	481	56.8%	1,615	929	57.5%	2,642	1,410	57.3%
Increase in new direct support staff	1,061	268	25.3%	1,763	492	27.9%	2,824	760	26.9%
If yes, increase in casual new staff	168	114	67.9%	411	199	48.4%	579	313	54.1%
Increase in staff on sick leave	1,037	345	33.3%	1,789	959	53.6%	2,826	1,304	46.1%
Holiday leave reduced/cancelled	-	-	-	1,773	430	24.3%	1,773	430	24.3%
Staff asked to take holiday leave if unable to attend work	-	-	-	1,735	387	22.3%	1,735	387	22.3%
Increased workload/number of shifts	-	-	-	1,744	695	39.9%	1,744	695	39.9%
Staff asked to take on additional tasks	-	-	-	1,788	925	52.0%	1,788	925	52.0%
Staff paid for additional tasks or shifts	-	-	-	1,562	855	54.7%	1,562	855	54.7%
Staff asked to live apart from their own families	-	-	-	1,733	127	7.3%	1,733	127	7.3%
If yes, staff asked to live with people they support in a residential setting	-	-	-	119	69	58.0%	119	69	58.0%

UNDERSTANDING COVID19

Direct Support Professionals' Wellbeing



31.6%
scored within moderate to severe range of depression

17.4%
scored within moderate to severe range of anxiety

53.9%
scored within moderate to severe range of stress

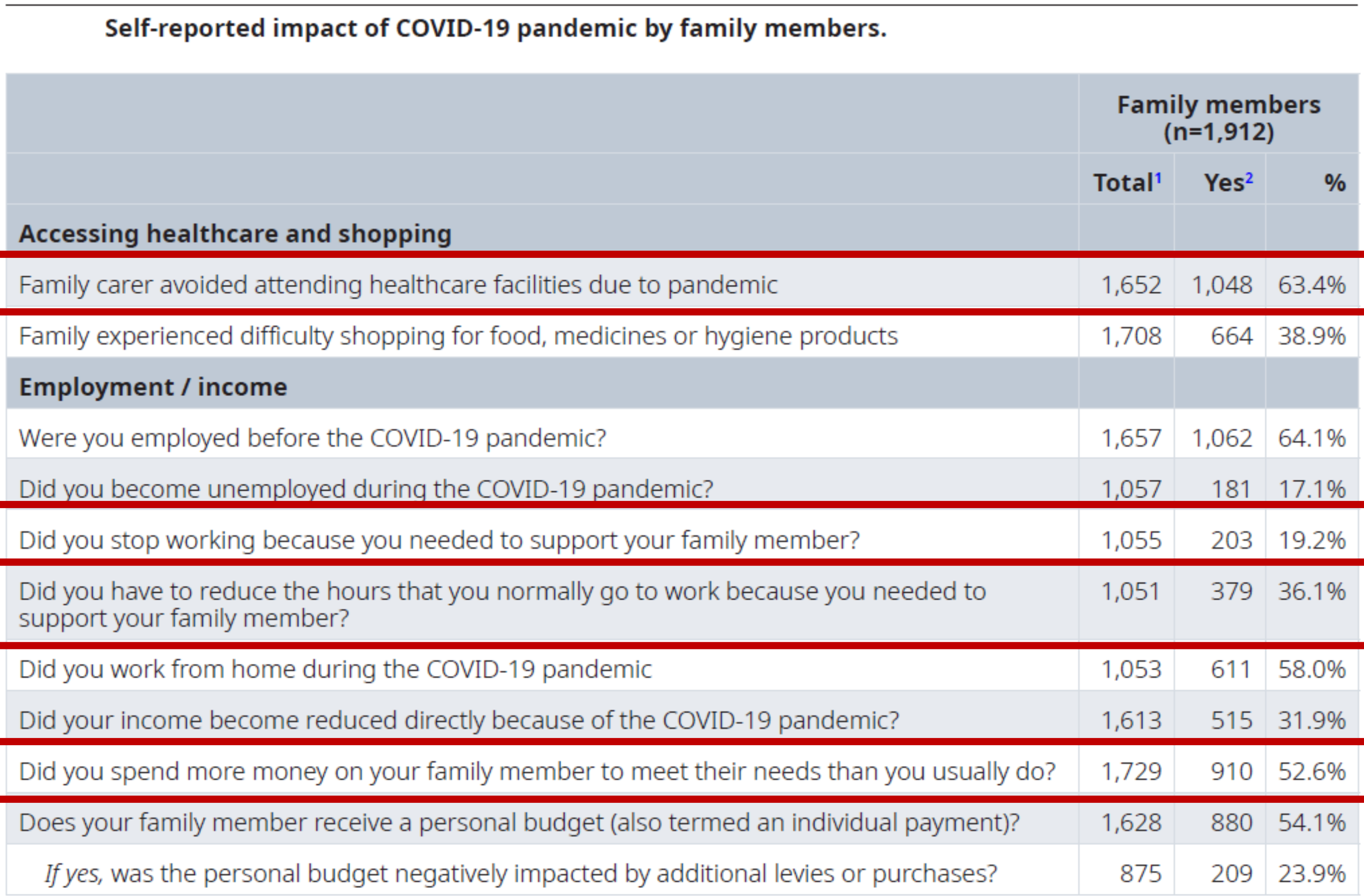
Predictors of depression, anxiety & stress in direct support workers

