PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	COVID-19 health and social care access for autistic people: A European policy review
AUTHORS	Oakley, Bethany; Tillmann, Julian; Ruigrok, Amber; Baranger, Aurélie; Takow, Christian; Charman, Tony; Jones, Emily; Cusack, James; Doherty, Mary; Violland, Pierre; Wroczyńska, Agnieszka; Simonoff, Emily; Buitelaar, Jan; Gallagher, Louise; Murphy, Declan G. M.

VERSION 1 – REVIEW

REVIEWER	Eric Rubenstein Boston University, USA
REVIEW RETURNED	09-Oct-2020

GENERAL COMMENTS	The authors report on a critically important topic of health policy and outcomes for autistic people and people with intellectual disabilities in Europe. They discuss two different projects, one a review of national policies aimed at detecting and treating covid in people with autism and ID and a survey autistic people and their caretakers. Both projects are important and I see how they complement one another. i have only minor suggestions that would improve the flow of the paper and add more clarity to the interpretation. 1. Throughout, I was a bit confused because the order of presentation between the policy and survey went back and forth. I think it could read better if you discussed just policies, then went and discussed the survey. I think that makes sense because the survey is just autistic people, not ID alone, and does not really line up with the country-level policy analyses. 2. Could you discuss heterogeneity in policy across countries? You mention this as a limitation but I think it is something that can be explicitly discussed. 3. Throughout, I think it is important to be very clear about what the timeline was, since COVID has moved so quickly. For example, add dates to the policies in table 2. I see it in the supplement but I think it is worth including in the main table. 4. Please add more detail about the survey. How were participants recruited? How often did both caretakers and autistic respondents complete the survey (i.e. both reported on the same autistic person)? Why and how did you select the quotes you used? There does not seem to be a description of any formal qualitative analysis. 5. Can you report demographics from the survey? Age, ID status, date taken the survey. I think its also important to describe prevalence of autism and ID early in the paper to orient lay readers

	6. Discuss a move away from long-term care facilities toward community living as an approach to reduce burden. Again, great work and thank you for your important contribution.

REVIEWER	Yona Lunsky Centre for Addiction and Mental Health
REVIEW RETURNED	24-Oct-2020

GENERAL COMMENTS	This is a very extensive review from 15 countries in a designated time period, looking at policies in 3 topic areas, and also where possible combining findings from policy with descriptive data and relevant quotes from autistic people or family caregivers. It is of extreme importance at this time, and successfully combines some priority issues across a number of domains. It also seeks to include the autistic perspective in the design and writing of the study, in addition to the results themselves, which is quite important. Strengths of the manuscript include the conceptual framework and attempts to augment policy documents with survey data. Because responses to COVID keep evolving, another strength was maintaining the same time period by country. 1. One main challenge with the paper is its combination of people with ID and autistic people. The policies reviewed are typically broader than just autism, and some refer primarily to people with ID, who may also be autistic (e.g,. triage protocols and congregate care risks). Yet the survey data were focused only on those with autism. It is tricky to draw conclusions based on autism survey data without including data from survey respondents with ID without autism. I also wonder whether a broader paper on what needs to change for ID and not just autism should include ID experts and not be written by a team of experts in autism only. It may be that the paper should specify that it is about autism, but acknowledge when policies are broader than autism, but may include autism (including mentioning when autism itself is specifically mentioned). The discussion could therefore also include comment that these recommendations would also be quite relevant to ppl with ID without autism, and perhaps to other neurodevelopmental disabilities including CP, FASD. Another option is to maintain the broader policy focus on autism and ID and not present the survey data as a main part of results, just focusing on the policies. 2. The second main challenge is with the survey data itself. The distribution of responses is heavily weighted toward caregiver input. When looking at the table, it is clear that the distribution between caregiver and self report varies by country. This means that survey data are heavily weighted by country as well, and perhaps by whether the person has autism and ID. I think the descriptions of responses should provide a breakdown by caregiver or self report since most people self reporting do not have ID, and many with caregiver do have ID. The information on proportion of caregivers with loved ones with autism and ID should be available from autism Europe and at least described. It is also important to know where people live (given that many of the issues relate to congregate care) but I realize that this may not be available broken down by response. I think if survey data are to be included in the study, then further demographic details on this dataset are required in the methods section. Below I add some additional comments to the manuscript itself, point by point.

