

Supplementary Report 03: Differences in pandemic anxiety, parent/carer stressors and reported needs between parent/carers of children with and without ASD; Change over time in mental health for children with ASD.

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The Co-SPACE Study

Background

COVID-19 has caused major disruptions to families' lives, through social distancing, school closures and lock-down. This is also a rapidly changing situation where different pressures will arise for children, young people and their families over time. While research has provided valuable information about how parents can support their children's mental health in general, we know little about what is most effective in the current, changing context.

The Co-SPACE project is tracking the mental health of school-aged children and young people aged 4-16 years throughout the COVID-19 crisis. An online survey is sent out and completed on a monthly basis by parents/carers and young people (if aged 11-16 years) throughout the pandemic. The study has full ethical and data protection approval (ethical approval ref: R69060) and is fully GDPR compliant.

The findings will help identify what protects children and young people from deteriorating mental health over time, and at particular stress points. Findings will be shared directly with health and education services to inform the development and provision of effective support for children and families.

Recruitment & Sample

The study sample has been recruited through a variety of means, including social media, distribution through partner organisations, networks and charities, the media and targeted online advertising. The self-selecting nature of recruitment means that *this will not be a nationally representative sample*. In the current report, 92.6% of all participants who completed the questionnaire at baseline were female, presumably mothers. Furthermore, the majority of the baseline sample was employed, either part-time (35.9%) or full-time (36.9%), had an average income of >£30,000 (72.8%), and were white British (93.3%).

For the long-term, we are aiming to have good representation across a wide range of socio-demographic and health factors (e.g., income, ethnicity, pre-existing mental/physical health difficulties) to investigate the experiences for different groups that may be particularly vulnerable during and after the pandemic.

We are keen to recruit as many families as possible to the study. Parents/carers can sign up and take part at any point: <https://cospaceoxford.com/survey>

Further information

For further information or to request specific analyses, please contact the research team at co-space@psy.ox.ac.uk

Focus of this report

Participants

To date, over 10,000 parents/carers and 1,000 adolescents have taken part in the Co-SPACE survey at baseline. Over 3,000 parents/carers and 600 adolescents have taken part in the first follow up survey so far and we continue to collect data at baseline and on a monthly basis.

Just under half of the participants who completed the baseline survey within the time window that we are currently looking at completed the survey again at follow up and completed all items on the measure reported here (Strengths and Difficulties Questionnaire; SDQ).

Parents/carers of children with ASD who completed the measure at follow up were more likely than those who did not to be working part time (and less likely to be working full-time), have a higher than average household income, and be a parent of a primary school aged child, a child with special educational needs (SEN). and without pre-existing mental health difficulties. Further information about participants' characteristics at baseline and follow up can be found at the end of the report.

Data analysed

This report provides data from 7,227 parents/carers who took part in the baseline questionnaire. Of these, 671 parents/carers had a child with ASD. Longitudinal data is also presented from 332 parents/carers of children with ASD who have so far taken part in the baseline questionnaire and the first follow up questionnaire. These participants completed¹ the baseline questionnaire between 30/03/2020 and 01/06/2020. Each participant completed the follow up questionnaire approximately one month after having completed their baseline questionnaires.

In this report, we examined differences between parents/carers of children with and without ASD, as well as changes in mental health for parents/carers of children with ASD.

This was examined for the following areas:

1. Parent/carer reported pandemic anxiety
2. Parent/carer reported needs
3. Parent/carer reported ability to meet the needs of work and childcare
4. Parent/carer reported stressors
5. Change in parent/carer reported child emotional, behavioural and restless/attentional difficulties

¹ 'Completion' of the baseline survey is based on participants having completed items up to the pre-defined main outcome measure (the Strengths and Difficulties Questionnaire – parent reporting on child).

Measurement of difficulties

This report uses the Strengths & Difficulties Questionnaire (SDQ) to measure emotional, behavioural and restless/attentional difficulties. This is a well validated questionnaire with excellent psychometric properties and there are versions for parents/carers and young people aged 11 and above to complete themselves.

- **Emotional difficulties (emotional symptoms subscale):** items relate to the child being worried, afraid, unhappy, clingy and having physical symptoms of anxiety (e.g. whether the child is “Often unhappy, down-hearted or tearful”, or has “many worries, often seems worried”).
- **Behavioural difficulties (conduct problems subscale):** items relate to the child doing what they are asked, having tantrums, fighting, lying or stealing things (e.g. whether the child “often lies, or cheats”, or is “generally obedient, usually does what adults request”).
- **Restless/attentional difficulties (hyperactivity/inattention subscale):** items relate to the child being restless, fidgety, distractible, impulsive and having a good attention span (e.g. whether the child “sees tasks through to the end, good attention span”, or is “restless, overactive, cannot stay still for long”).