Reorganisation of staff shifts

Increase in new staff

Dissatisfaction with timing of PPE

Impact on family caregivers

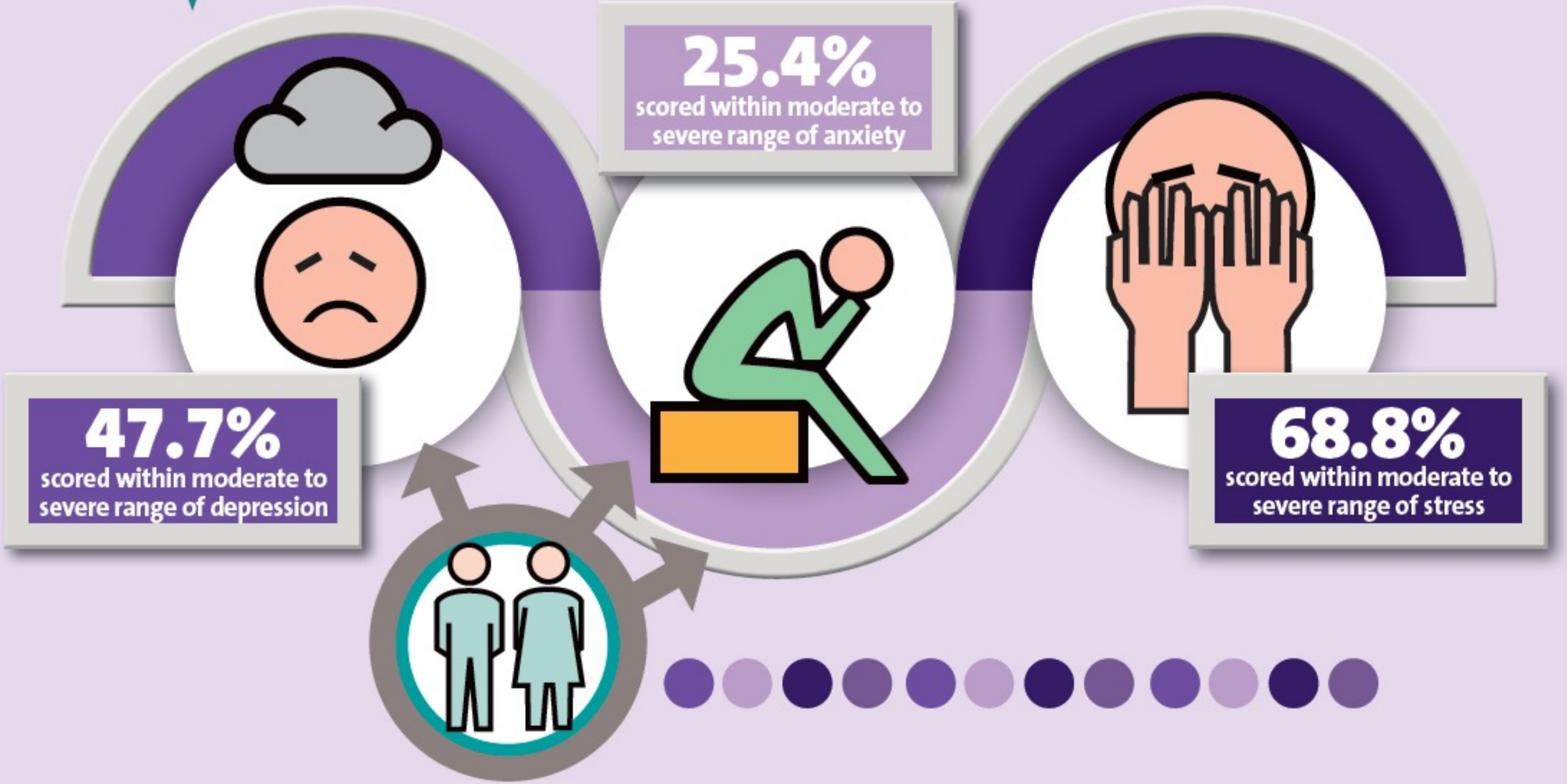


Self-reported impact of COVID-19 pandemic by family members.