Introduction:
3. “These barriers include: communication difficulties, which can lead to misunderstandings by healthcare providers and reduced involvement of patients in healthcare decision making; sensory sensitivities (e.g. around physical examinations);”
I might add difficulties navigating or adjusting to new procedures, or interpreting information while masked, sensory sensitivities including difficulties with masks, and problems hearing information
4. "Health providers may also misattribute COVID-19 symptoms to existing medical, mental health or behavioural problems (‘diagnostic overshadowing’)"
diagnostic overshadowing may also relate to misattributing symptoms to symptoms of autism itself.
Method
5. Greater detail on survey respondents is required. The age of the people with caregivers is quite important and whether they also have ID would be helpful. I would like to see the table divided into caregiver and adult perspectives. It would also be helpful to know the breakdown by country.
Results
6. “As explicitly acknowledged in documentation released by several European regions reviewed in this study - including the UK, Netherlands and Belgium (26–28) - a large proportion of autistic people and those with ID meet criteria for priority COVID-19 testing”

Please clarify that this means that the documentation mentioned these groups as priority

7. “This was also reflected in AutismEurope survey responses, where 26·1% (N=327) of autistic people reported that they were considered to be at high risk from COVID-19 – slightly higher than average estimates for the general population (~22%; 27)”

Was this based just on the autistic ppl or including caregivers? Would be important to break down because caregivers more likely to be reporting on ID and autism
8. “Second, approximately 5-25% of autistic people live in residential care and up to a further 27% in supported accommodations”

These terms are interpreted differently by different places – in UK care homes include nursing homes and larger group homes. In Netherlands residential care refers to larger institutional settings. May not be clear to reader what supported accommodations refer to. Although one operational definition may not match each country, since we are talking about congregate care settings, it is important to try to describe to international readers.

9. “Despite evidence that autistic people and those with ID may be at increased risk of poor outcomes from COVID-19, our review indicated that these groups have not been routinely specified for priority access”

Be clear whether the evidence is that they may be at risk, or that policies have documented that they are at risk – count X of X policies acknowledged….
10. “Description of countries prioritizing residential care” – again, it is important to document when this occurred for settings with

	autistic people or people with ID. My sense is they did not always specify, and it may represent a minority of individuals 11. “However, we did not identify any additional published guidance, nor strategies for prioritising autistic people and those with ID living in ‘high risk’ settings for access to testing in case of shortages across the other regions reviewed in this study; and those living in supported accommodation and the community remain particularly overlooked.” I think this requires a bit more explanation – Maybe state that even in regions where residential care did prioritize, there was no direction for people in supported accommodations (btwn X and X autistic ppl in these settings) 12. “Tolerability of COVID-19 test procedures - In addition to difficulties accessing COVID-19 tests, the tolerability of test procedures for autistic people and those with ID must be considered. For example, sensory sensitivities are highly associated with autism (35,36) and COVID-19 diagnostic tests frequently involve nasal/ throat swabs or aspiration (37). Some test procedures also require travel to an unfamiliar location, which can present difficulties for some individuals around uncertainty and change in routine.” I would add that the tolerability of procedure in addition to requiring travel, and unfamiliar people, it also requires long waits and ppl donning PPE so can’t see them etc. And sometimes can’t have care person there. This is also described after with quotes. Again, I would split results with adults and caregivers, especially if some of the caregivers were reporting about children. (where parents are allowed to be present and accommodations are made. 13. With regard to unique treatment pathways, it would be important to clarify whether these were in hospitals in a specialized unit or whether they were within institutional settings for people with ID/autism, or in newly created places, or whether pathway simply refers to new processes within general hospitals. Suggestion that this may be good, but is there the same access to COVID specialists in these alternate pathways? In the UK there was NHS based guidance immediately advising for different treatment (e.g, caregiver allowed) in standard services. I do not see this discussed in results. 14. With regard to restrictions in services, important to acknowledge cancelation of programming and support. In Canada, the closures were not simply financial, but also for safety reasons. This was the same in other countries where due to lockdown etc, programs were closed. 15. In the section describing visit restrictions, It may not be the case that providing virtual options is sufficient. For many people who are autistic or have ID, this was not an appropriate option. That said, people are learning skills in this regard. So reports from an early survey may shift over time. 16. I would separate the discussion on easy to understand documentation from the discussion on ease of family visits. Otherwise, it is not clear whether the need for easy to understand documentation is specific to family visits or a broader statement? 17. Easement of documentation – was there no evidence anywhere else besides UK of reductions in documentation? Was this looked for explicitly? Or just a comment based on what is known? If it was not looked for, I would not include it as a result, for only one country.