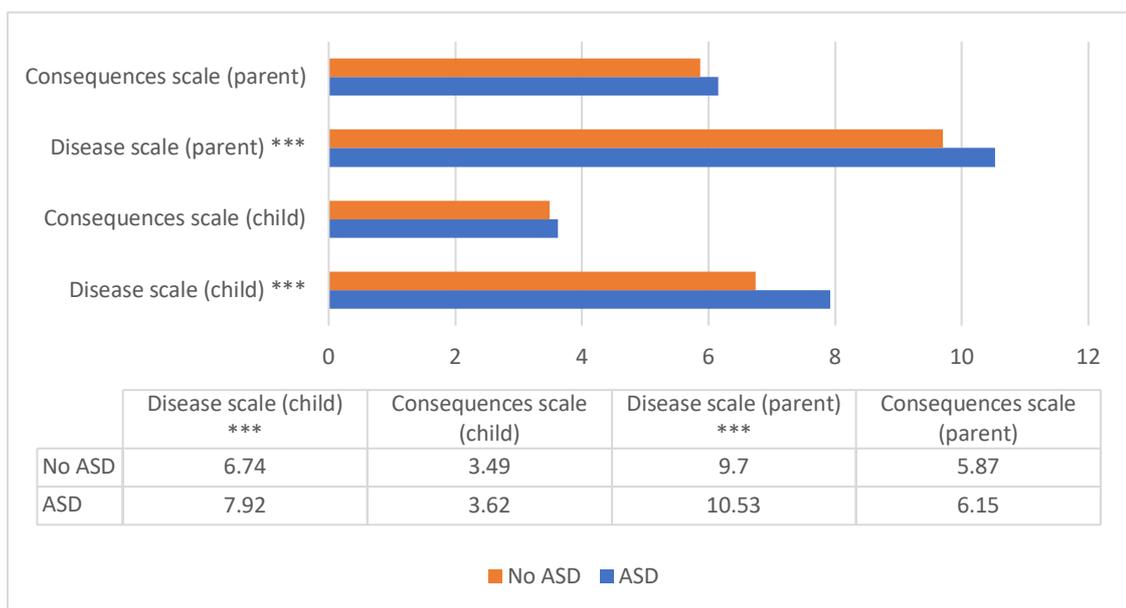
Each subscale consists of 5 items, are summed to compute a total score, with a maximum of 10 indicating the most severe difficulties.

The report also uses the Pandemic Anxiety Scale to measure COVID-19 concerns. This scale consists of a “disease” subscale (e.g. “I am/my child is worried that I/they will catch COVID-19”) consisting of 4 items, and “consequence” subscale (e.g. “I am/my child is worried about missing work/school”) consisting of 3 items. The items are scored on a 4-point scale from “not at all” to “extremely” and items are totalled to create the subscales. The questionnaire is validated with excellent psychometric properties and there are versions for parent/carer’s to report on their child’s and their own anxiety.