	Family members (n=1,912)		
	Total[1]	**Yes**[2]	**%**
Accessing healthcare and shopping			
Family carer avoided attending healthcare facilities due to pandemic	1,652	1,048	63.4%
Family experienced difficulty shopping for food, medicines or hygiene products	1,708	664	38.9%
Employment / income			
Were you employed before the COVID-19 pandemic?	1,657	1,062	64.1%
Did you become unemployed during the COVID-19 pandemic?	1,057	181	17.1%
Did you stop working because you needed to support your family member?	1,055	203	19.2%
Did you have to reduce the hours that you normally go to work because you needed to support your family member?	1,051	379	36.1%
Did you work from home during the COVID-19 pandemic	1,053	611	58.0%
Did your income become reduced directly because of the COVID-19 pandemic?	1,613	515	31.9%
Did you spend more money on your family member to meet their needs than you usually do?	1,729	910	52.6%
Does your family member receive a personal budget (also termed an individual payment)?	1,628	880	54.1%
If yes, was the personal budget negatively impacted by additional levies or purchases?	875	209	23.9%

UNDERSTANDING COVID19

Wellbeing of family caregivers during COVID-19



47.7% scored within moderate to severe range of depression

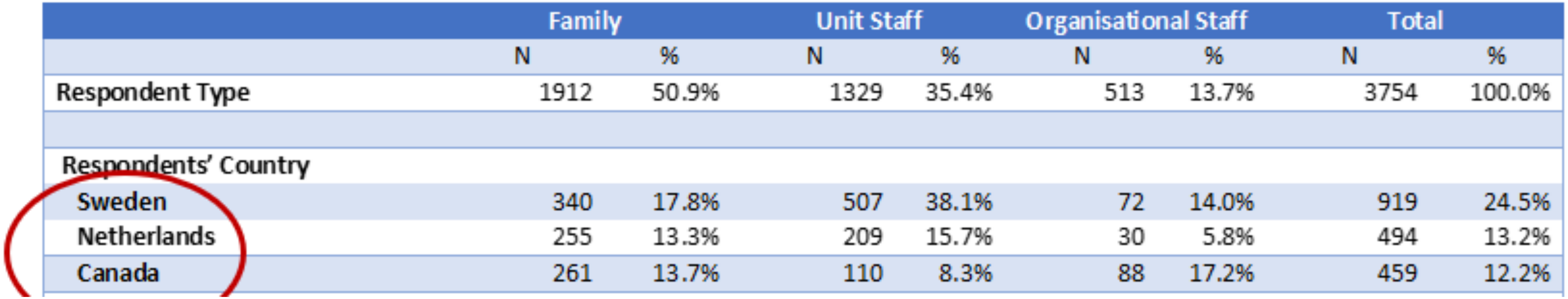
25.4% scored within moderate to severe range of anxiety

68.8% scored within moderate to severe range of stress

Predictors of depression, anxiety & stress in family caregivers

- Observed mood change in person with IDD
- Person living in family home
- Restricted visits with family and friends
- Dissatisfaction with level of support

Experiences in different jurisdictions – too skewed for analysis



	Family		Unit Staff		Organisational Staff		Total	
	N	%	N	%	N	%	N	%
Respondent Type	1912	50.9%	1329	35.4%	513	13.7%	3754	100.0%
Respondents' Country								
Sweden	340	17.8%	507	38.1%	72	14.0%	919	24.5%
Netherlands	255	13.3%	209	15.7%	30	5.8%	494	13.2%
Canada	261	13.7%	110	8.3%	88	17.2%	459	12.2%

Experiences in different living arrangements

Outcome: Caregiver well-being during Covid

Overall, we found high rates of stress (62%), depression (40%) and lower rates of anxiety (21%).

Those supporting someone in the family home or own home compared with those supporting someone in a community group home or residential campus setting are:

more likely to be moderately or severely stressed

more likely to be moderately or severely depressed

more likely to be moderately or severely anxious

Outcome: Caregiver experiences of Covid

Those supporting someone in the family home or own home compared with those supporting someone in a community group home or residential campus setting are:

less likely to be tested for Covid

less likely to self-report symptoms

Same rates of diagnosis across both types of settings

Are those in service settings more likely to have routine testing?