	Discussion 18. In recommendations, was flexibility in allowing a carer to be present while hospitalized for someone with ID or autism reviewed explicitly? This has always been the case in UK. Important to note that while may be the policy, may not always happen that way. 19. Concern about referring to telehealth in regard to daily support services in the social care domain. The research on provision of telehealth for acute care visits or diagnostic services is very different than for use of any type of support, for which there is less research, and for which in person services may be more needed (and for longer duration).

REVIEWER	Eric Emerson Lancaster University, UK University of Sydney, Australia Flinders University, Australia
REVIEW RETURNED	09-Dec-2020

GENERAL COMMENTS	While this paper addresses an important issue, I consider it would require significant revisions before it could be considered of a publishable standard. My main concerns are listed below. 1. This is clearly an initiative that is primarily focused on autism (e.g., the survey data are solely on autism). Given this, it is very unclear why much of the text refers to people with autism or ID. I think it would be much clearer to focus solely on autism and possibly raise the intersection between autism and ID in the Discussion section. 2. Please give much more information on the survey sampling strategy, mode of implementation and estimated response rates. I suspect that the survey has some limitations, but none are mentioned in the Discussion section. 3. Given the small numbers responding to many of the survey questions, I would suggest reporting percentages as integers. In addition, all percentages should be reported with 95% confidence intervals. 4. A comparison is made between the percentage of survey respondents considered to be at high risk from COVID-19 and the general population. The statistical significance of the difference between these two estimates should be presented. 5. The Discussion and recommendations seem to go way beyond the data presented (from the policy review and survey). I some ways this feels more like a commentary than an empirical paper. 6. The MS could be considered over-referenced. Are 118 references really necessary?

VERSION 1 – AUTHOR RESPONSE

Reviewer: 1

We wish to take this opportunity to thank the reviewer for their careful consideration of our work and recognition of this topic as critically important for improving health policy and outcomes for autistic people, including those with intellectual disabilities.

Reviewer comments (with responses):

1. Throughout, I was a bit confused because the order of presentation between the policy and survey went back and forth. I think it could read better if you discussed just policies, then went and discussed the survey. I think that makes sense because the survey is just autistic people, not ID alone, and does not really line up with the country-level policy analyses.

We agree with the reviewer's suggestion and have therefore completely restructured the Results section to first detail policy review findings and second results from the Autism-Europe survey, which we believe has provided greater clarity and flow to the manuscript (please see Pages 11-24).

2. Could you discuss heterogeneity in policy across countries? You mention this as a limitation but I think it is something that can be explicitly discussed.

We agree with the reviewer that heterogeneity in policy across countries is a relevant factor, as detailed in our Limitations section where we highlight that there were regional differences both within and between countries, also reflecting the fast evolving situation and differences in the impact of COVID-19 across Europe in terms of both overall and severe cases (please see Page 35, Paragraph 1). However, we chose not to discuss heterogeneity of policy documentation across countries in the main Discussion because the wide variation in health and social care systems and their structure across European countries means that direct comparison is very challenging – as noted on Page 35, Paragraph 2.

One exception to this is that, considering the reviewer's recommendation and highlighting heterogeneity, we have added context to our discussion of ICU triage protocols that 8 out of the 14 European regions reviewed included guidance for reducing discrimination against those with neurodevelopmental/ physical disabilities (please see 30, Paragraph 2). We therefore recommend an aligned European strategy for incorporating such guidance across the board (and in other aspects of health and social care planning) to reduce inequalities in public health emergencies (please see Page 36, Paragraph 2).

3. Throughout, I think it is important to be very clear about what the timeline was, since COVID has moved so quickly. For example, add dates to the policies in table 2. I see it in the supplement but I think it is worth including in the main table.

To specify the timeline for the reader throughout, we have followed the reviewer's suggestion by including the pre-specified date range for the policy review (March-July 2020) in the first subheading of the Results section on Page 11 and by adding publication dates to Table 2.

4. Please add more detail about the survey. How were participants recruited? How often did both caretakers and autistic respondents complete the survey (i.e. both reported on the same autistic person)? Why and how did you select the quotes you used? There does not seem to be a description of any formal qualitative analysis.