Key findings

1. Parent/carer reported parent and child pandemic anxiety

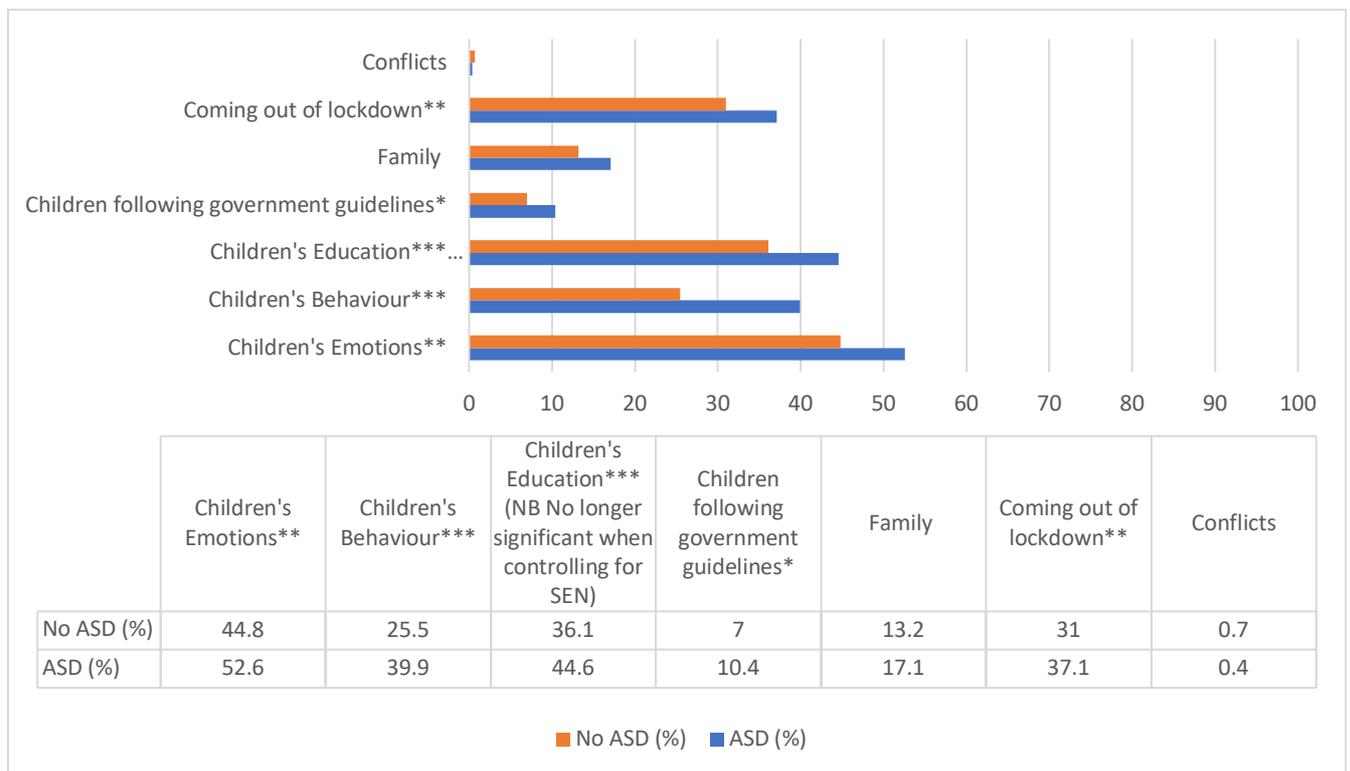
Figure 1. Pandemic Anxiety Scale score (***) $p < 0.001$.



2. Parent/carer reported needs

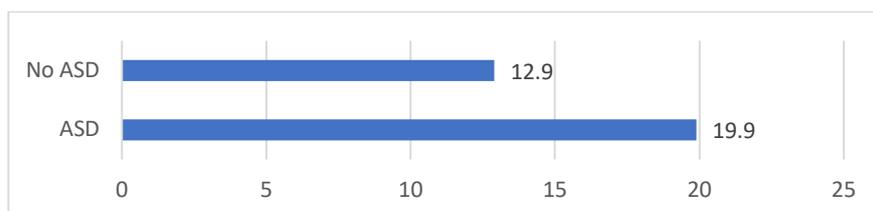
Figure 2. % of parent/carer reporting needing support in particular areas.

(*** p < 0.001, ** p < 0.01, *p < 0.05)



