

## EPICC-ID

### Evaluation of Parent Intervention for Challenging Behaviour in Children with Intellectual Disabilities (EPICC-ID)



#### **How your input is helping our research**

You may remember that we contacted you in May 2020 to take part in a survey about the impact of COVID-19 on you and your family. We are pleased to announce the findings from this work have been published in an academic journal (Journal of Mental Health Research in Intellectual Disabilities). Your input has been invaluable and we are really grateful to every single person that completed the survey.



The screenshot shows the journal's cover and the first few lines of the article abstract. The journal title is 'Journal of Mental Health Research in Intellectual Disabilities'. The article title is 'My Son Can't Socially Distance or Wear a Mask: How Families of Preschool Children with Severe Developmental Delays and Challenging Behavior Experienced the COVID-19 Pandemic'. The authors listed are Laura Paulauskaite, Ola Farris, Helen M. Spencer, EPICC-ID group & Angela Hassiotis.

Journal of Mental Health Research in Intellectual Disabilities

ISSN: (Print) (Online) Journal homepage: <https://www.tandfonline.com/loi/umid20>

My Son Can't Socially Distance or Wear a Mask:  
How Families of Preschool Children with Severe  
Developmental Delays and Challenging Behavior  
Experienced the COVID-19 Pandemic

Laura Paulauskaite , Ola Farris , Helen M. Spencer , EPICC-ID group & Angela Hassiotis

-> This is a screenshot of the paper

88 parents completed the survey. Here is a summary of what we found:

- 91% of parents reported a disruption in access to adequate support during lockdowns
- 90% of parents reported a lack of relevant information to assist them in explaining changes to routine for their child
- Many parents were concerned with the impact that home schooling will have on their child's development
- Many parents also felt the government response to the pandemic did not fully consider the impact on children with significant needs

#### **Some helpful tips:**

There are lots of tools available online to help explain routine changes to your child. You can use social stories using pictures to describe upcoming events/situations or visual schedules:

[https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-coversations#H2\\_1](https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-coversations#H2_1)

Contact are a charity linked with our study and they are able to offer support and advice. Visit their website here: <https://contact.org.uk/> or contact their helpline on 0808 808 3555.

We hope the situation will improve in the coming months as we come out of lockdown. Continue to look after yourselves and your families...brighter times are coming!



## A few words from Prof Angela Hassiotis-Chief Investigator

We are a national study funded to evaluate whether 9 weeks of Stepping Stones Triple P (SSTP) reduces challenging behaviour in children with moderate to severe intellectual disability.

We have now finished recruitment for the study and will continue following up parents until December 2021. This is when the study will come to an end and we really appreciate you all dedicating your time to help finish the assessments. We will be ready to share the results in Spring 2022.

We hope you are continuing to keep safe and would like to thank you for your continued support to our study.

If you have any questions about the study, please do not hesitate to contact us:

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## Study Collaborators



FUNDED BY

**NIHR**

National Institute  
for Health Research

**Priment™**  
Clinical Trials Unit

If you have any suggestions regarding future newsletters please email Rachel on [r.royston@ucl.ac.uk](mailto:r.royston@ucl.ac.uk)