As recommended by the reviewer, we now include additional details regarding the Autism-Europe survey on Page 11, Paragraph 2, where we specify that participants were recruited via Autism-Europe, UK autism charities and social media to complete the publicly available online survey, which resulted in a convenience sample. We also confirm that anonymised quotations were included for illustrative purposes, rather than as part of a formal qualitative analysis. For the reviewer, a list of anonymised quotations with permissions to be included in a publication were sent by Autism-Europe and the authors selected those that provided depth of explanation in relation to the policy and quantitative survey findings reported in the manuscript.

5. Can you report demographics from the survey? Age, ID status, date taken the survey. I think its also important to describe prevalence of autism and ID early in the paper to orient lay readers.

We agree with the reviewer that more detailed survey demographics would be beneficial for further contextualising the results presented. Therefore, we have updated Supplementary Table 1 to more clearly specify the number of respondents (both autistic person and caregiver), age ranges and gender, split by country. Due to the nature and design of the Autism-Europe survey, we were unable to present additional demographic information about respondents (for example, it was not possible to note how many respondents provided both self- and caregiver- report, due to the fully anonymised nature of the survey data). However we further detail on Page 11, Paragraph 2 that all responses were provided between April 7th and May 31st 2020; and add this information also to the title for Supplementary Table 1.

Further, and as per the reviewer's suggestion, we now state in the Introduction that the estimated prevalence of autism is approximately 1%, with up to 32% of autistic people having a co-occurring intellectual disability (please see Page 6, Paragraph 2).

6. Discuss a move away from long-term care facilities toward community living as an approach to reduce burden.

We thank the reviewer for this suggestion and have consequently added the shift to more community-based services both in our Recommendation #4 (Page 28) and section on enhancing access to existing health and social care services (Page 33, Paragraph 3).

Reviewer: 2

We thank the reviewer sincerely for their time and close consideration of our work – and all of the valuable comments and suggestions that we believe have enabled us to greatly improve our manuscript.

Reviewer comments (with responses):

1. One main challenge with the paper is its combination of people with ID and autistic people. The policies reviewed are typically broader than just autism, and some refer primarily to people with ID, who may also be autistic (e.g,. triage protocols and congregate care risks). Yet the survey data were focused only on those with autism. It is tricky to draw conclusions based on autism survey data without including data from survey respondents with ID without autism. I also wonder whether a broader paper on what needs to change for ID and not just autism should include ID experts and not be written by a team of experts in autism only. It may be that the paper should specify that it is about autism, but acknowledge when policies are broader than autism, but may include autism (including mentioning when autism itself is specifically mentioned). The discussion could therefore also include comment that these recommendations would also be quite relevant to ppl with ID without autism, and perhaps to other neurodevelopmental disabilities including CP, FASD. Another option is to maintain the broader policy focus on autism and ID and not present the survey data as a main part of results, just focusing on the policies.

We agree with the reviewer that the manuscript would be significantly strengthened by explicitly specifying that its focus in on autism. Therefore, we have adjusted the text throughout to reflect this. We also explicitly note where results refer specifically to those with autism and ID, which further highlights the stark lack of policy documentation available to suggest strategies for promoting accessibility of COVID-19 services for autistic people without ID, many of whom still experience significant barriers in terms of equitable access to health and social care resources.

This issue is also now further detailed in the Discussion (please see Page 28, Paragraph 2 and Page 29, Paragraph 1), where we also comment that our recommendations are relevant also for those with ID but not autism, as well as other neurodevelopmental and also physical disabilities (please see Page 31, Paragraph 5) – following the reviewer's suggestion.

2. The second main challenge is with the survey data itself. The distribution of responses is heavily weighted toward caregiver input. When looking at the table, it is clear that the distribution between caregiver and self report varies by country. This means that survey data are heavily weighted by country as well, and perhaps by whether the person has autism and ID. I think the descriptions of responses should provide a breakdown by caregiver or self report since most people self reporting do not have ID, and many with caregiver do have ID. The information on proportion of caregivers with loved ones with autism and ID should be available from autism Europe and at least described. It is also important to know where people live (given that many of the issues relate to congregate care) but I realize that this may not be available broken down by response. I think if survey data are to be included in the study, then further demographic details on this dataset are required in the methods section.