Outcome: observed for persons with particular support needs

Those supporting someone in the family home or own home compared with those supporting someone in a community group home or residential campus setting observed:

Similar odds of increased challenging behaviour (64%-60%)

Similar odds of increased seizures (19%-15%)

Similar odds of sleep problems (42%-36%)

We found no differences in these observations across settings

Outcome: experiences of Covid for supported persons

People with ID supported in the family home or own home compared with people supported in a community group home or residential campus setting are:

less likely to be tested for Covid (19.7%-44.5%)

less likely to be observed to experience symptoms (12.8% - 30.8%)

less likely to be diagnosed (15.5% - 26.6%)

Suspect differential awareness and access to testing & diagnosis

Practices during Covid

2.6x less likely to observe an increase in the use of physical restraint during the pandemic

Physical restraints is defined as any manual method or physical or mechanical devise, material or equipment attached or adjacent to the person's body that the individual cannot easily remove that restricts freedom of movement or normal access to one's body

Practices during Covid

3.4x less likely to observe an increase in the use of environmental restraint during the pandemic

Environmental restraint is defined as intentional restriction of a person’s normal access to their environment, with the intention of stopping them from leaving, or denying a person their normal means of independent mobility, means of communication or intentional taking away of ability to exercise civil and religious liberties.

Issues for consideration

Considerable focus on older persons in congregated settings during COVID-19 – ID not acknowledged.

Observed behaviours indicating distress, including behaviours that challenge and seizure activity.

Family members impacted via employment and finances.

Reliance on new casual staff may be across multiple settings.

Testing and diagnostic practices in service settings not matched in family homes.

Some broader questions

What needs to happen to address issues of wellbeing?

What supports could be provided?

How do we respond to reduction in behaviours and seizures?

How do we respond to the exclusion of people in RCT for vaccines?

How do we ensure people with intellectual and developmental disabilities are identifiable in population-based monitoring systems?

Continuation of research

Exploring the lived experiences of adults with intellectual disabilities during the COVID-19 pandemic in Ireland

Sadhbh Ni Chuanachain, Louise Farrelly, Christine Linehan

Interviews with 14 Irish adults with ID about their experiences during COVID-19 pandemic.

Preliminary findings – paper under review

Theme	Quote
Boredom	*“No, I didn’t like it at all. It’s very boring, like the same things every day. Watching telly or just going for a walk . . . it’s been very hard on me.”*
Regulations at personal cost	*“Nobody enjoys having to wear masks every time they’re out, but it has to be done. I suppose it’s for the greater cause, they’re doing it for a reason and… it’s annoying, like.”*
Frustration at other flouting the rules	*“Selfish! They want to go on holidays, and they don’t care if anybody lives or dies.”*
Choice to vaccinate?	*“Ah, I didn’t want it at first. I was nervous with it. . . . In case you get sick with it, in case you get a virus with it.”*

International qualitative comparison

Irish team

26 interviews

- Michael Tully
- Eilis Rojack
- Aoife Fennelly
- Catherine Jackman
- Tracy Jones
- Karen Henderson
- Christine Linehan

Swedish team

34 interviews

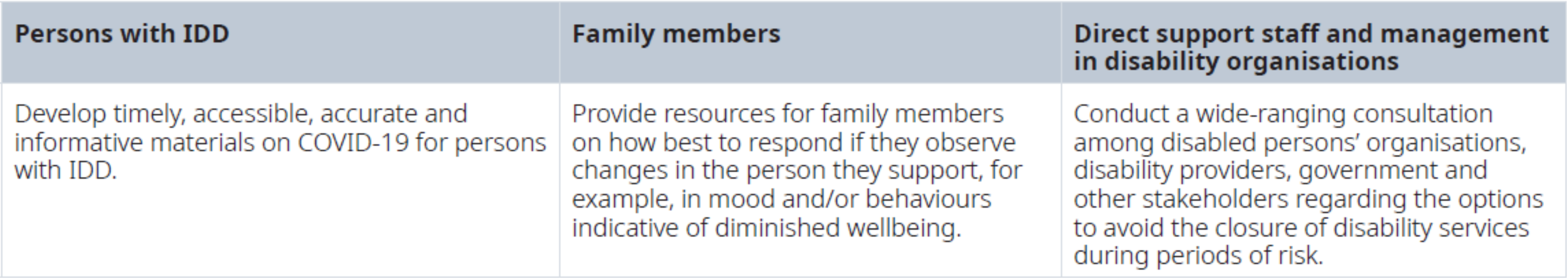
- Helena Taubner
- Jenny Aspling Fredriksson
- Magnus Tideman

International qualitative comparison

Two jurisdictions with very differing public policies to lockdown.