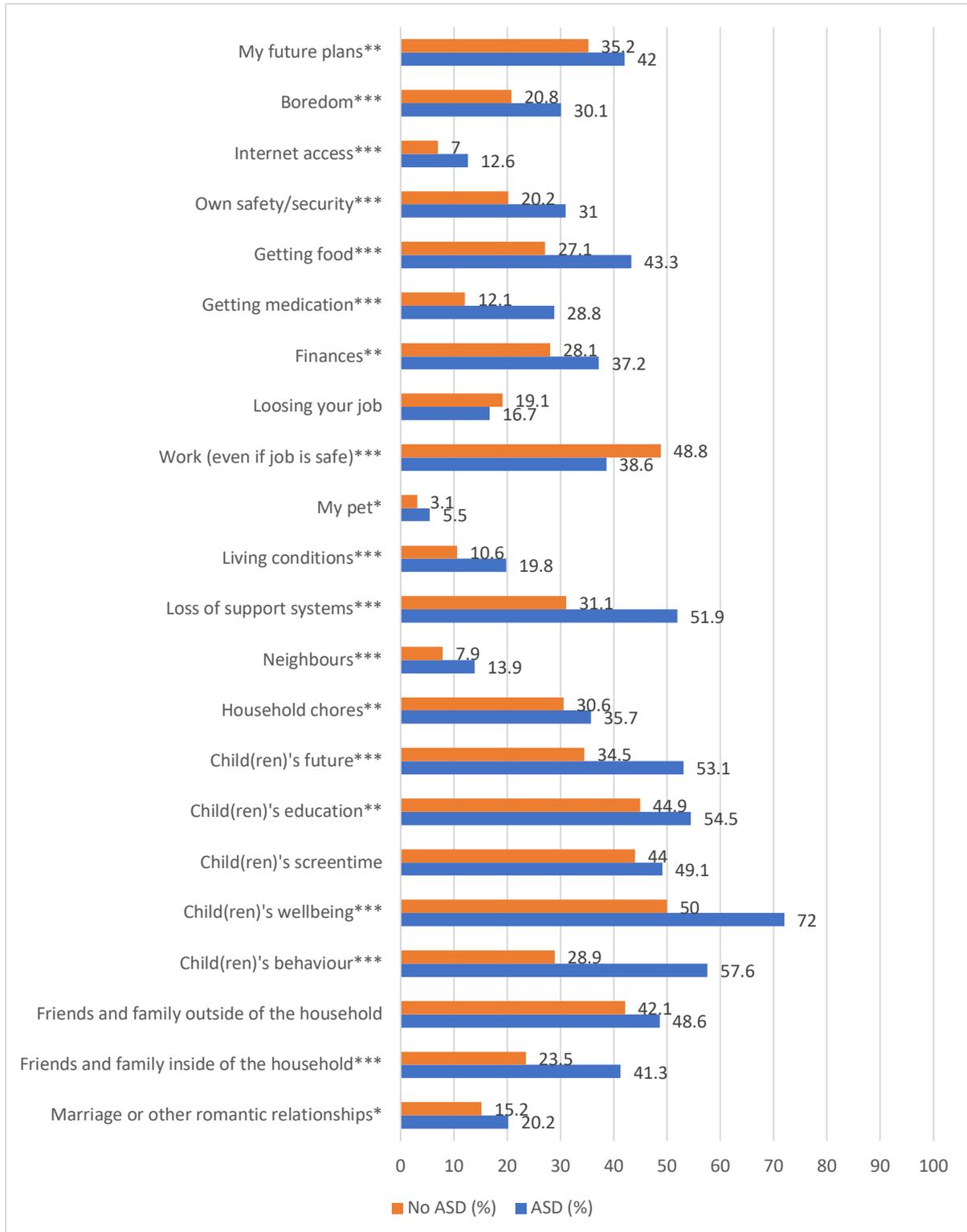
3. Parent/carer reported ability to meet the needs of work and childcare.

Figure 3. % of parent/carer's reporting that they are "not at all" able to meet the needs of both work and childcare



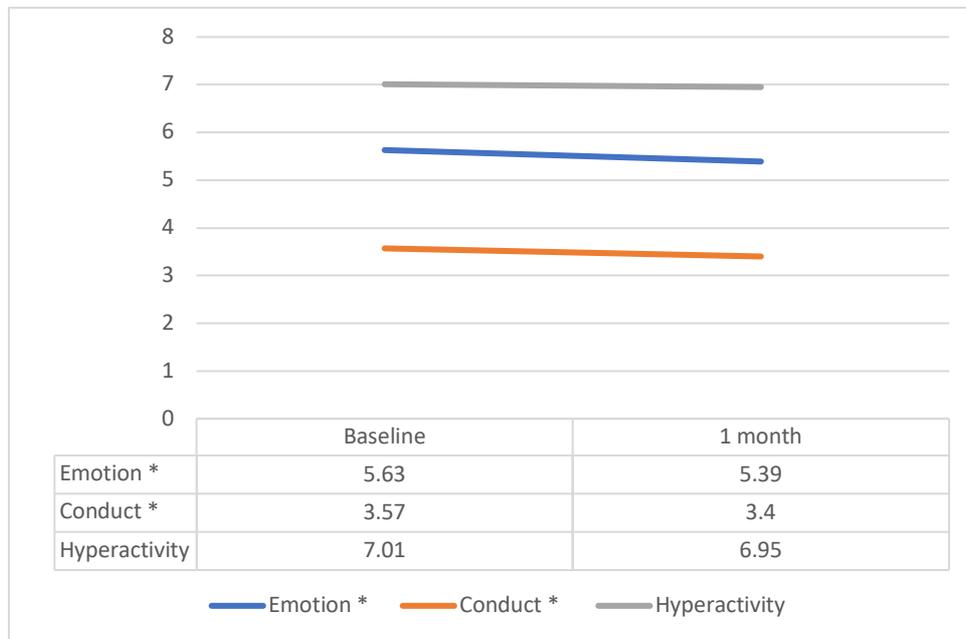
4. Parent/carer reported stressors

Figure 4. % of parent/carer's reporting that they are stressed about several areas either "Quite a lot" or "A great deal". (***) $p < 0.001$, ** $p < 0.01$, * $p < 0.05$)