We thank the reviewer for this valuable suggestion for strengthening our manuscript. Firstly, we have updated Supplementary Table 1 to more clearly specify the number of respondents (both autistic person and caregiver), age ranges and gender, split by country. Due to the nature and design of the Autism-Europe survey, we were unable to present additional demographic information about respondents. For example, it was not possible to note how many respondents provided both self- and caregiver- report due to the fully anonymised nature of the survey data; and disclosing specific regions within a country where responses were provided may pose a risk for anonymisation.

However, following the reviewer's recommendation, we now break the results displayed in Table 2 down by informant to be transparent for the reader. We do not break results down by informant in the main text to enhance the flow and readability of the manuscript. Nevertheless, we do note in the limitations (please see Page 36, Paragraph 2) that it was not possible to determine the proportion of Autism-Europe survey respondents with/ without co-occurring ID – though, while it is likely that the majority of self-informants did not have co-occurring ID, it cannot necessarily be presumed that caregiver-informants were weighted toward those with co-occurring ID.

Introduction:

3. "These barriers include: communication difficulties, which can lead to misunderstandings by healthcare providers and reduced involvement of patients in healthcare decision making; sensory sensitivities (e.g. around physical examinations);"
   I might add difficulties navigating or adjusting to new procedures, or interpreting information while masked, sensory sensitivities including difficulties with masks, and problems hearing information.

We agree with the reviewer and have updated this paragraph to specify that: communication/ interpretation difficulties may be exacerbated by mask wearing, as it reduced the availability of non-verbal facial cues during interaction; that difficulties adjusting to change and novel procedures are also a difficulty experienced by some autistic people when accessing health services; and that mask wearing may be an additional sensory sensitivity that poses a challenge for accessing services (e.g. where mask wearing is a mandatory requirement; please see Page 7, Paragraph 1).

4. "Health providers may also misattribute COVID-19 symptoms to existing medical, mental health or behavioural problems ('diagnostic overshadowing')"
   diagnostic overshadowing may also relate to misattributing symptoms to symptoms of autism itself.

This is a crucial point and we now reflect that diagnostic overshadowing often also relates to misattribution of symptoms to autism itself on Page 7, Paragraph 1.

Method

5. Greater detail on survey respondents is required. The age of the people with caregivers is quite important and whether they also have ID would be helpful. I would like to see the table divided into caregiver and adult perspectives. It would also be helpful to know the breakdown by country.

We agree with the reviewer that more detailed survey demographics would be beneficial for further contextualising the results presented. Therefore, we have updated Supplementary Table 1 to more clearly specify the number of respondents (both autistic person and caregiver), age ranges and gender, split by country. Due to the nature and design of the Autism-Europe survey, we were unable to present additional demographic information. However we further detail on Page 11, Paragraph 2 that all responses were provided between April 7th and May 31st 2020; and add this information also to the title for Supplementary Table 1. Lastly, we now break the results displayed in Table 2 down by informant to be transparent for the reader.

Results

6. "As explicitly acknowledged in documentation released by several European regions reviewed in this study - including the UK, Netherlands and Belgium (26–28) - a large proportion of autistic people and those with ID meet criteria for priority COVID-19 testing"

   Please clarify that this means that the documentation mentioned these groups as priority.

We apologise for the lack of clarity in this section and have now updated the sentence to specify that these groups were not mentioned as a priority for access to testing, however factors such as physical comorbidity and living in residential care were explicitly noted for prioritisation of testing and these issues are highly relevant for a high proportion of autistic people (please see Page 12, Paragraph 1).

Furthermore, in the Discussion we now explicitly detail why autism should be specified in policy documentation (please see Page 28, Paragraph 2) – with the major issue being that, although not every autistic person will have physical comorbidities/ be living in high risk settings (i.e. residential care), the additional barriers for tolerating testing/ screening, identifying symptoms and providing treatment services experienced by many autistic people (e.g. issues like atypical symptom presentation, diagnostic overshadowing, undiagnosed comorbidities, communication differences – as also noted in the Introduction) require close additional clinical consideration to ensure that these individuals receive equal access to high quality health and social care services.

7. "This was also reflected in AutismEurope survey responses, where 26·1% (N=327) of autistic people reported that they were considered to be at high risk from COVID-19 – slightly higher than average estimates for the general population (~22%; 27)"

   Was this based just on the autistic ppl or including caregivers? Would be important to break down because caregivers more likely to be reporting on ID and autism.