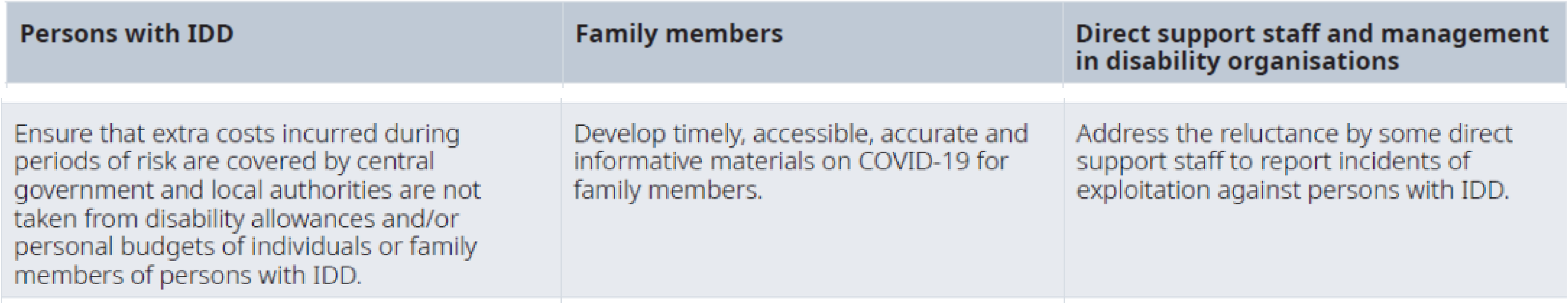
Did individuals with ID experience the pandemic differently?

Sample of recommendations



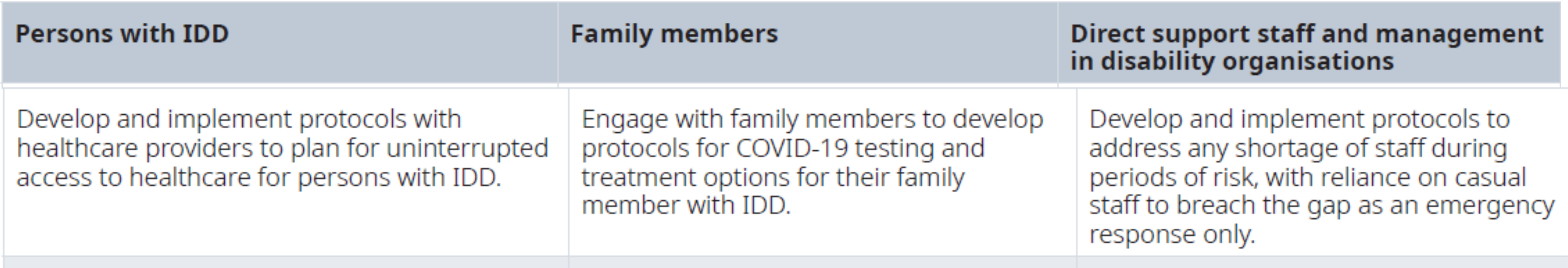
Persons with IDD	Family members	Direct support staff and management in disability organisations
Develop timely, accessible, accurate and informative materials on COVID-19 for persons with IDD.	Provide resources for family members on how best to respond if they observe changes in the person they support, for example, in mood and/or behaviours indicative of diminished wellbeing.	Conduct a wide-ranging consultation among disabled persons' organisations, disability providers, government and other stakeholders regarding the options to avoid the closure of disability services during periods of risk.

Sample of recommendations



Persons with IDD	Family members	Direct support staff and management in disability organisations
Ensure that extra costs incurred during periods of risk are covered by central government and local authorities are not taken from disability allowances and/or personal budgets of individuals or family members of persons with IDD.	Develop timely, accessible, accurate and informative materials on COVID-19 for family members.	Address the reluctance by some direct support staff to report incidents of exploitation against persons with IDD.

Sample of recommendations



Persons with IDD	Family members	Direct support staff and management in disability organisations
Develop and implement protocols with healthcare providers to plan for uninterrupted access to healthcare for persons with IDD.	Engage with family members to develop protocols for COVID-19 testing and treatment options for their family member with IDD.	Develop and implement protocols to address any shortage of staff during periods of risk, with reliance on casual staff to breach the gap as an emergency response only.

Thank you

To all our participants and partners

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for Disability Studies

UCD School of Psychology