4. Change in parent/carer reported child mental health

Figure 5. Mean parent/carer reported emotional, behavioural and restless/attentional difficulties. (** $p < 0.001$, ** $p < 0.01$, * $p < 0.05$)



Appendix A

Participants' demographics (Whole sample)

		Baseline (ASD)		Baseline (no ASD)		Follow up 1 (ASD)		Did not do follow up 1 (ASD)		National Figures (%)*
		n	%	n	%	n	%	n	%	
Parent Gender	Female	636	94.8	6055	92.4	317	95.5	319	94.1	51
	Male	31	4.6	469	7.2	13	3.9	18	5.3	49
	Other/Prefer not to say	4	0.6	32	0.5	2	0.6	2	0.6	-
6										
Employment status	Not working	226	35	946	14.4	116	34.9	120	35.4	3.8
	Working full time	178	26.5	2487	37.9	73	22	105	31.0	50.7
	Working part time	188	28	2406	36.7	106	31.9	82	24.2	16.9
	Self employed	69	10.3	717	10.9	37	11.1	32	9.4	8.5
6										
Household income	< £30,000	249	37.1	1190	18.2	118	35.5	131	38.6	58
	> £30,000	376	56	4888	74.6	195	58.7	181	53.4	42
	Prefer not to say	46	6.9	478	7.3	19	5.7	27	8.0	-
6										
Child Gender	Female	200	29.8	3279	50	104	31.3	96	28.3	52
	Male	455	67.8	3245	49.5	216	65.1	239	70.5	48
	Prefer not to say	16	2.4	32	0.5	12	3.6	4	1.2	-

Child age group	Child (4-10)	345	51.4	4281	65.3	171	51.5	165	48.7	55
	Adolescent (11-16)	326	48.6	2275	34.7	161	48.5	174	51.3	45
Mental health conditions	Any MH	270	40.2	413	6.3	122	36.7	148	43.7	12.8
	Depression	18	2.7	40	0.6	11	3.3	7	2.1	2.1
	Anxiety	122	18.2	203	3.1	55	16.6	67	19.8	7.2
	Other	43	6.4	94	1.4	15	4.5	28	8.3	-
	ADHD	165	24.6	173	2.6	78	23.5	87	25.7	3-5
SEN	Any SEN	631	94	576	8.8	315	94.9	316	93.2	14.7
	Social/emotional	537	80	265	4	264	79.5	273	80.5	2.1
	Communication/interaction	452	67.4	147	2.2	229	69	316	93.2	2,7
	Cognitive/learning	271	40.4	324	4.9	134	40.4	223	65.8	4.4
	Sensory/physical	379	56.5	172	2.6	184	55.4	195	57.5	0.6
Ethnicity	Asian/Asian British - Indian, Pakistani, Bangladeshi, other	4	0.6	135	2.1	1	0.3	3	0.9	6.8
	Black/Black British - Caribbean, African, other	4	0.6	34	0.5	3	0.9	1	0.3	3.3
	Chinese/Chinese British	1	0.1	12	0.2	0	0	1	0.3	0.7
	Middle Eastern/Middle Eastern British - Arab, Turkish, other	2	0.3	31	0.5	2	0.6	0	0	0.4

	Mixed race - other	13	1.9	89	1.4	6	1.8	7	2.1	11
	Mixed race - White and Black/Black British	2	0.3	38	0.6	1	0.3	1	0.3	1
	Other ethnic group	3	0.4	43	0.7	1	0.3	2	0.6	0.5
	Prefer not to say	8	1.2	64	1	2	0.6	6	1.8	-
	White - British, Irish, other	634	94.5	6110	93.2	316	95.2	318	93.8	86

*This data was extracted from the following sources on 12/05/2020:

<https://digital.nhs.uk/data-and-information/publications/statistical/mental-health-of-children-and-young-people-in-england/2017/2017>

<https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/z1zippedpopulationprojectionsdatafilesuk>

<https://www.ons.gov.uk/employmentandlabourmarket/peopleinwork/employmentandemployeetypes/bulletins/employmentintheuk/september2019#:~:text=Main%20points%20for%20May%20to%20July%202019,and%20unchanged%20on%20the%20quarter.>

<https://www.ons.gov.uk/peoplepopulationandcommunity/personalandhouseholdfinances/incomeandwealth/bulletins/householddisposableincomeandinequality/yearending2018>

<https://www.gov.uk/government/collections/statistics-special-educational-needs-sen>

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/814244/SEN_2019_Text.docx.pdf

<https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/demographics/age-groups/latest#data-sources>