Following the reviewer's recommendation, we now break the results displayed in Table 2 down by informant to be transparent for the reader. We do not break results down by informant in the main text to enhance the flow and readability of the manuscript. Nevertheless, we do note in the limitations (please see Page 36, Paragraph 2) that it was not possible to determine the proportion of Autism-Europe survey respondents with/ without co-occurring ID – though, while it is likely that the majority of self-informants did not have co-occurring ID, it cannot necessarily be presumed that caregiver-informants were weighted toward those with co-occurring ID.

8. “Second, approximately 5-25% of autistic people live in residential care and up to a further 27% in supported accommodations”

   These terms are interpreted differently by different places – in UK care homes include nursing homes and larger group homes. In Netherlands residential care refers to larger institutional settings. May not be clear to reader what supported accommodations refer to. Although one operational definition may not match each country, since we are talking about congregate care settings, it is important to try to describe to international readers.

We thank the reviewer for raising this point and have provided examples for clarification for international audiences that we refer to residential care in the sense of long-term/ high intensity nursing/ large group homes and supported accommodation as lower intensity congregate care dwellings in the community (please see Page 12, Paragraph 2).

9. “Despite evidence that autistic people and those with ID may be at increased risk of poor outcomes from COVID-19, our review indicated that these groups have not been routinely specified for priority access”

   Be clear whether the evidence is that they may be at risk, or that policies have documented that they are at risk – count X of X policies acknowledged….

We clarify that existing evidence suggests that autistic people may be at elevated risk of poor outcomes from COVID-19, yet no policies reviewed specifically documented strategies for identifying/ screening symptoms in autistic people. The Netherlands were the only region to directly specify individuals with “serious behavioural problems in residential care” for priority testing (please see Page 13, Paragraph 1).

10. “Description of countries prioritizing residential care” – again, it is important to document when this occurred for settings with autistic people or people with ID. My sense is they did not always specify, and it may represent a minority of individuals.

We agree with the reviewer that this is a necessary detail and now note that the Netherlands were the only region to directly specify individuals with “serious behavioural problems in residential care” for priority testing (please see Page 13, Paragraph 1).

11. “However, we did not identify any additional published guidance, nor strategies for prioritising autistic people and those with ID living in ‘high risk’ settings for access to testing in case of shortages across the other regions reviewed in this study; and those living in supported accommodation and the community remain particularly overlooked.”
    I think this requires a bit more explanation – Maybe state that even in regions where residential care did prioritize, there was no direction for people in supported accommodations (btwn X and X autistic ppl in these settings).

We agree with the reviewer and have updated the opening sentences of this paragraph accordingly (please see Page 13, Paragraph 2).

12. “Tolerability of COVID-19 test procedures - In addition to difficulties accessing COVID-19 tests, the tolerability of test procedures for autistic people and those with ID must be considered. For example, sensory sensitivities are highly associated with autism (35,36) and COVID-19 diagnostic tests frequently involve nasal/ throat swabs or aspiration (37). Some test procedures also require travel to an unfamiliar location, which can present difficulties for some individuals around uncertainty and change in routine.”
    I would add that the tolerability of procedure in addition to requiring travel, and unfamiliar people, it also requires long waits and ppl donning PPE so can’t see them etc. And sometimes can’t have care person there. This is also described after with quotes. Again, I would split results with adults and caregivers, especially if some of the caregivers were

reporting about children. (where parents are allowed to be present and accommodations are made.

We thank the reviewer for this suggestion and have now added waiting times, the use of necessary PPE (as a potential sensory and communication barrier) and, in some cases, restrictions on being accompanied by a caregiver as additional accessibility issues with regard to COVID-19 testing for autistic people (please see Page 13, Paragraph 2).

As noted previously, we now break the Autism-Europe survey results displayed in Table 2 down by informant to be transparent for the reader.

13. With regard to unique treatment pathways, it would be important to clarify whether these were in hospitals in a specialized unit or whether they were within institutional settings for people with ID/autism, or in newly created places, or whether pathway simply refers to new processes within general hospitals. Suggestion that this may be good, but is there the same access to COVID specialists in these alternate pathways? In the UK there was NHS based guidance immediately advising for different treatment (e.g, caregiver allowed) in standard services. I do not see this discussed in results.

As per the reviewer's recommendation, we now clarify that this guidance refers to existing designated specialist neurodevelopmental/ neuropsychiatric pathways (which may be within hospitals or residential settings, depending on the severity of illness and regional service structure), rather than newly created processes/ places (please see Page 13, Paragraph 3). We agree with the reviewer that there are some benefits to this recommendation, including access to a greater range of specialist staff and resources, as outlined on Page 14, Paragraph 1). However, also in agreement with the reviewer, there are equally limitations to recommending care in some existing designated settings, where there may be shortages of staff with both medical/ surgical (including in relation to COVID) and psychiatric expertise and experience, greater challenges for controlling infection spread and reduced access to testing/ PPE – as detailed on Page 14, Paragraph 2.

We also reference in the Discussion that to support autistic people who develop severe COVID-19 symptoms in general hospital settings, it may be necessary to introduce flexibility to some regulations (where appropriate), such as allowing a caregiver or support person to accompany the individual into hospital, following all necessary infection control procedures (already in place in regions of the UK, Germany and the Netherlands, according to clinician reviews; please see Page 31, Point #4).

14. With regard to restrictions in services, important to acknowledge cancelation of programming and support. In Canada, the closures were not simply financial, but also for safety reasons. This was the same in other countries where due to lockdown etc, programs were closed.

We agree with the reviewer and have updated this paragraph to reflect that, while closure of many in-person services was an important and necessary safety precaution to prevent infection spread, a lack of appropriate mitigation measures in place has led to some services ceasing altogether, with an impact on autistic people and their caregivers (please see Page 21, Paragraph 1).

15. In the section describing visit restrictions, It may not be the case that providing virtual options is sufficient. For many people who are autistic or have ID, this was not an appropriate option. That said, people are learning skills in this regard. So reports from an early survey may shift over time.

Based on the reviewer's comment, we have added a line to this section noting that it should be acknowledge that virtual contact is not a sufficient/ appropriate option for all individuals (please see Page 22, Paragraph 1).

16. I would separate the discussion on easy to understand documentation from the discussion on ease of family visits. Otherwise, it is not clear whether the need for easy to understand documentation is specific to family visits or a broader statement?

Also following the suggestions of Reviewer 1, we have completely restructured the Results section to first detail policy review findings and second results from the Autism-Europe survey, which we believe has provided greater clarity and flow to the manuscript (please see Pages 11-24) and separates these two points out more clearly.

17. Easement of documentation – was there no evidence anywhere else besides UK of reductions in documentation? Was this looked for explicitly? Or just a comment based on what is known? If it was not looked for, I would not include it as a result, for only one country.

This evidence was explicitly looked for in the policy documentation from other European regions reviewed but evidence for care easements was not identified. Relatedly, one of the most important points noted in this section is the significant lack of reliable data gathered and published on community-based health and social care provision across Europe (noted on Page 22, Paragraph 2), which creates a significant challenge for reviewing the current situation. We explicitly raise this point again in the Discussion section, noting the significant need for high quality and reliable data to identify key areas for targeted restructuring and investment for improving health and social care provisions (please see Page 33, Paragraph 3).

Discussion

18. In recommendations, was flexibility in allowing a carer to be present while hospitalized for someone with ID or autism reviewed explicitly? This has always been the case in UK. Important to note that while may be the policy, may not always happen that way.

We agree with the reviewer and reference in the Discussion that to support autistic people who develop severe COVID-19 symptoms in general hospital settings, it may be necessary to introduce flexibility to some regulations (where appropriate), such as allowing a caregiver or support person to accompany the individual into hospital, following all necessary infection control procedures (already in place in regions of the UK, Germany and the Netherlands, according to clinician reviews); and that reasonable adjustments should be made to ensure this flexibility is made possible in real-world clinical settings (please see Page 31, Point #4).

19. Concern about referring to telehealth in regard to daily support services in the social care domain. The research on provision of telehealth for acute care visits or diagnostic services is very different than for use of any type of support, for which there is less research, and for which in person services may be more needed (and for longer duration).

To reflect this concern regarding the potential limitations of telehealth in providing health and social care services for some autistic people we have added a line to the opening of Page 33, Paragraph 2 emphasising the lack of research on the most effective/ appropriate methods for implementing telehealth services to ensure continuity of care and to identify which in-person services (particularly in the social care domain) are vs. are not conducive for remote implementation.

Reviewer: 3

We would like to express our appreciation for the reviewer's time and valuable suggestions regarding our work.

Reviewer comments (with responses):

1. This is clearly an initiative that is primarily focused on autism (e.g., the survey data are solely on autism). Given this, it is very unclear why much of the text refers to people with autism or

ID. I think it would be much clearer to focus solely on autism and possibly raise the intersection between autism and ID in the Discussion section.

We agree with the reviewer that the manuscript would be significantly strengthened by explicitly specifying that its focus in on autism, though around 32% of autistic people have a co-occurring ID. Therefore, we have adjusted the text throughout to reflect this. We also explicitly note where results refer specifically to those with autism and ID, which further highlights the stark lack of policy documentation available to suggest strategies for promoting accessibility of COVID-19 services for autistic people without ID, many of whom still experience significant barriers in terms of equitable access to health and social care resources.

This issue is also now further detailed in the Discussion (please see Page 28, Paragraph 2), where we also comment that our recommendations are relevant also for those with ID but not autism, as well as other neurodevelopmental and also physical disabilities (please see Page 31, Paragraph 5).

2. Please give much more information on the survey sampling strategy, mode of implementation and estimated response rates. I suspect that the survey has some limitations, but none are mentioned in the Discussion section.

As recommended by the reviewer, we now include additional details regarding the Autism-Europe survey on Page 11, Paragraph 2, where we specify that participants were recruited via Autism-Europe, UK autism charities and social media to complete the publicly available online survey, which resulted in a convenience sample. We have also updated Supplementary Table 1 to more clearly specify the number of respondents (both autistic person and caregiver), age ranges and gender, split by country.

We also now include an additional paragraph outlining the main limitations of the Autism-Europe survey data in the Discussion (please see Page 36, Paragraph 2).

3. Given the small numbers responding to many of the survey questions, I would suggest reporting percentages as integers. In addition, all percentages should be reported with 95% confidence intervals.

We agree with the reviewer and have converted all percentages to integers throughout (please see Pages 22-24 and Table 2).

4. A comparison is made between the percentage of survey respondents considered to be at high risk from COVID-19 and the general population. The statistical significance of the difference between these two estimates should be presented.

Given the large disparity between the number of survey respondents vs. data points in risk estimates in the general population, we have opted to remove the comparison and instead report only on the percentage of autistic people at high risk in the Autism-Europe survey.

5. The Discussion and recommendations seem to go way beyond the data presented (from the policy review and survey). I some ways this feels more like a commentary than an empirical paper.

We acknowledge in the Methods section (Page 8, Paragraph 2) and Supplementary Table 2 that in collating policies/ guidelines for review we included professional perspectives and commentary from clinical and autism experts from the AIMS-2-TRIALS Clinical Trials Network. We felt that this was an important step, as one of the key applied outcomes of this work is to inform future policy and clinical guidelines to enhance the accessibility of health and social care services for autistic people in public health emergencies, through a multi-disciplinary,

participatory collaboration, including autistic people, non-profit autism stakeholder organisations, clinical experts and researchers from across Europe and the rest of the world.

6. The MS could be considered over-referenced. Are 118 references really necessary?

We note the reviewer's concern, however a significant proportion of the references included in the manuscript relate to policy documentation across the 15 European regions included in the policy review, which are central to the results reported.

VERSION 2 – REVIEW

REVIEWER	Eric Rubenstein Boston University School of Public Health
REVIEW RETURNED	30-Jan-2021

GENERAL COMMENTS	Thank you for addressing my comments. There were two formatting errors ('Error Reference Source Not found' on page 9 and 23. Other than that, no other comments.

REVIEWER	Yona Lunsky CAMH, Canada
REVIEW RETURNED	05-Feb-2021

GENERAL COMMENTS	I appreciate the extensive revisions made by the authors based on feedback from all 3 reviewers. I like the additional data in the table on lived experience and the restructuring of the results. And the introduction reads much better without trying to speak about autism as well as intellectual disability. One of the challenges with these papers is the length of time it takes to get them published. With every week that passes, new issues emerge. I think the one issue alluded to in the discussion that is important is vaccines. I appreciated mention of it. I don't think you need to say much more, but if another resubmission is required, you could mention that given the experience people are having, it is important that vaccines be prioritized. Future study could explore how policies earlier in the pandemic have impacted vaccine strategies.